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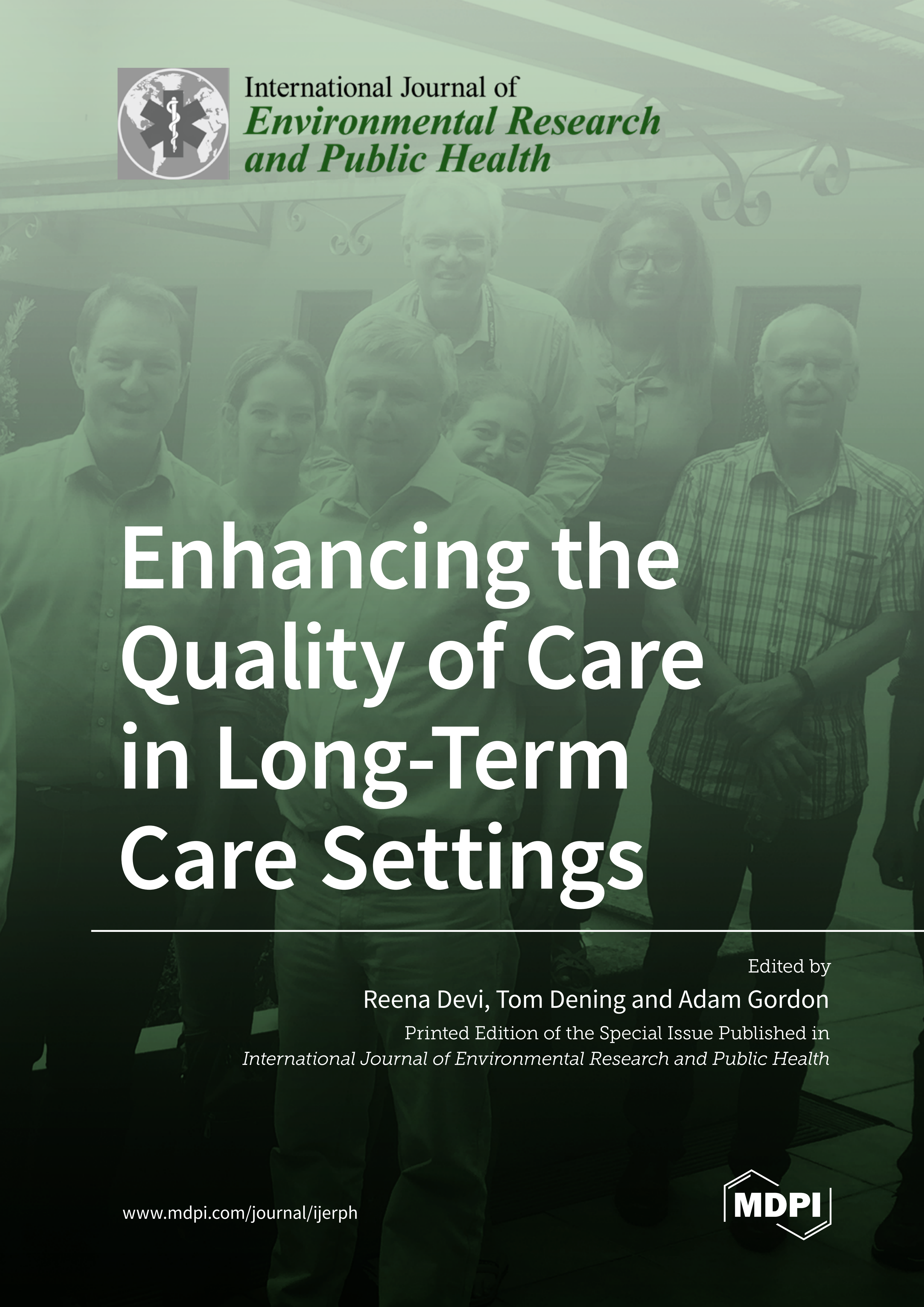

Enhancing the Quality of Care in Long-Term Care Settings

Edited by
Reena Devi, Tom Dening and Adam Gordon

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Editors

Reena Devi
Tom Dening
Adam Gordon

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Editorial

Enhancing the Quality of Care in Long-Term Care Settings

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The quality of care in long-term care settings is a concern felt across the world given the growing number of dependent older people [1]; a population whose health and care needs are increasing over time [2]. This Special Issue set out to attract research focused around enhancing the quality of care in this setting. Since 2019, we have received articles at a regular pace and this Special Issue offers a collection of 22 manuscripts focused on a wide variety of topics. This Special Issue will now close, and in this closing editorial we summarise the content and share our thoughts on future research in this area.

Research included took place around the world (UK, Australia, Taiwan, The Netherlands, Belgium, Korea, USA, Spain, Brazil, Germany, and Italy), used a range of methods, and examined quality of care from different angles. Five papers focused on workforce, adding important evidence around supporting staff with training [3], the influences on job competency, satisfaction, and intention to stay in work [4,5], staff burnout [6], and the relationship between staff and organisation with quality of care [7]. Evidence aimed at teams who work with the sector to improve quality of care was also included. One paper presented a tool containing questions designed to help initiate conversations between innovators and care home staff [8], and another paper outlined essential learning directed at teams applying a Quality Improvement Collaborative tool in this context [9]. This Special Issue also comprises intervention studies, with interventions aimed at addressing depressive symptoms in nursing home residents [10,11], adjustment for new residents [12], social and psychological support [13], and loneliness and isolation [14]. Other studies present evidence which developed and tested quality indicators [15,16], and tools which capture the experience of quality from a resident's perspective [17,18], and assess partnership working between staff and families [19]. We also included studies that investigated factors associated with older people's experiences, such as the association between length of stay and end of life care [20], dry eyes or ocular lubricants with medication use, dementia, frailty and dry eyes [21], resident characteristics and their palliative care service use and comfort in the last week of life [22] and causes of infection-related hospitalizations [23]. Finally, the issue also includes a systematic review describing the current evidence base of care home research conducted in Brazil [24].

The articles published in this Special Issue on enhancing care in long term care offer an array of insights, contributions and perspectives from different angles. This highlights that enhancing quality is a complex issue, one that requires relevant stakeholders to take into consideration different types of knowledge. For example, there is a need to understand causes and associations of poor and good quality, the needs of the workforce, effective interventions that have undergone robust testing, and tools which can help to effectively guide implementing evidence into practice and measure the effectiveness of change. As editors of this Special Issue, we would have liked to see more evidence uncovering how to stimulate and sustain change in care home practice. From our experience of working in this area, care homes within their day to day "business as usual" activities have made progress with initiating changes. This activity though is rarely captured in the academic literature. We suggest that future researchers bring to the centre stage evidence around the specific processes and organisational structures that help care homes to successfully initiate and sustain improved outcomes in this setting.

We are pleased to offer interesting papers from across the world in this important field and bring them together in this way. The regular pace at which we received submissions to this Special Issue indicates significant interest and relevance of the issue. We hope that readers will both enjoy and use these findings in their own research and practice.

Author Contributions: All authors played a key role in editing this special issue. R.D. wrote a first draft of this closing editorial, and T.D. and A.G. reviewed and edited the editorial. All authors have read and agreed to the published version of the manuscript.

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Article

'This Adds Another Perspective': Qualitative Descriptive Study Evaluating Simulation-Based Training for Health Care Assistants, to Enhance the Quality of Care in Nursing Homes

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Abstract: Much of the UK's ageing population lives in care homes, often with complex care needs including dementia. Optimal care requires strong clinical leadership, but opportunities for staff development in these settings are limited. Training using simulation can enable experiential learning in situ. In two nursing homes, Health Care Assistants (HCAs) received training in clinical communication skills (Situation-Background-Assessment-Recommendation Education through Technology and Simulation, SETS: group training with an actor simulating scenarios); and dementia (A Walk Through Dementia, AWTD: digital simulation, delivered one-to-one). In this qualitative descriptive study, we evaluated the potential of this training to enhance HCAs' clinical leadership skills, through thematic analysis of 24 semi-structured interviews with HCAs (before/after training) and their managers and mentors. Themes were checked by both interviewers. HCAs benefitted from watching colleagues respond to SETS scenarios and reported greater confidence in communicating with registered healthcare professionals. Some found role-play participation challenging. AWTD sensitised HCAs to the experiences of residents with dementia, and those with limited dementia experience gained a fuller understanding of the disease's effects. Staffing constraints affected participation in group training. Training using simulation is valuable in this setting, particularly when delivered flexibly. Further work is needed to explore its potential on a larger scale.

Keywords: long-term care; nursing homes; implementation science; quality improvement

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1. Introduction

1.1. Background: The Ageing Population and Care Home Sector in England

England has an ageing population, and a growing number of older people live in care homes (at 329,000, more than three times the number of hospital beds) [1,2]. Half of care home residents aged 65 years or older have complex health and social care needs [3] with the majority having multiple co-morbid conditions [4]. Increases are expected in the number of residents with complex care needs, the number of years of old age spent in dependency, and the size of the care sector as a whole. Across the UK it is estimated that 311,730 care home residents have dementia, of which 131,230 live in nursing homes (where there is 24-h nursing provision on site) [5,6]. People living with dementia have, on average, more than four chronic conditions [7].

Nursing homes in the UK are situated within social care, or private care, and outside of the country's National Health Service (NHS). (This is for historical reasons: in 1948 when the NHS and Social Care were established as two separate public services, life expectancy in general, and for disabled adults requiring care, was shorter, and dependent adults were more likely to be cared for solely by their families. As this situation has changed, demand for social care has risen hugely, but whilst NHS care is free at the point of use, means-tests are in place for social care [8]). Yet nurses and healthcare assistants (HCAs) in nursing homes have to manage residents' very complex care needs, including dementia, comorbidities and frailty. There is a lack of consensus on how best to meet these needs, and support for care homes from primary and secondary healthcare services is variable, often leaving care homes isolated from the wider healthcare system [9]. Delayed provision of healthcare and support leads to an increased risk of unplanned hospital admissions, morbidity and mortality [10–13], and there is often poor acknowledgement in care homes of adverse events (e.g., a fall or infection) that can be indicative of decline in frail residents [14]. Over half of older care home residents lack appropriate access to the NHS services they need, and consequently many are inappropriately admitted to hospital [15]. Compared with people of the same age living in the community, older care home residents are 40–50% more likely to attend Emergency Departments or be admitted to an acute hospital bed, and are less likely to have planned hospital admissions or attend out-patient appointments [13]. The latter necessitate liaising with NHS medical and nursing staff, at the individual and institutional level. When care homes and health services work closely together, impressive results have been demonstrated, e.g., reductions in urgent admissions to hospital of 30% or more [16].

1.2. Skills and Staff Development Needs of Health Care Assistants in the Care Home Sector

Strong clinical leadership—being able to recognise changes in residents' health status and having high-level decision-making skills regarding appropriate care needs—is necessary for delivering high quality care. The range of clinical leadership skills care home staff require includes complex communication skills to communicate with older people with a diverse range of sensory needs; end of life care skills; specialist dementia care; and knowledge and skills in assessment related to many conditions and comorbidities with a very complex client group [17]. Skills gaps within the sector are linked to problems in education and training, and to challenges in staff turnover and recruitment [17]. Staff retention in the UK's care home sector is poorly understood, but recognised to be problematic, with high rates of vacancies [15,18,19]. Problems with clinical leadership in the sector can lead to lost productivity, high replacement costs (including training), low staff morale, low job satisfaction, and inconsistent or compromised quality of care [15,17,20].

Health Care Assistants (HCAs) are the main providers of direct care to nursing home residents [21], and in the UK, no degree or professional qualification is needed to work in this role (although many care home providers now require non-professionally registered staff to complete a care certificate [22], and may ask for relevant care experience). The majority of care staff in the sector's workforce are low paid, low status and have no clear career path. Within social care in the UK, there are low levels of literacy and numeracy; furthermore, many staff have English as a second or additional language [23], as there is a significant reliance on migrant workers [24]. In the absence of mandatory entry qualification requirements, and with disparities in basic skills, new starters often lack appropriate leadership skills and subsequently learn on the job [15]. Despite the need for skills training, opportunities for staff development in the care home sector are often sparse; there is a shortage of funding to provide training, particularly non-statutory, advanced or specialist training [15]. Educational opportunities need to be more clinically relevant and tailored to the care home setting [17,25–29]. Person-centred care—i.e., care that meets individuals' needs and preferences, which in practice involves relationship-building [30]—is widely recognised as desirable yet may be overlooked in task-oriented work [31]. Education and ongoing staff training that fosters person-centred care can facilitate the development of a culture of person-centred care within healthcare settings [32,33]. Being supported to provide person-centred care may benefit care staff (as well as residents), through greater satisfaction with their work [20,30].

SBAR (Situation, Background, Assessment, Recommendation or Request for action) is a widely used situational briefing model which provides a concise, predictable structure to communication about patients'/residents' health situations between people involved in their care [34–36]. (For examples of SBAR use in practice, see: [37,38]). A systematic review of SBAR's impact on patient safety found moderate evidence for an improvement, especially when used to structure communication over the phone [38]. This review included only three studies in care home settings, each with a very specific focus (reducing hospital transfers of nursing home residents [39]; a warfarin communication protocol [40], and transfers, hospitalisations, and 30-day readmissions from long-term care to acute-care [41]). Despite its wide use in clinical settings there is limited research in care home contexts, and high-quality research on SBAR is lacking (only one controlled trial [40] included in the systematic review was 'strong' in quality) [38]. SBAR can be taught in diverse ways, for instance through an online module, lecture, written material or simulation.

1.3. Effective Learning in the Care Sector, and the Potential Role of Simulation

In traditional views of workplace learning, development of practical competencies involves learning and gaining experience in order to obtaining attributes (appropriate attitudes, conceptual knowledge, and practical skills) [42]. Dall'alba and Sandberg, however, emphasise the importance of developing skills in context, and of embodied understandings of practice as ways in which learners develop [42]. Specific forms of learning may be preferred by learners working in settings where they have a considerable need for interaction and construction as their expertise grows [43], such as care homes.

A systematic review [44] that aimed to identify characteristics of effective dementia education and training for health and social care staff across service settings, found that the training/education most likely to be effective included several important features. It needed to be relevant and realistic, tailored to the roles, experience, and practice of learners. It should include active participation and underpin practice-based learning with theoretical or knowledge-based content. It was also effective when experiential and simulation-based learning included adequate time for debriefing and discussion, and was delivered by an experienced trainer/facilitator who was able to adapt it to the needs of each group. Effectiveness was also attributed to not relying on written materials or in-service learning as the sole teaching method. Learning activities that supported the application of training into practice, and provided staff with a structured tool, method or practice guideline to underpin care practice, were also shown to be effective.

Simulation-based education can have many of these characteristics, and is effective for practice-relevant training of the health workforce [45]. It is increasingly popular in nursing education, enabling students to practice their clinical and decision-making skills through real-life situational experiences [46,47]. Virtual patients expose learners to simulated clinical experiences, providing mechanisms for rehearsing information gathering and clinical decision making in a safe zone [48]. Whilst there is a growing evidence base for simulation-based education with healthcare professionals and in acute settings (including large-scale evaluations [49]) there is less evidence from care settings or with non-registered care staff such as HCAs. Our study addresses this gap.

1.4. Study Aims

We aimed to investigate how simulation-based training can enhance the clinical leadership skills of HCAs within nursing homes, in order for them to improve the quality of life of people in care. Our study explored the need for and potential role of simulation-based training, and qualitatively evaluated two types of simulation-based training, exploring their acceptability to HCAs, and the impact that they may have on HCAs' practice (as reported by HCAs and their colleagues):

1. 'A Walk Through Dementia' (AWTD) interactive smartphone app, which uses virtual reality (VR) to simulate the experience of having dementia [50], implemented on a one-to-one basis. AWTD is self-contained and does not require input from a trainer.

2. SBAR Education through Technology and Simulation course (SETS). The SETS course was delivered to a group of HCAs by a consultant geriatrician who is an experienced medical educator (and a Fellow of Advance HE, the UK's Higher Education Academy). SETS uses an actor to simulate scenarios appropriate to the settings' needs. The training focused on deterioration in health.

The two types of training were chosen because they are both relevant to HCAs working in nursing homes for older people, yet they are very different, with contrasting ease of implementation and use of resources. Our study therefore offers an opportunity to generate tentative findings about the role and value of simulation-based training per se, and the role and value of each, including preliminary evidence of feasibility of implementation, with HCAs in nursing home settings.

2. Materials and Methods

Our two-phase evaluation study used a qualitative description approach [51] to explore the impacts of training on HCAs. This method was suited to our study's aim, as it enabled us to generate a description of the role and value of simulation-based training and its impacts on HCAs' work, from the perspectives of those working in nursing homes. Compared to other qualitative methods, qualitative description is less 'theoretical' [51], which suited our study as we sought to stay close to the data, imposing minimal interpretation on it.

2.1. Study Population, Setting and Recruitment

The study took place in two nursing homes for older people, run by an independent care organisation which operates multiple care homes in southern England. The homes, both located in villages, have 48 beds and 60 beds, and both have a dedicated wing for residents with dementia although not all residents have this condition. The offer of free staff training constituted an incentive for managers, staff, and the organisation as a whole, to engage with the study.

Care home managers introduced us to HCAs (we use this term inclusive of care assistants and senior care assistants) who they considered would benefit from training, and to staff in supervisory and/or mentorship roles (including Clinical Lead Nurses and Assistant Managers) whom we refer to as 'mentors' for brevity. Prior to commencing the study, we understood from our initial contact with the care home organisation that mentors were members of care home staff whose primary role is to support the development of front-line care staff. However, when we visited the homes, we found that the term 'mentor' was not used by staff, and there were no staff in this dedicated role. Assistant Managers, Clinical Lead nurses and some HCA supervisors identified HCAs' training needs and supported their development as part of their work in the care homes.

We requested that staff were released from their duties for the duration of recruitment discussions, interviews and training, i.e., they should not forfeit their breaks due to study participation. Potential participants were offered a Participant Information Sheet to read and keep, and given the opportunity to discuss the study with the researcher and ask questions. Participants signed an informed consent form prior to participation in a voluntary, confidential interview.

2.2. Data Collection

One-to-one semi-structured interviews were conducted in private rooms in the homes (an empty lounge, staff room or office), and audio-recorded with consent. Researchers (CA and LH, both trained and experienced in qualitative interviewing and analysis) additionally reassured staff of our independence from the care home organisation, and that no individually identifying information would be shared with employers or published.

Figure 1 outlines the study design, which included interviews with HCAs before and several weeks after receiving training, and interviews with mentors and managers over the duration of the study. We sampled purposively by job role, and in Phase 2 sought only to interview those who had participated in AWTD and/or SETS training. Data collection materials are provided in Supplementary Files. Training was prioritised for HCAs, but we allowed other staff to participate where desired and feasible.

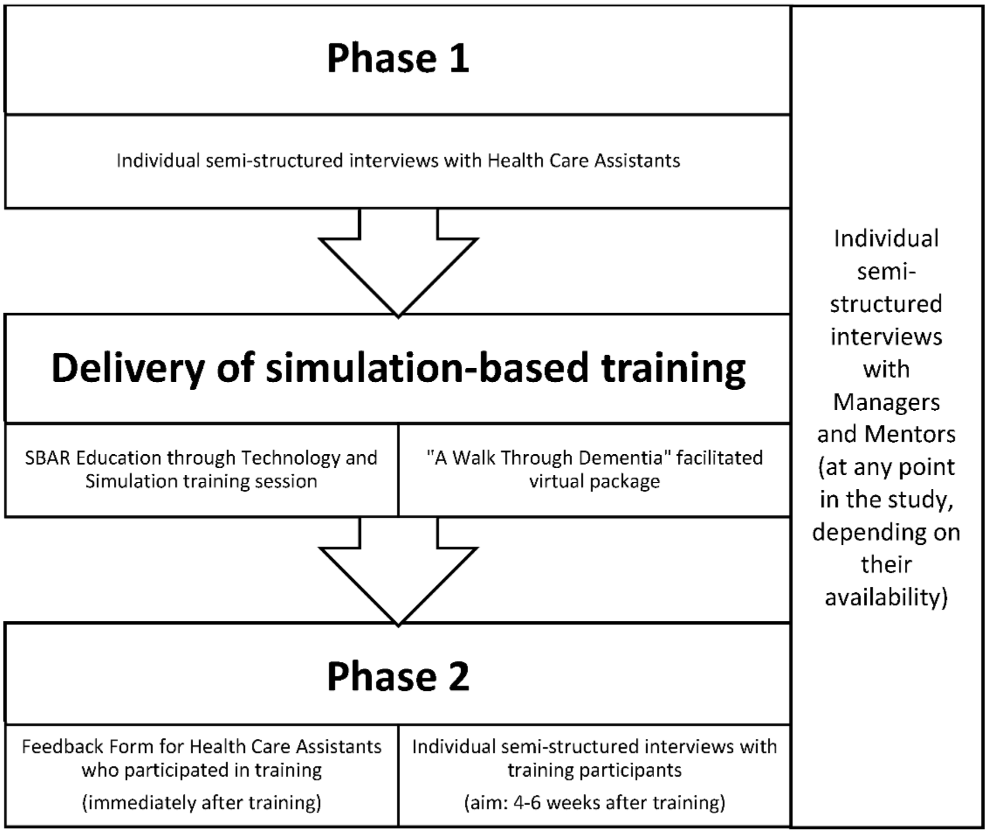

Figure 1. Flowchart showing study data collection in relation to training activities.

2.2.1. Steps Taken to Enable Participation of HCAs

Mindful of high staff turnover within the sector, high use of agency staff and changeable shift patterns, we knew at the outset that it would be challenging to retain the same HCAs in Phase 1, training, and Phase 2 of the study. This influenced our study design in three ways. We made a priori decisions (i) to seek brief quantitative and qualitative feedback from HCAs immediately after each training session via an anonymous Feedback Form (see Section 2.2.3, and Supplementary File S5) in case we could not achieve Phase 2 interviews; and (ii) to conduct Phase 2 interviews with HCAs who had participated in training whether or not we had not interviewed them in Phase 1. In Phase 2, a researcher provided a list of HCAs who had participated in training to the managers and sought to visit the homes when these people were working. Despite multiple visits, these people were often unavailable due to rota changes, sickness, annual leave, and being too busy to be interviewed. We took an additional step, (iii) relaxing the requirement of Phase 2 interviewees to be HCAs: we interviewed any staff member who had participated in training, asking those in other roles to reflect on the impact of the training on their HCA colleagues.

2.2.2. Manager and Mentor Interviews

Interviews with managers and mentors covered the following topics: the manager/mentor's role in supporting HCAs; perceptions of HCA training needs; how HCAs could best be supported; barriers and facilitators to HCA training and development (Supplementary File S1, Supplementary File S2). Manager and mentor interviews were not restricted to Phase 1 or Phase 2 but could occur at any point in the study, to minimise the impact of data collection on busy staff.

2.2.3. Pre- and Post-Training Interviews and Feedback Questionnaire

Topic guides from Phase 1, and for mentor and manager interviews were developed based on an understanding gained from the literature about care staff's training needs, and the sector's challenges with training and retention (see Introduction). Interviews with HCAs prior to training covered: experience of, and route to, care work; views/feelings about care work; self-identified training/development/support needs; experience of, and attitude to, training; experience of working with residents with dementia; experience of communicating with registered healthcare professionals about residents' health (Supplementary File S3). Where senior HCAs mentioned that they had supervisory/supportive roles over other HCAs, we additionally asked relevant questions from the mentor interview topic guide.

Immediately after each training session, HCAs were asked to complete a questionnaire which invited brief quantitative and qualitative feedback about the training (Supplementary File S5).

Staff who had participated in at least one training session were invited to another one-to-one interview (Supplementary File S4). A 4–6 week gap between training and the interview was planned to allow sufficient time to have elapsed for HCAs to put the training into practice, but for memory of the training to be still fresh. Phase 2 topic guides were designed to explore staff's experiences of training, and any impacts of this training. This interview covered: how things have been recently at work; views/feelings about care work; reflections on the training received; and (depending on which training had been undertaken) recent experience of: working with people with dementia (after AWTD training) and/or communicating with registered healthcare professionals about residents (after SETS training). Staff who were not HCAs were asked to reflect on the impact of the training on their HCA colleagues.

2.3. Training Implementation

AWTD was implemented in a quiet room in the home, using the research team's smartphone, placed within a cardboard headset (or held by the user, if preferred, or if the headset pressed on the phone's off-button). Researchers invited HCAs to attend one by one during their shift, and managers and senior staff encouraged participation. A researcher remained present during use of AWTD, in case of problems with using the app or headset, and for safety (as the headset covers the user's eyes). Three interactive scenarios were available, simulating experiences of dementia (a street setting, a shop, making refreshments for visitors at home). Researchers encouraged HCAs to try at least two, which took less than half-an-hour, although we allowed more time if desired. We provided participants with the website address from which AWTD can be viewed online or downloaded as a free app.

SETS training required participants to attend a half-day group session. Researchers liaised with home managers to identify dates when up to 10 HCAs could participate, and one SETS session was delivered in each home. SETS required use of a training room (we used an empty lounge), and a vacant bedroom where scenarios took place. The trainer (IW) began by describing SBAR and its utility as a communication tool. Four scenarios focused on deterioration in health in a care home resident living with dementia or a cognitive impairment, played by a professional actor (experienced in acting SETS role-plays). In each role-play, two training participants entered the 'resident's' room, whereupon the scenario began, and other participants observed the scenario via video-link. In each scenario, participants were told that they should communicate with at least one other person, using SBAR to structure this communication. The participants chose who they would communicate with (e.g., the resident's GP, social worker, or relative), and the trainer acted as this person. This communication should be about the 'resident's' state of health and should include a recommendation or request for action (e.g., that the GP needs to check on the resident on their weekly visit to the home; that they would like the relative to give the resident a reassuring phone call today). After each scenario the trainer facilitated a discussion which followed the 'TeamGAINS' structured debriefing model. This debriefing model was chosen as it has been designed specifically for simulation-based training and is suited to situations where there is an 'expert model' (in this case, SBAR) to refer back to [52]. During the debrief, sections of the recording of the simulation video were played when this added educational value.

2.4. Data Management and Analysis

Interview recordings were transcribed by a commercial transcription agency, and checked for accuracy by researchers. Thematic Analysis [53] was chosen as it is a theoretically flexible, transparent method, suited to the analysis of qualitative data in evaluation research. The two researchers who conducted the interviews read interview transcripts repeatedly for data familiarisation. One researcher led the analysis (using tables in MS Word and Excel for data management), and the other checked the themes. Identification of the main themes was driven largely by the research questions, whilst sub-themes were identified inductively, emergent from researchers' interaction with the data. After identifying candidate sub-themes, we searched for negative cases, in order to refine the sub-themes and give greater depth to the analysis. Interview data formed the bulk of the qualitative data, supplemented by free-text responses from Feedback Forms. Visual inspection of the quantitative data from the Feedback Forms indicated that it corroborated (or did not contradict) the findings of our qualitative analysis. (Due to the small size, exploratory nature of the study, and successful implementation of Phase 2 interviews, quantitative analysis of the data in the Feedback Forms was not undertaken).

3. Results

The primary, descriptive themes were: (1) experience of working as a HCA; (2) training provision, training needs and responsibilities for staff development; (3) experiences of taking part in simulation-based training; (4) impacts of the simulation-based training. Appropriate to this study's focus, the first two themes are outlined briefly for context. Themes 3 and 4, which speak to the study's aim, are described in depth, with sub-themes, the names of which clarify whether they apply to AWTD, SETS, or both.

In Phase 1, 15 interviews were undertaken (Table 1): 10 with HCAs (of which four had some role in supervising other HCAs); two with assistant managers of which one was also clinical lead; one clinical lead who was not in a managerial role; and two managers.

Researchers showed the AWTD app to 14 HCAs, and SETS participants included 12 HCAs (some completed both trainings whilst others did only one). It was considerably easier to implement AWTD than SETS, due to its brevity, one-to-one nature, and minimal resource and planning requirements. AWTD participants often watched more than one scenario, although rarely all three, citing the need to return to work. We obtained 25 completed Feedback Forms from HCAs who participated in training (one HCA returned to her work straight after AWTD and did not return her form despite reminders). Researchers and managers had hoped that more HCAs would participate in SETS (neither course was full), although at least two HCAs came to work on their days off to participate.

In Phase 2, we undertook nine interviews: four with staff who had experienced AWTD (two HCAs, one nurse and one activities co-ordinator, the latter two with experience of working as HCAs), and five with staff who had participated in SETS (quotes from Phase 2 interviews are labelled 'postSETS' or 'postAWTD', indicating which training participants had done.) Whilst all HCAs who we interviewed had some awareness and training on dementia, no HCAs had come across SBAR before. In Phase 2 interviews it was often difficult to distinguish between their views on SBAR as a communication tool, and views on the use of simulation in SBAR training.

Table 1. Interview participants' current job role, phase of study participation and training undertaken.

	HCA	Nurse	Manager or Assistant Manager *	Total Interviews
Phase 1: pre-training interviews (including manager/mentor interviews)	10	1	4	15
Phase 2: post-training interviews	7 **	1	1	9
Training undertaken by phase 2 interviewees:				
AWTD	*2*	*1*	*1*	*4*
SETS	*5*	*0*	*0*	*5*
Total interviews	17	2	5	24

* One Assistant manager was concurrently working in a nursing role at the home (as Clinical Lead); another Manager had a nursing background. ** Including one currently working as an Activities Co-ordinator in the home.

3.1. The Experience of Working as a Health Care Assistant

HCAs described how their duties sometimes gave them little time to sit with residents, or to take their entitled breaks. The HCA role was described as emotionally and physically tiring, with risk of burn-out and high staff turnover. In the context of these challenges their dedication to a caring role was apparent; HCAs often explained how it was not possible to do the job if you did not enjoy care work: *'I like to take care for the people. If you don't like, you can't have this job'* (CA08).

HCAs described diverse career trajectories, with and without ambitions to become registered healthcare professionals. Several described being qualified nurses in their countries of origin, and working as HCAs whilst gaining the appropriate English language and other accreditations to become registered nurses in the UK.

Within the nursing homes, HCAs described clearly defined roles in terms of who communicated with GPs, ambulance staff or other professionals. Nurses and managers did this; HCAs rarely communicated with external health professionals about accidents/incidents or a resident's clinical need. Communication and working relationships between different staff roles within the homes were described positively.

3.2. Training Provision, Training Needs and Responsibilities for Staff Development

3.2.1. Provision of Training and Development Activities

Care home managers described how HCAs were required to participate in a 4-day induction (encompassing mandatory training) prior to working in the homes, and regular ongoing training. The company made further training (including updates to mandatory training) and career progression opportunities available to staff through training delivered in person at the company's Academy and sometimes in the homes; and through online training, which now encompassed a large proportion of the available training. They described how staff and managers could request further relevant training, and individuals might then be sent to other training providers or Academy trainers might visit the homes.

Managers and clinical leads (nurses) described how they identified training needs through supervision of HCAs, referring to this as '*supporting*' HCAs to fulfil their roles.

3.2.2. Modes of Delivery of Existing Training

Online training could be accessed via staff's own devices, or via company computers in the Academy or workplace. As such, it could be completed in paid work time, or outside of work time unpaid: *'obviously we can't pay them, because we don't know how long* [it took]*'* (CA02). In contrast, attending face-to-face training would be paid whether or not it took place during staff's work time.

3.2.3. Attitudes to Training and Development; Barriers and Facilitators

A range of attitudes towards training and career progression was described. Whilst one Deputy Manager and former HCA described '*if it's free and they provide it you might as well do it*' (CA01), a view accepted as ideal by many HCAs, she described that some HCAs would do little or no non-mandatory training. Managers and most staff interviewed described how the company encouraged staff development and progression, including through National Vocational Qualifications (NVQs). One manager explained how employment contracts now stated that staff had to pay back training costs if they left the company within a few months of gaining their NVQ, adding that this change had reduced staff retention problems.

Managers tended to discuss how accessible the training was, and how they and the company sought to enable this. On further discussion, they identified some barriers to training uptake: older staff could feel '*daunted*' by new training requirements (stemming from legal requirements affecting the sector), or '*frightened*' or '*worried*' by the idea of completing training online; staff with children, and those who wished to take longer to read and absorb new material might prefer the flexibility and relaxed pace of doing their online training from home.

There was a slight contrast with the views expressed by HCAs, none of whom expressed that the training was daunting. Instead, they discussed that although computers were available in the homes, it was challenging to find time to use them during a shift, which meant that their training was frequently unpaid. Accessing the Academy was difficult for HCAs who did not drive, as '*there's no public bus*' and although the organisation provided transport '*the driver leaves erm at three and sometimes the training finishes at four. So it's a problem getting back*' (CA12), and barriers included needing childcare.

3.3. Experiences of Taking Part in the Simulation-Based Training

3.3.1. Disorientation and Fear as Ambivalent or Positive Features of AWTD

Some users felt disorientated by the AWTD app (especially when using the headset), a feeling they described as unpleasant and unanticipated. The most extreme example of this was nausea:

> *it made me feel quite, erm ... disorientated. [...] ... I thought I was falling off the chair when I went to look round. I actually felt I was falling over on that* [hole: simulated experience of perceiving a puddle as a hole] *[...] I was surprised actually. I was not expecting that when I started the video. Well I didn't know what to expect before I started. I didn't think it would have such a physical reaction from me like feeling sick*. (LH02 postAWTD)

Whilst disorientation was experienced negatively, it was simultaneously understood as a positive feature of the training: '*it was really, really good because it was so disorientating and quite scary*' (LH05 postAWTD). Disorientation provoked sympathy about what life might be like for a person with dementia. Despite prior knowledge and experience of working with people with dementia, AWTD was '*quite an eye opener*':

> *a big reminder for me or acknowledgement for me, that it's actually physical feeling as well [...] I had to like re-orientate myself. And if you have got dementia you can't necessarily do that*. (LH02 postAWTD)

> *you work in dementia, and I have done for four year, but you know things, you know that it can impact them in the way think, you know levels of confusion exists with the most simplest of things, but you gave us those goggles* [headset], *you still know all that, but you see it differently because you see it through your eyes. It is like it is giving you a taste of what it is like, what they see and perceive things. Very strange, good, but scary feeling...* (LH05 postAWTD)

One interviewee explained how the person with dementia's internal dialogue (which could be heard whilst using the app) enhanced the visual simulated experience:

> *So it was bringing it to life, erm, the hesitation in their voice, what was confusing, how scared they are feeling. That's why it is good to train with it I think.* (LH06 postAWTD)

3.3.2. Learning from Watching Others, and Discomfort about Being Watched (SETS and AWTD)

Nervousness and discomfort were dominant feelings described by SETS participants, including those who described the training positively:

> *It was interesting and I'm glad I got to do it even if I was a little nervous to start with. Once I got over that I really enjoyed taking part.* (LH08 postSETS)

In particular, staff expressed nervousness about taking part in SETS role-plays with their colleagues watching. Watching others go first could aid learning, or could prolong this nervousness such that it interfered with the learning process, as these contrasting quotes illustrate:

> *... I had time to think and learn even from the previous scenarios. Which helped me a lot. I would have been too nervous to go first* [laughs]. (LH03 postSETS)

> *the first one I was nervous watching and I'm not sure how much of what they were doing I took in because I kept thinking of my turn next [...] after I had my go I was much better, I had relaxed and seen what it was like so erm I think I could relax and not worry and I could erm ... erm ... take part a lot more than I did in the first feedback before my go.* (LH08 postSETS)

Once their turn at the role-play began, the realism of the scenarios could help participants relax and become less aware that their colleagues were watching:

> *The actor was really good. He played the situation realistically erm so I think you just went into a realist reaction. I mean I was aware that I was being watched but as it played out erm ... I think I must have forgotten about the cameras, well, until I got back in the room and could see the screen.* (LH08 postSETS)

The trainer's manner helped lessen participants' sometimes considerable apprehension about receiving feedback on their role-play:

> *although I was intimidated by it, he was very good and fun with it, putting nerves at ease.* (LH07 postSETS)

> *I think the tone of it was just set by the way he approached it. Steady, easy feedback, nothing horrible you see. You weren't told you were wrong, we were just shown other ways to do it, which may not have been thought of ... [...] ... and he told a little bit about the scenarios, so* [debriefs] *weren't necessary all about what we were doing* [in the role-play] (LH08 postSETS)

Participants generally considered that SETS was a valuable learning experience despite the discomfort of being watched, with the feedback after each role-play providing space for reflection and further learning:

> *I was uncomfortable doing the role-play but liked watching and talking through our actions at the end. That was really helpful, we learnt about the conditions more or the cause of situations more, the theory if you like. The trainers shared nuggets of information why something might cause an illness or a reaction. That was really interesting.* (LH07 postSETS)

> *... it was useful, so although it is uncomfortable, on reflection, once you had a go, you relax and talk and you start seeing the pieces come together about what you did and did not do.* (LH03 postSETS)

> One HCA, who also described the experience as '*uncomfortable*', commented how she would have preferred to know in advance that she would be taking part in an observed role-play: '*I didn't like that it was being watched. I think I would have liked to have known that before we got started, not when I was in there*' (LH09 postSETS)

Discomfort about being watched was unexpectedly experienced by some AWTD participants, but without the benefit and reciprocity experienced by SETS participants. While researchers were showing AWTD, other staff occasionally entered the room to obtain equipment or to check whether the previous participant had finished. HCAs who were using the headset found it unsettling as they could not see who was there, and '*they distract you as well and they laugh at you*' (LH01 postAWTD). In contrast, SETS role-plays were uninterrupted, perhaps because it was clearer to colleagues that a training event was taking place.

3.3.3. Realism and Learning through Practice (SETS)

Use of scenarios to teach SBAR was helpful to people who preferred to learn through doing:

> *I'm quite a practical person rather than being theory based. So that helped me to learn.* (LH08 postSETS)

Later in her interview the same HCA expanded on this, explaining how the trainer:

> *gave us some background about why a resident might act or be acting a certain way, which really was interesting to me [. . .] and because it related to a practical situation which we had just acted out so it stays in my head better. Erm, probably stuff I never had thought of before, but actually was factual and interesting. Not boring at all because it could be practically applied to what we had gone through.*

> She explained that although '*you can learn a lot from reading*', if it is '*too hard or too much jargon you don't always understand it and it becomes impossible to see, erm, you can't then link it to things. The way the trainer did it was to apply that knowledge and for me that worked so well. Helped me learn it anyway and I don't learn easily.*' (LH08 postSETS)

Whilst a colleague explained that the simplicity of the SBAR acronym made it easy to remember, she added that '*because we had the practical exercise and then it just stayed with us*' and '*then we discussed it, I think it was better that way*' in comparison to reading about SBAR:

> *otherwise it is just a lot of words, not so helpful. Helpful but not in the same way. We also had the theoretical part first and then that helped because we need to see how, and then the case studies, everything was really good. It all come together.* (LH03 postSETS)

Interviewees agreed that the SETS scenarios effectively evoked real situations that might occur in the homes, although HCAs expressed differing views about how likely they were to be the ones to take the lead on communicating in these situations (discussed below). During the training and in post-training interviews, participants remarked on how effectively the actor mimicked an unwell resident. When he responded to their questions '*he had you know the physical response as well so it was really, it felt like a real situation*' (LH03 postSETS).

The experience of SETS realistic scenarios was concisely described by this HCA:

> *When you do a scenario, you act out what you would do. What is natural for you to do. Then you're back into the room where the trainer is and everyone else too and you talk about it then. Really eye opening actually.* (LH08 postSETS)

3.3.4. Applicability of SETS and AWTD Scenarios to HCAs

Although none of the AWTD scenarios were set in a care home, no AWTD participants questioned the applicability of the app or its subject matter—dementia—to HCAs' work. In contrast, divergent views were expressed about the applicability of the SETS scenarios, and SBAR, to HCAs. According to one HCA (a nurse in her country of origin), the scenarios were '*real situations that we are put through every, every day in our jobs so it helps us see what to do*' and SBAR was '*just a communication tool so we can use it everywhere*' (LH03 postSETS). However, another HCA remarked that she only appreciated the possible applications of SBAR after the training, when she discussed it with colleagues. For her, and some other interviewees, the sticking point seemed to be that HCAs in the homes do not usually relay information to outside health professionals This limited the apparent relevance of some scenarios:

> *What you do on a daily basis, it didn't come up, I'm not sure that they do scenarios around that but we didn't experience it. I have struggled to use it every day since, in my job, so I think that would have been really good for me to have seen, a different practical side to the tool not just in an incident* (LH07 postSETS)

Others discussed the applicability of SETS to situations that they deal with (discussed further in Section 3.4).

3.3.5. Usefulness of Further Resources (AWTD and SETS)

No additional resources were provided with AWTD. When asked whether further resources would be helpful there was a general consensus that AWTD was 'enough' (as a complement to the dementia training that all HCAs had already received), but possibly with more time available to explore the app fully. In post-training interviews, none of the staff reported having looked at AWTD again, although some had recommended it to others.

Printed and online resources were available to complement SETS, which HCAs appreciated. In post-training interviews, some participants described having used these, and some had not.

3.4. Impacts of the Simulation-Based Training

3.4.1. Insight into How a Person with Dementia May Experience the World (AWTD)

HCAs described how the AWTD app gave them a new perspective on the experience of living with dementia—even when they already knew about dementia and its effects, had worked with people with the condition, and considered themselves caring and compassionate:

> *... you hear about what dementia is about [...] But it is always harder to appreciate what that actually might be like from a different point of view. Seeing it is so different, it's weird, yeah, so strange to feel like you're in that situation. That is different from hearing something and it's not really impacting you, or your body. I mean, we hear information and obviously you can empathise, understand and digest, but you never truly appreciate. The app, those videos gave you an impression, a taste of what it could be like.* (LH01 postAWTD, former HCA)
>
> *it is difficult to get into a mind of someone with dementia, you hear about it, you understand the mechanics of the disease, but experience and the way the app makes you feel, it gives you those sense of disorientation, confusion, even the way you see things it changes that. I mean you can't feel that when you read something about dementia. You understand its impact, but feeling it I think had a different kind of impact. I think it could even teach you more about the way you care, if you reflect, it could make you stop in your tracks, examine what you do and that is for all the work you do with all the residents I think, not just those suffering with dementia* (LH02 postAWTD, Manager)

AWTD gave participants a sense of the embodied nature of living with dementia, as they felt a physical reaction to seeing things that disorientated or frightened them:

> *it's physical as well as just like you know a perceived thing. You body reacts with this condition, your brain reacts.* (LH02 postAWTD)
>
> They described greater insight and understanding of the possible experiences of people with dementia, as a result of AWTD: '*I was a bit more compassionate to people I think afterwards*', having realised '*how terrifying it must be for them.*' (LH05 postAWTD)

A more experienced staff member, currently a nurse in the home, described that her awareness of dementia and its effects was quite high, but that she thought the app would be helpful to less experienced people. The training she had received previously was detailed:

> *. . . but not as erm, how do you call it, not as helpful as this because it really shows you what's happening to them I think, like real life what happens to a person who has dementia.* (LH06 postAWTD)

3.4.2. '*It Puts You in Their Shoes*'—Enhancing Person-Centred Dementia Care (AWTD)

By placing the carer in the position of a person with dementia, staff described how AWTD reminded them to be more patient, taking into account the different reality that some residents may experience:

> *you're carrying out a job, you have tasks to do to meet individual needs, and you want to do the best to meet those needs for every resident, you don't not want to fulfil the simple things, but it, erm, it does mean sometimes, sometimes forget what the experience is. It takes things like this to remind you. [. . .] . . . it gives you some appreciation of what they live with all day and every day. We get to go home and be ourselves, and forget, but that doesn't happen for some of the residents does it.* (LH02 postAWTD, manager)

> *. . . since then I think I've viewed things differently and I think I treat PWD* [people with dementia] *as differently now because you get a bit more of an understanding they are not being difficult or trying to be annoying, you know they don't know. It's just they don't know, the surroundings for them are completely different to what we can see.* (LH05 postAWTD)

3.4.3. AWTD's Subtle Impacts on Practice

Staff described a qualitative change in their approach to people with dementia after experiencing AWTD, although they were often quick to explain that they were already performing their roles well:

> *. . . we all know what to do and what is at the centre of our work. This just adds a layer to it.* (LH02 postAWTD, manager)
>
> Responding to whether what she did has changed, one HCA explained:
>
> *Well yeah and no really. What I do practically hasn't changed. The needs of the patient has not changed, but I think my perception of the disease has. Like I said about* [own family member with dementia]. *I think it has now made me stop and think more when there a situation and say to myself, it's not them, it is the condition. That is what I really think has changed.* (LH05 postAWTD)

This very slight defensiveness was echoed in her colleague's account, where she acknowledged the frustrations carers may feel working with people with dementia:

> *I don't think [I am] any more confident, just appreciate, awareness to see it differently, makes you more patient, even though I am a quite a patient person anyway. But I think it's just given me more patience [. . .] it does obviously get frustrating for everyone, I think people don't always admit it. But it does, it gets like but I think once seeing it through their eyes, it is . . . it does extend that patience a lot.* (LH01 postAWTD)

HCAs offered few practical examples of how their practice changed, but described reflecting on current and past actions. For instance, one described how she used to take a lady with Alzheimer's disease, who was unable to communicate verbally, on regular trips to a café. After using AWTD, she reflected that although '*me and her family thought it was a good outing, she might have inside been terrified*' (LH05 postAWTD). Another described how staff sometimes '*struggle*' getting residents into the lift. She now realised that the gap at the entrance to the lift might be perceived as:

> *a massive, like a hump in road kind of thing. So that's why they were like hesitating trying to step over it. [. . .] So it did open my eyes in that sense, erm . . . yeah they see what we don't kind of thing. It is like you can know that, but when you experience it, like the app, it adds a level of understanding that you did not before.* (LH01 postAWTD)

She went on to explain how she intended to use this understanding, by putting a picture in the back of the lift to for residents to look at, '*so it kind of like stops them getting stressed*' when entering the lift. She was confident that the manager would allow this when they had time to implement it.

> *I can see the relevance of using it for anyone having to deal with a relative or have to work with dementia patients. It is so easy to forget in the moment what they might be experiencing, or not have full understanding of what they are going through. This, this erm, stops you in your tracks and maybe examine how you approach things.* (LH02 postAWTD)

3.4.4. SETS and Efficient, Organised Communication

Some interviewees found that learning to use SBAR, through SETS, had helped them to communicate in a way which was '*more methodical*' and organised:

> *Just to have you know organised approach to every situation, just to think well what do I have here? What do I know? How am I going to report it and afterwards how am I going to resolve this so just to have an organised thought. I think that's better if we want to give information and don't forget anything.* (LH03 postSETS)

Some interviewees were more sceptical about the training's impact on their own practice, but despite this, observed changes in colleagues:

> ... *before she would be so rushing information, she's much better now at giving it [...] You [interviewer] are going to meet people and they'll say it has done nothing for them but I can tell you from watching, working with them that yes it certainly has.* (LH04 postSETS)

For one HCA though, the scenarios did not help her learn much '*I think I get what I'm doing, I'm good at my job and I know how to do it. It might have been [useful] for others though.*' She described how she had been doing her job for a long time '*and this just seemed to be telling me what I know*' (LH09 postSETS).

Another HCA explained how the video of her role-play showed her standing over the 'resident':

> *that showed me how I was doing something I actually didn't think I did do. Then you got suggestions about how you could do it differently. That made me really think about situations ever since. Not in incidents only, but just daily. I asked myself a little while after that, maybe the next day, was I standing rather than bending or erm sitting down, was I looking them in the face and eyes. So I think I corrected myself, made sure I took on board what was told to me. It was also not because I felt I was doing it badly, it was just that I thought it was better to do it another way. I learnt something that helped me communicate better, or maybe put the resident at ease.* (LH08 postSETS)

As in the previous sub-theme, this HCA was keen to clarify that her current practice was adequate.

3.4.5. SBAR's Fit with Roles and Processes within the Homes

Whilst some identified that they might use SBAR when communicating with their nurse colleagues, for others, the fixed roles regarding communication in the homes (see Theme 1, Section 3.1) made some SETS scenarios seem inapplicable:

> *if there could be some examples or discussion around how it is applies in our daily routines or roles. I think then that would be easier to see its application* (LH07 postSETS)

However, one HCA explained how on one occasion since the training, she had spoken to a locum doctor. She was unsure if she used SBAR but recalls being '*direct*' and approaching the situation with confidence, which she said was possibly helped by the training:

> *I think I felt good, I felt confident. I do remember saying to myself, be straight forward, think about what they and the resident needs.* (LH08 postSETS)

Another HCA, despite also describing the limitations of SBAR within her role, described stepping in when a new member of nursing staff became stressed and was not managing to communicate clearly about an incident. She described drawing on the SETS training to help the colleague improve her communication:

> *I said this is the way you need to do it. If you are speaking to someone and you do it this way it's going to happen. If you just say it in like an open-ended way it's not going to. And it is very good for teaching the differences between what an open-ended question is to what a direct communication is.* (LH04 postSETS)

None of the staff interviewed had used the SBAR paper forms, which they described as duplicating the paperwork they routinely complete after an incident, in a context where '*we have hundreds of paperwork*' (LH04 postSETS):

> . . . *accident book, and you know we have other things we need to complete in an incident like, Erm we have to complete a carers' report, talk to the person in charge. So, I don't think it has its place then to be honest. Too busy for it.* (LH07 postSETS)

However, she also explained that '*for that information I need give over immediately* [SBAR] *is great.*'

3.4.6. SBAR as a Panacea, or a Tool for Specific Jobs

When the trainer introduced the SBAR tool, he gave examples from everyday life, as well as from health and care contexts. Some interviewees agreed that it could be used '*every day*' as well as when communicating about incidents or changes in residents' states of health. However, others took the examples as literal instructions to apply SBAR in much of their workplace communication. In these cases they tended to be more critical, discussing how different approaches were needed with different people, although acknowledging that '*for specific things it is actually very good*' (LH04 postSETS). They offered examples of where SBAR was not so helpful, for instance during staff handovers, where it might be necessary to repeat information, starting with an overview and then giving further details; or when showing new staff around. They further mentioned that not all carers' English was good:

> *when it is supposed to be a communication tool it can be difficult if someone doesn't have a good grasp of English in the first place* (LH07 postSETS)

Both of these interviewees explained that there was sometimes the need to be more '*personable*' than SBAR allowed, e.g., an encouraging approach was needed when asking a resident to participate in an activity. For one interviewee, SBAR could even impede personalised, caring communication:

> *Well, not sure if this is the right thing to say, but I'm going to say it, I actually find it so impersonal. I have a very chatty nature, a very personable approach and it felt a little unnatural to ask things in the way it structured. I guess it is personal preference.* [. . .] . . . *it is basically a tool, but we work in such a way that really suits my caring side [. . .] and all residents can be so different from one another* (LH07 postSETS)

Despite these two interviewees' reservations, they both identified situations where SBAR could be useful, which were different to those covered in the SETS scenarios. For example, one HCA had used SBAR with the family of a resident receiving palliative care; she described using it '*as a defensive mechanism just to keep myself at a professional level*' in a context where she too was emotionally involved:

> [The family] . . . *will want to know what's going on and they will want, but it is going to hurt them and you are mentally trying to prepare yourself to give... not that we are giving them the news that this person is dying, that's not up to us, that's not us but during the last couple of days there would be moments where you know you're trying*

> *to do the right thing [by providing some information] but you're also having to protect yourself and in those cases you case use it.* (LH04 postSETS)

Her words also illustrate HCAs' defined roles with regard to communication: they are not the ones to tell relatives that their loved one is dying.

Similarly, this interviewee, who was the most critical of SBAR, explained:

> *I haven't used it with family members, but yeah, I think it could be especially if you need to be precise, not take too long or wanted to be drawn into something because it was not good for the resident or the family. It is simple, factual and it is about sharing enough information that does not overload someone.* (LH09 postSETS)

4. Discussion

4.1. Main Findings

We found that two very different simulation-based training sessions were acceptable to HCAs working in nursing homes, and could be delivered in the workplace.

HCAs described benefits to both types of training, including potential improvements in practice. They expressed dedication to their roles, and assured researchers that they were already well able to care for residents with dementia and to communicate effectively in the workplace (and researchers had no reason to doubt this). This contrasted with HCAs' considerable nervousness and under-confidence about demonstrating such skills in front of colleagues in the SETS role-plays. Despite this, HCAs found the SETS feedback discussions interesting and valuable, and specifically mentioned how debriefings after each role-play scenario aided learning, and the trainer's manner put them at ease. In contrast, AWTD—a self-contained digital package—required no interpretation when used by dementia-trained HCAs. HCAs felt that AWTD did not provide new knowledge (beyond what they already knew), but brought the experience of living with dementia to life, and so may enhance person-centred care.

AWTD was quick and easy to deploy in care home settings, requiring minimal additional resources. SETS was more resource-intensive and time-consuming, and therefore cannot be implemented ad hoc, which presents challenges to uptake in care homes, where staff changes make it difficult to anticipate who can attend on a particular day. HCAs' perceptions of the value of SETS was somewhat limited by their views SBAR's utility. First, there was a strong sense that communicating with external professionals was outside of the HCA role. Such tightly defined roles may prevent HCAs from developing their clinical leadership abilities, with impacts on residents' care. Second, they described needing to provide information in different ways when communicating with colleagues and residents, to repeat information, and to be personable—related to their caring role and comprehension difficulties. Self-consciousness about their own English may have contribute to nervousness about SETS role-play participation.

4.2. Discussion of Findings in the Context of Existing Research

Simulation-based training evolved in hazardous professions such as aviation, to maximise training safety and minimise risk, and has only relatively recently been used in nursing practice. Our study contributes to the limited research on the use and impact of simulation training in care home settings. Of three recent studies, one focuses on ethical dilemmas in caring for persons living with dementia, and suggested that simulation training helps nursing students to adapt to these situations in clinical practice. The exposure that simulation gives in a supportive learning environment helps to foster security in learning, but as we have shown, the facilitator's role is important in the creation of this environment [54]. The second study (linked with ours, concerning SETS) explored the feasibility of delivering in situ simulation *within* care homes, concluding that simulation is acceptable to staff and leads to increased knowledge on the recognition and management of common conditions in older people [55]. The final study was small and highly specific in its use of simulation: concerning care home staff's ability to facilitate advance care planning for patients with advanced dementia [56].

Supporting our findings about the discussions within SETS training, others have identified the importance of the human facilitator's role in debriefing role-play simulations, which is key to the success of such training [57]. The need for skilled facilitation, and the barrier to implementation posed by limited staff time, are not unique to SETS or to simulation-based training; they have been found for diverse types of training in care home settings [58]. We found that SETS was feasible to implement with HCAs, with the support of the care organisation which runs the homes and home managers. Indeed, SETS has been delivered in a large number of care homes, with participants valuing the discussion elements within the debriefing [55]. SETS is currently funded and so its implementation required no financial outlay from the homes, however we acknowledge that if this situation were to change, care home organisations might have to find funding for such a scheme, with implications for feasibility.

AWTD has been used in education programmes in the UK and elsewhere. An evaluation of AWTD and an accompanying workbook (the latter unavailable at the time of our study) has been undertaken [59], but is not yet published, and we have found no other published evaluations. Other interventions using VR to simulate experiences of dementia have been studied, with similar findings to our own, particularly in terms of increased empathy and understanding of what it is like to live with dementia. Slater et al. evaluated the Virtual Dementia Tour® (VDT), a 'sensory distortion programme' where vision, touch and sound are distorted through use of goggles, shoe inserts, gloves and headphones, and facilitators subject participants to curtness and aloofness to simulate the experiences of people with dementia in healthcare environments, followed by a debriefing session [60]. Evaluation participants included 72 health care personnel and community and family carers, in hospitals, community and voluntary services, in the Republic of Ireland. VDT was found to enhance a sense of empathy among participants, which led to greater confidence, compassion and person-centred practice. The Dutch 'Through the D'mentia Lens' (TDL), a simulation movie played on a VR device, accompanied by an online course, has been evaluated through surveys with informal/family carers, in pilot study with a before-and-after design [61]. After experiencing TDL, informal carers were more empathic, and felt that they understood better what it was like to have dementia and the perceptions of people with dementia. In contrast to our findings and those of Slater et al., they found no change in person-centredness, perhaps because informal/family caring relationships may already be highly person-centred. A multimedia arts exhibit in Canada, about the experience of living with dementia, including VR, was evaluated using mixed methods. Researchers concluded that it increased empathy and understanding of dementia among nursing students, with VR being among the most engaging media [62].

SBAR itself may usefully lead to a common language between healthcare providers, increasing confidence in communication and ultimately leading to more efficient communication [63], as our findings suggest. Studies of SBAR in care home settings demonstrate that staff consider it potentially useful, and that it may provide cues for effective communication [64], but key champions are needed to ensure its success as a tool at handover more generally [65].

4.3. Strengths and Limitations

A strength of our qualitative evaluation is that we trialed two contrasting forms of simulation-based training, enabling us to explore the benefits common to both types of training, and thus draw out tentative findings about the use of simulation per se with HCAs in nursing home settings. In addition to the contrasts noted in the introduction (Section 1.4), we found that whilst one training topic was familiar (dementia), the other (SBAR) was unfamiliar to HCAs. Our use of two nursing care homes run by the same organisation in the same region, both providing specialist dementia care, may limit the transferability of our findings to other older people's care settings. Differences with other settings may include availability of existing training (existence of the Academy perhaps indicates greater investment in staff training than smaller care home providers can offer). However, we have no reason to believe that the care homes were especially unusual.

The position of HCAs in nursing homes and care homes globally is hugely diverse; across European countries they are referred to by up to 18 different titles, and their education and training is also enormously varied [66]. The transferability of our findings to HCAs in nursing homes outside the UK is therefore difficult to assess; we could make no comparisons or contextualise this study to HCA experiences in other countries.

We experienced no challenges in engaging staff with AWTD training, which was quick and easy to deliver. However, although we and the care home managers made efforts to enable and encourage SETS attendance, neither course was full, and despite multiple visits to both homes we experienced challenges in obtaining post-training interviews. These issues relate to staffing challenges which are typical of the care home sector: staff were busy and unavailable at short notice (e.g., needed to provide cover, or had changed shifts), and some had moved on. Whilst we were able to obtain valuable feedback on the experience and impact of both types of training, and to identify themes across the post-training interview dataset—encompassing shared and divergent views and experiences—we may not have achieved thematic saturation. In future research with staff in these settings we could explore measures to increase post-training interview participation, such as offering interviews outside of staff's work time, perhaps by telephone or online and/or with an incentive/voucher.

4.4. Future Directions for Practice and Research

We suggest that due to the minimal resources and staff time required, and its ease of use, AWTD could be used in the induction of HCAs new to working with people with dementia, and in conjunction with existing dementia training, it may enhance the ability of HCAs with and without prior experience of dementia care to provide person-centred care.

Our study was conducted before the COVID-19 pandemic. The impact of COVID-19 on older care homes residents [67] is well-documented, whilst COVID-19-related morbidity and mortality have been high amongst people living with dementia, who are also at increased risk of neuropsychiatric disturbances due lockdown and the social isolation measures which have been applied stringently in nursing homes [68–70]. During the pandemic, nursing home staff have been at considerable personal risk [67], exacerbating the challenges already experienced in this sector (see Introduction). Enhanced training and support for new and existing staff are needed, to grow and develop the nursing home workforce [71]. Simulation-based training, which does not involve contact with residents, may play an important role in the pandemic context, and this requires further exploration. The pandemic has also led to changes in ways of working across older people's care—in the community as well as in care home settings—and people who do not usually work as carers (e.g., cleaners, council workers) have sometimes taken on caring roles [72]. As these people may lack awareness of dementia and its effects, AWTD may be helpful in this context.

Further research could explore the barriers and facilitators to giving HCAs a greater role in clinical communication, supported by training such as SETS.

As existing studies on simulation for dementia awareness and clinical communication training with care staff have limited generalisability and/or lack long-term objective outcome measures, larger-scale mixed-methods evaluation of the two trainings is warranted. These could be undertaken with a more diverse range of care settings, trainees and resident/patient populations.

5. Conclusions

Simulation-based training, delivered in the workplace, is an acceptable and impactful means of skills development training for HCAs working in nursing homes. Our findings suggest that in these settings, AWTD may be effective in enhancing person-centred care as a complement to existing dementia training, requiring little staff time or resources to implement. SETS may improve communication with colleagues and other professionals, however this training requires more resources, and time, co-ordination and commitment from both managers and care staff to attend the training.

Supplementary Materials: The following are available online at https://www.mdpi.com/article/10.3390/ijerph18083995/s1, Sup-plementary File S1: Manager in-depth interview topic guide; Supplementary File S2: Men-tor/clinical lead/supervisor in-depth interview topic guide; Supplementary File S3: Topic Guide for Phase 1 HCA In-Depth Interviews: pre-training; Supplementary File S4: Phase 2 interviews: post training; Supplementary File S5: Feedback form.

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Article

Job Competency and Intention to Stay among Nursing Assistants: The Mediating Effects of Intrinsic and Extrinsic Job Satisfaction

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Abstract: This study investigated the influences of nursing assistants' job competency on their intrinsic and extrinsic satisfaction and intention to stay in the profession of long-term care institutions. Understanding the relationship between job competency and job satisfaction, both intrinsic and extrinsic, would enable institutions to strengthen service workers' intention to stay and to retain essential personnel. This study was a cross-sectional study in which nursing assistants from 26 nursing homes and 15 elderly welfare institutions in Taiwan. The relationship between job competency and intention to stay was discovered to be significantly mediated by intrinsic and extrinsic job satisfaction. Given the staff shortages and difficulty retaining staff in long-term care environments, organizations must be able to strengthen employees' intention to stay; one suggestion is to improve the employees' competency, because higher competency results in higher quality of care and greater extrinsic job satisfaction. Furthermore, greater job competency is more likely to result in affirmation and accomplishment, both of which increase intrinsic job satisfaction and thus positively influence intention to stay.

Keywords: job competency; intention to stay; intrinsic job satisfaction; extrinsic job satisfaction; nursing assistants

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1. Introduction

Although Taiwan implemented a 10-year long-term care project (2007–2016) in which a comprehensive community care model was developed, the project experienced nursing assistant shortages and a weak intention to stay in long-term care services among employees [1]. At present, nursing assistants are on the front line of long-term care and have wide-ranging responsibilities for daily living care. They have become the people with whom care recipients have their most intimate relationship. Consequently, their professional performance directly affects the quality of life of older people, and measuring nursing assistants' intention to stay is thus a crucial topic.

Many studies discuss the intention to stay of nursing assistants, which is mainly related to job satisfaction [2–5]. Although many studies have explored factors affecting the job satisfaction of nursing assistants (e.g., job stress [2], psychological empowerment [6], and received support from peers and managers [6], these studies did not consider the personal abilities of nursing assistants. Studies have revealed that employees with greater "demands–abilities fit" can more efficiently complete the tasks assigned by their organizations [7], thereby achieving greater job satisfaction [8]. Nursing employees with higher job competency can exercise their abilities more confidently when completing nursing tasks, which subsequently affects their job satisfaction and intention to stay. A few studies related to job satisfaction have set job satisfaction as a single-dimension variable in their analyses [9,10]. However, Tsounis and Sarafis contended that job satisfaction is a multidimensional variable [11]. This study sought to validate the mediating effects of intrinsic and extrinsic satisfaction on job competency and intention to stay. The aim is to increase nursing assistants' intention to stay in their position through greater understanding of their job competency and job satisfaction—intrinsic and extrinsic—thereby enabling retention of essential talents in Taiwan's long-term care industry. After reviewing important literature, the research hypotheses of this study were formulated.

1.1. Relationship between Job Competency to Intention to Stay

Job competency refers to the knowledge, attitude, and skills that employees must have to perform their work. These competencies can be evaluated and can be improved through training [12]. Any discussion of job competency must involve the concept of person–job fit. According to Edwards, person–job fit can be divided into the fit between demands and abilities—how the employee's abilities and knowledge meet the work requirements—and that between need and supplies—whether the salary compensation and sense of achievement provided by the job satisfy the employee's needs [13].

Relevant studies have shown that person–job fit is negatively associated with turnover intention [14]. Organizations must pay greater attention to person–job fit to increase employees' level of engagement and decrease voluntary turnover rate [15]. Thus, employees who identify as having a higher job competency regarding their work gain more resources (e.g., work-related skills) and are more hesitant to consider leaving their jobs [5]. Based on the above arguments, we formed an initial expectation of a positive association between nurse job competency and nursing assistants' intention to stay.

1.2. Extrinsic Satisfaction and Intrinsic Satisfaction

Job satisfaction reflects how employees feel about their current work duties; it is the emotional response generated by the role that the employee plays in the organization [16]. Motivation-hygiene theory states that humans have two types of basic needs [17]. One type is motivator needs, otherwise known as intrinsic factors, which are relevant to the work itself and can be satisfied on the job, because they represent an employee's psychological needs and prompt long-term impetus [18]. By contrast, hygiene factors are influenced by the external environment and can be considered extrinsic factors. These factors are related to the work environment and include the workplace environment, channels of promotion, salary, support from managers, and rapport with coworkers.

In this study, job satisfaction was distinguished into being from intrinsic and extrinsic factors. Intrinsic factor satisfaction refers to satisfaction gained from the actual work, such as a sense of achievement, a sense of responsibility, and self-respect; extrinsic factor satisfaction is defined as satisfaction gained from the work environment or organization, such as salary, system of promotion, and leadership. Scholars have stated the influence of extrinsic satisfaction on intrinsic satisfaction [19,20]. Using motivation-hygiene theory, this study posited that when nursing assistants' basic hygiene needs—salary and benefits—are met, nursing assistants begin pursuing motivator needs—personal growth and a sense of accomplishment. Therefore, the following hypothesis was proposed:

Hypothesis H1. *Extrinsic satisfaction has a positive influence on intrinsic satisfaction.*

1.3. Relationship between Job Competency and Job Satisfaction

A widespread belief is that a closer fit between demands and abilities leads to greater job satisfaction. Thus, employees with a closer demands–abilities fit are more likely to be competent at their job and adapt to the job more quickly; they are also less likely to experience work pressure, resulting in greater job satisfaction [21]. According to Peng and Mao, employees with closer demands–abilities fit can more efficiently complete tasks, have less work stress, and are more likely to earn their manager's recognition and praise [7]. Therefore, they are more confident in their work and have greater self-efficacy and a higher sense of accomplishment. Employees with greater self-efficacy have more confidence when faced with challenges in their work, leading to greater job satisfaction [8].

The most direct result of closer demands–abilities fit in an employee is higher work performance. This is because organizations typically reward high performers rather than low performers [22,23]. One study argued that being able to meet demands to merit rewards—such as bonuses and promotion—is dependent on whether the individual's work meets the conditions of demands–abilities fit [21]. More competent nursing assistants have higher work performance, which may lead to higher compensation, more promotion opportunities, increased welfare, or recognition from superiors. These benefits then affect the job satisfaction of employees in their work environment or organization. The following two hypotheses were proposed in this study:

Hypothesis H2. *Higher job competency leads to greater intrinsic satisfaction.*

Hypothesis H3. *Higher job competency leads to greater extrinsic satisfaction.*

1.4. Relationship between Job Satisfaction and Intention to Stay

Intention to stay refers to an employee's intention either to remain in their current job or to resign [24]. It reflects the likely behavior of employees who are carefully considering their options. Job satisfaction is considered the most decisive factor influencing intention to stay, and job satisfaction and intention to stay are strongly positively correlated [25,26].

Salary and benefits are relevant to job satisfaction and influence intention to resign [27]. Although extrinsic satisfaction is crucial to an employee's intention to stay, research into job satisfaction has discovered that the intrinsic value of work has a similar influence on intention to stay as extrinsic satisfaction. All employees hope to be respected in an organization and be more than a simple laborer; therefore, when an individual thinks that their colleagues or manager finds them valuable, their self-esteem increases [28], and when an individual believes themselves to have value in and to have made contributions to the work environment, they have stronger intention to stay [29].

In summary, if an organization can create a supportive work environment, satisfactory salary, and benefits, it can strengthen employees' intention to stay [30]. This study hypothesized that the intrinsic and extrinsic satisfaction that nursing assistants obtain from their job—such as a sense of accomplishment, a sense of responsibility, esteem, salary, and promotions—influence employees' intention to stay. The following two hypotheses were thus made:

Hypothesis H4. *Higher intrinsic satisfaction results in stronger intention to stay.*

Hypothesis H5. *Higher extrinsic satisfaction results in stronger intention to stay.*

1.5. Job Satisfaction as a Mediator between Job Competency and Intention to Stay

Porter, Bigley, and Steers stated that employees receive compensation and rewards for outstanding work performance, and these rewards increase the employee's job satisfaction [31]. When employees are satisfied, their intention to stay is stronger [25]. Morley et al. discovered that poor fit between an individual and organization leads to job dissatisfaction, influencing intention to stay [32]. Job satisfaction has been proven to have a mediating effect on the relationship between person–job fit and intention to resign. When the person–organization fit is closer and the compatibility between needs and abilities is high, the person tends to have a more positive work attitude and more positive behavior [22,23]. A person with abilities highly compatible with their organization's needs is a highly competent employee with high work performance. This results in high job satisfaction for the employee from their work environment or organization, as well as possibly a greater salary, a promotion, a sense of accomplishment, a sense of responsibility, or high self-esteem. Increasing these intrinsic and extrinsic factors of satisfaction affects intention to stay. Furthermore, extrinsic satisfaction strongly influences intrinsic satisfaction [19,20]. Therefore, the following hypotheses were proposed in this study:

Hypothesis H6. *Intrinsic satisfaction mediates the relationship between job competency and intention to stay.*

Hypothesis H7. *Extrinsic satisfaction mediates the relationship between job competency and intention to stay.*

Hypothesis H8. *Job competency influences intrinsic satisfaction through extrinsic satisfaction, ultimately influencing intention to stay.*

2. Materials and Methods

2.1. Sample and Procedure

This study adopted a cross-sectional design. All certificated long-term care institutions in Taichung city, Taiwan were surveyed, including 26 nursing homes and 15 elderly welfare institutions. All nursing assistants from those institutions were interviewed using a self-designed structured questionnaire for a quantitative investigation and analysis. The study was reviewed and approved by the institutional review board (IRB) of the Taichung Jen-Ai Hospital (No: 10817). The researchers visited the institutions to explain the purpose and procedure of the study and emphasized the voluntariness, privacy, and confidentiality of the participants. Participant willingness to participate was determined by whether they were willing to answer the questionnaire and submit their responses to us. Sealed envelopes containing a brief description of the study, the questionnaire, and a return envelope were distributed to the participants, who were required to complete the questionnaire within two weeks and return it using the return envelope. In addition, one NT $100 voucher for 7-Eleven was included in each of the sealed envelopes to increase the participation rate. A total of 383 questionnaires were distributed, and 333 valid questionnaires were recovered, yielding a recovery rate of 87%. The four major components of the questionnaire were personal information, scales on job competency, job satisfaction, and intention to stay.

2.2. Job Competency Scale

After an extensive review of the available literature, the job competency scale employed in this study was adapted from the "Long-term care, supports, and services competency model" [33]. The model has five domains: those related to personal effectiveness, academic, workplace, industry-wide technical, and industrial-sector technical competencies. Among them, "industry-wide technical competency" was used to refer to job competency in the long-term care industry and was measured using seven aspects: (1) long-term care, supports, and services; (2) supporting daily living; (3) crisis prevention and conflict resolution; (4) ethics; (5) documentation; (6) laws and regulations; and (7) patient health and safety.

The Aspect 5 and 6 were excluded from the final questionnaire because the respondents of this study were frontline nursing assistants and not managers. The self-designed job competency scale used in this study for frontline nursing assistants consisted of 21 items in five dimensions (Aspects 1 through 4, and Aspect 7) (see Appendix A). Six experts reviewed the questionnaire with a content validity index (CVI) of 0.94. These items were scored using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) and were combined into a formative measurement construct.

To explore the structure of the job competency scale, an exploratory factor analysis (EFA) was conducted. Five dimensions were identified that explained 72.7% of the variability. As shown in Table 1, the job competency scale and its subscales showed very good internal consistency (job competency scale: Cronbach's α = 0.87; long-term care, supports, and services: Cronbach's α = 0.849; supporting daily living: Cronbach's α = 0.829; crisis prevention and conflict resolution: Cronbach's α = 0.849; ethics: Cronbach's α = 0.898; patient health and safety: Cronbach's α = 0.787).

Table 1. Reliability and convergent validity of the reflective metrics.

Dimension	Variable	Loading	T-Value	CR	AVE	α Value	VIF
Long-term care support and services	Self1	0.864	53.928	0.898	0.688	0.849	2.489
	Self2	0.828	36.829				2.262
	Self3	0.806	36.015				1.897
	Self4	0.819	33.477				1.912
Support daily living	Sub1	0.723	23.764	0.880	0.595	0.829	1.449
	Sub2	0.801	32.910				1.834
	Sub3	0.790	31.236				1.750
	Sub4	0.752	23.639				1.659
	Sub5	0.787	30.305				1.712
Crisis prevention and conflict resolution	BE1	0.833	35.182	0.888	0.664	0.849	1.944
	BE2	0.865	53.66				2.123
	BE3	0.793	30.116				1.684
	BE4	0.766	22.796				1.568
Ethics	Eth1	0.872	52.974	0.924	0.710	0.898	3.197
	Eth2	0.849	44.485				2.823
	Eth3	0.858	46.891				2.614
	Eth4	0.815	37.159				2.080
	Eth5	0.817	29.521				2.278
Patient health and safety	Heal1	0.849	43.785	0.876	0.702	0.787	1.835
	Heal2	0.861	44.928				1.893
	Heal3	0.801	35.664				1.443
Intrinsic satisfaction	IS1	0.750	28.564	0.945	0.588	0.936	2.442
	IS1	0.760	29.214				2.467
	IS2	0.750	25.273				2.302
	IS3	0.810	41.448				2.627
	IS4	0.733	23.300				2.164
	IS5	0.794	36.666				2.526
	IS6	0.641	17.457				1.679
	IS7	0.722	25.480				1.968
	IS8	0.810	41.314				2.817
	IS9	0.824	43.910				3.036
	IS10	0.835	47.396				3.858
	IS11	0.751	25.156				2.484
	IS12	0.750	28.564				2.442
Extrinsic satisfaction	ES1	0.794	23.752	0.922	0.6	0.902	3.872
	ES2	0.853	44.066				4.613
	ES3	0.844	44.579				3.738
	ES4	0.825	35.895				2.775
	ES5	0.804	32.266				2.572
	ES6	0.594	10.733				1.553
	ES7	0.661	13.385				1.892
	ES8	0.785	31.653				2.209
Intention to stay	Stay1	0.972	192.901	0.972	0.946	0.943	4.931
	Stay2	0.974	213.064				4.931

2.3. Job Satisfaction Scale

The Minnesota Satisfaction Questionnaire [34] was referenced and revised to create a measure of job satisfaction. The scale had 12 and 8 items for the intrinsic and extrinsic satisfaction dimensions, respectively. Intrinsic satisfaction refers to the values, sense of responsibility, sense of belonging, and social standing originating from the work itself, whereas extrinsic satisfaction refers to salary and benefits, promotion, on-the-job training, and feelings from interactions with managers and coworkers. The 20 items were scored using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The Cronbach's alpha reliability coefficient of job satisfaction in this sample was 0.923.

2.4. Intention to Stay

The scale of Milliman, Gatling, and Kim was referenced and revised to measure whether nursing assistants intended to remain in their job at present and in the long term [24]. The two items were "I currently intend to continue in my work as a nursing assistant" and "I intend to still be a nursing assistant a year from now"; they were scored using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The Cronbach's alpha reliability coefficient of intention to stay in this sample was 0.943.

2.5. Reliability and Validity of the Model

The construct of the job competency scale used in this study was first-order reflective, second-order formative. Formative metrics do not need to be measured for internal consistency or reliability [35] but must prevent overly strong correlations among the measurement variables, which prevents overly high collinearity. For this purpose, variance inflation factor (VIF) values were calculated; if VIF > 10, the collinearity was too high. The VIFs of the formative metrics in this study were between 1.55 and 3.07, indicating that the job competency scale did not have any collinearity issues. The VIF values for all items are presented in Table 1. The standardized root-mean-square residual (SRMR) was used to evaluate the fit of the study model. An SRMR for the saturated and estimated models smaller than 0.08 indicated an acceptable model fit [36]. The SRMR for the saturated and estimate models in this study was 0.74, indicating that the models had an acceptable fit. The individual item reliability indicated the factor loading that the measurement variables had on the latent variables and tested each factor loading for statistical significance. All factor loadings in this study were greater than the suggested value of 0.5, indicating significance. The factor loading values of the sample were 0.594–0.974, meeting the threshold suggested by Hair et al. [37] (Table 1).

The measurement model of this study's reflective indicators was appraised by calculating the individual item reliability, composite reliability (CR), and average variance extracted (AVE). The CR of the latent variables was the composite of the reliability of all the measurement variables and represented the internal consistency of the constructed index. Higher reliability indicated higher internal consistency of the latent variables. China suggested a CR of 0.7 or greater [38]; Table 1 shows that the CR for each variable in this study was between 0.880 and 0.972, greater than the 0.7 standard, indicating favorable internal consistency. The AVE of the latent variables indicated the power of each measurement variable to explain the latent variable; higher AVE indicated that the latent variable had higher discriminatory validity and convergent validity. Fornell and Larcker suggested that the AVE must be greater than 0.5 [39]; as detailed in Table 1, the AVEs of the latent variables were between 0.588 and 0.710, all greater than the 0.5 standard value, indicating that the reflective measurement variables had favorable convergent validity.

Lastly, discrimination validity was measured by calculating the square root of the AVE. If the square root was greater than the other coefficients in the same construct, the relationships among the latent constructs were weaker than the relationships within the construct, indicating that the measurement model had favorable discrimination validity. Because the formative metrics do not require measurement of the square root of the AVE [40], only the square root of the AVE for the reflective metrics was measured and the matrix compared. This study was greater than the coefficients of every dimension (Table 2). Therefore, the dimensions had high discrimination validity.

Table 2. Matrix of latent constructs in the measurement model.

Constructs	Mean	SE	1	2	3	4	5	6	7	8	9
1	16.96	2.30	**(0.83)**								
2	21.66	2.43	0.659	**(0.77)**							
3	17.22	2.14	0.531	0.674	**(0.82)**						
4	22.57	2.52	0.519	0.66	0.651	**(0.84)**					
5	12.93	1.61	0.603	0.735	0.672	0.596	**(0.84)**				
6	48.53	6.58	0.546	0.579	0.546	0.471	0.553	**(0.77)**			
7	31.34	4.91	0.403	0.414	0.403	0.35	0.419	0.753	**(0.78)**		
8	91.36	9.26	0.817	0.769	0.817	0.751	0.831	0.663	0.499	NA	
9	8.20	1.77	0.332	0.314	0.332	0.378	0.327	0.549	0.553	0.404	**(0.97)**

Note 1: 1. Long-term care, supports, and services; 2. Supporting daily living; 3. Crisis prevention and conflict resolution; 4. Ethics; 5. Patient health and safety; 6. Intrinsic satisfaction; 7. Extrinsic satisfaction; 8. Job competency; 9. Intention to stay. Note 2: NA indicates that formative metrics do not require measurement of the square root of the AVE. Note 3: The square root of the AVE values shown in bold represent.

2.6. Data Analysis

The causal model between the latent variables was analyzed using partial least squares (PLS) for constructing predictive models. The PLS method is suitable for simultaneously constructing formative and reflective models for measuring variables; the obtained models are superior to general linear structural relationship models, so PLS is suitable for exploratory research. PLS can accept dimensions with a single item and is not limited by variable allocation or the number of sizes; it has satisfactory predictive and explanatory abilities [41]. In this study, the measurement and structural models were analyzed using SmartPLS. The bootstrap resampling method was then used to draw 5000 samples as parameter calculations and inferences for estimation [42].

3. Results

3.1. Demographics and Characteristics

The vast majority of the respondents were women (n = 281; 84.4%); only 52 of the respondents were men (15.6%). Furthermore, 72 respondents were 30–39 years (21.6%), whereas 71 were 40–49 years (21.3%), 94 were 50–59 years (28.2%), and 43 were 60 years or older (12.9%). The mean age of the respondents was 44.24 (standard deviation = 12.54). Regarding level of education, 68 respondents had a junior high school education or lower (20.4%), 128 had a high school or technical school education (38.4%), and 70 had a junior college education (21%). Regarding marital status, 221 of the nursing assistants were married (66.4%), whereas 112 were unmarried (including divorced or widowed; 33.6%). Most of the respondents were employed in a nursing home (236 respondents, 70.9%), but 97 worked in an elderly welfare institution (29.1%). Regarding work experience, 86 respondents had 5–10 years of experience (25.8%), and 109 respondents had 10 or more years of experience (21.7%). The average number of years of experience was 7.5 years. The average number of cases per respondent was 12.74, and the average number of daily work hours was 9.18 hours.

To prevent and mitigate CMV problems, pretest prevention and post-test detection were employed in this study [43]. The pretest prevention involved respondents completing the questionnaire anonymously. For the post-test detection, Harman's single factor test was used to extract six factors with eigenvalues greater than 1 under unrotated circumstances; the cumulative explained variance was 64.6%, and the explained variation of the first factor was 40.01%, which was smaller than 50%. Therefore, the preliminary determination was that CMV had little effect.

3.2. Mediation Regression Models of Study Variables

Using PLS to estimate the path relationships for each dimension, the path values are represented using standardized coefficients, which are detailed in Figure 1. Extrinsic satisfaction had a positive effect on intrinsic satisfaction ($\beta = 0.625$, $t = 17.204$, $p < 0.001$); therefore; H1 was supported. Nursing assistants' job competency also had a positive effect on their intrinsic satisfaction ($\beta = 0.345$, $t = 8.995$, $p < 0.001$), indicating that H2 was supported. This study thus found that greater job competency led to higher intrinsic satisfaction. Together, these effects explained 72% of the variance in intrinsic satisfaction. Nursing assistants' job competency had a positive effect on extrinsic satisfaction (β = 0.488, t = 10.733, $p < 0.001$); therefore, H3 was supported. Greater job competency led to higher intrinsic satisfaction. This effect explained 23.8% of the variance in extrinsic satisfaction. Nursing assistants' intrinsic satisfaction had a positive effect on their intention to stay (β = 0.237, t = 2.104, $p < 0.05$); therefore, H4 was supported. Nursing assistants' extrinsic satisfaction had a positive effect on their intention to stay (β = 0.321, t = 3.303, $p < 0.01$); therefore, H5 was supported.

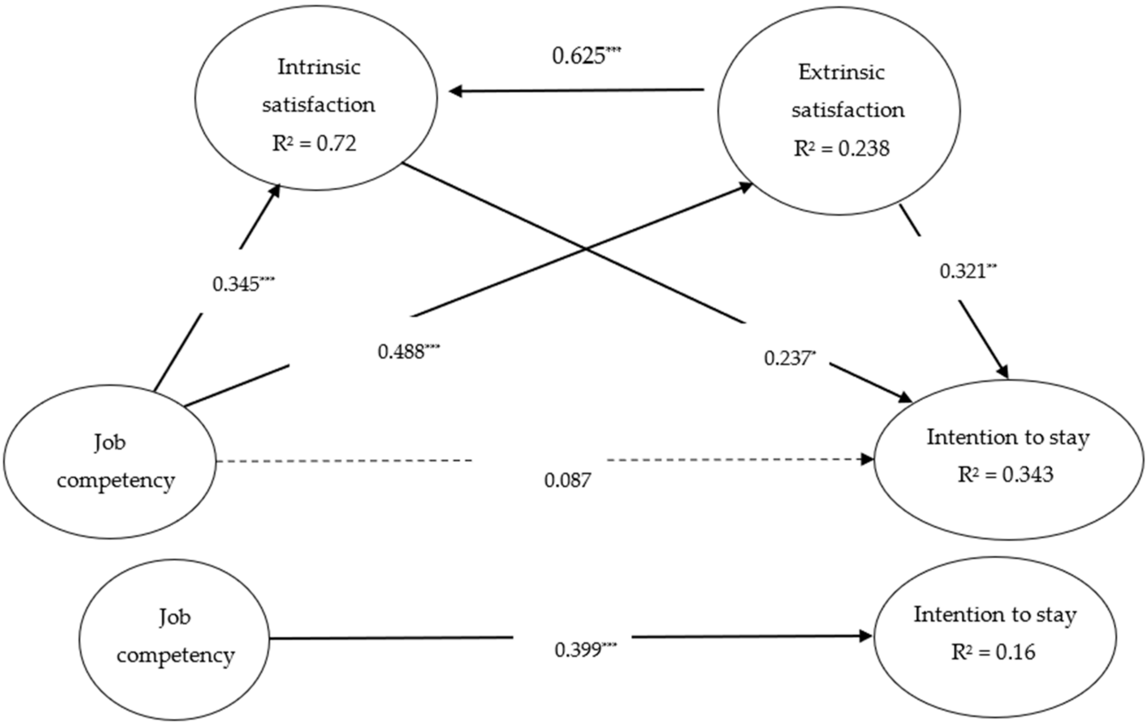

Figure 1. Theoretical model. Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

The study used Hair et al.'s, (2016) steps to apply Preacher and Hayes' approach to the mediation model. First, the study confirmed the direct effect between job competency and intention to stay. This effect was positive and significant (β = 0.399, t = 7.502; $p < 0.001$; Figure 1). The second step consisted of including the effect of the mediator variable (intrinsic and extrinsic satisfaction). The indirect effect was positive and significant (H2, H3, H4, and H5 were supported; Figure 1). The mediating effect completely suppressed the direct effect, because the direct relationship between job competency and intention to stay had a β = 0.087, t = 1.106; $p > 0.05$, thus producing mediation.

The study analyzed the indirect effects using the bootstrap procedure described (Hair et al., 2016). If the 95% CI of the mediation effect did not contain 0, the mediation effect was significant—that is, a mediation effect existed. The effect of job competency on intention to stay through intrinsic satisfaction was 0.082 (standard error (SE) = 0.074, 95% CI (0.009, 0.158)). The effect of job competency on intention to stay through extrinsic satisfaction was 0.157 (standard error (SE) = 0.048, 95% CI (0.065, 0.256)). The indirect effect on intention to stay from job competency influencing intrinsic satisfaction through extrinsic satisfaction was 0.072 (SE = 0.037, 95% CI (0.006, 0.150)). The three paths did not contain zero, indicating that mediation effects existed, and H6–H8 were supported (Table 3).

Table 3. Hypothesis constructs.

Effect	Relations	Estimate	SE	95% CI LL	95% CI UL	Support
Direct						
	H1: ES–IS	0.625 ***	0.036			Yes
	H2: JC–IS	0.345 ***	0.038	0.584	0.715	Yes
	H3: JC–ES	0.488 ***	0.045	0.410	0.584	Yes
	H4: IS–ITS	0.237 *	0.113	0.016	0.434	Yes
	H5: ES–ITS	0.321 **	0.097	0.135	0.497	Yes
Mediating						
	H6: JC–IS–ITS	0.082 *	0.074	0.009	0.158	Yes
	H7: JC–ES–ITS	0.157 ***	0.048	0.065	0.256	Yes
	H8: JC–ES–IS–ITS	0.072 *	0.037	0.006	0.150	Yes

Note 1: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. Note 2: IS: intrinsic satisfaction, ES: extrinsic satisfaction; JC: job competency; ITS: intention to stay.

4. Discussion

Studies on job satisfaction have typically analyzed job satisfaction using a single dimension [9,10]. Tsounis and Sarafis (2018) stated that job satisfaction is a multidimensional concept, and the present study discovered that extrinsic job satisfaction directly influences intrinsic job satisfaction. This signifies that the external factors affecting satisfaction—such as salary—influence the satisfaction employees gain from internal factors affecting satisfaction—such as a sense of accomplishment, a sense of responsibility, and self-esteem. A similar conclusion was made by another study [20]. Furthermore, this study verified the relationships among job competency and intrinsic and extrinsic job satisfaction, discovering that more competent employees are more likely to experience high job satisfaction. This matches the findings of several studies [21]. Scholars have argued that closer person–job fit is linked to higher job competency and job satisfaction. Employees' job satisfaction influences their intention to stay in their job; this has been verified in many studies [30,44]. The present study also verified the influences of intrinsic and external satisfaction on intention to stay.

Most critically, this study discovered that the relationship between employees' job competency and intention to stay was subject to the mediating influences of intrinsic and extrinsic job satisfaction. Morley et al. supported this conclusion in their study [32], arguing that when individuals' job competencies are compatible with the organization's needs, the individuals display a positive work attitude and receive compensation and a sense of accomplishment due to their high work performance; consequently, the individuals have greater job satisfaction and stronger intention to stay. The relationship between an individual's job competency and intention to resign is not a direct relationship; more competent employees have stronger intention to stay providing they are satisfied with their job. Similar conclusions were drawn in another study [45].

Recent studies have shown that long-term care workers with higher job competency may pursue career development by resigning from their current jobs [5] because of the gap that exists between their job competency and job satisfaction. This study extended the above concept and explored whether job satisfaction mediated the relationships between ability and intention to stay. The study results verified said mediation effects; that is, for employees with a closer person–job fit and higher job competency, the organizations can offer them salaries commensurate with their performance, and assign them tasks to meet their satisfaction for self-growth, thereby increasing their intention to stay.

Unlike other studies, this study found that job satisfaction has a mediating influence on the relationship between job competency and intention to stay, with extrinsic satisfaction having the strongest effect. This indicates that more competent employees prioritize their extrinsic satisfaction and increase their intrinsic satisfaction through extrinsic satisfaction, ultimately influencing their intention to stay. This is the principal conclusion of this study, and it has not been posited by any other study. In the argument of Maslow that human behavior is caused by needs not being met, the hierarchy of needs must be addressed starting from the lowest level—the deficiency needs—and progress to the highest level—growth needs [46]. This study verified that job satisfaction needs are met starting from the most basic hygiene factors, and when the lowest level of deficiency needs are met, growth needs become important. An employee's job competency affects whether they receive a decent salary and thus have extrinsic job satisfaction; when extrinsic satisfaction is met, the individual's sense of accomplishment and confidence in their work rises, increasing their intrinsic satisfaction and ultimately strengthening their intention to stay.

Retaining care staff is vital to long-term care institutions. To address staff shortages and staff being unlikely to remain in the long-term care sector, organizations should first improve the competency of employees. More competent employees can provide higher quality care, and organizations should be willing to provide attractive benefits that increase employees' extrinsic satisfaction. Furthermore, greater job competency leads to more recognition and approval from residents or family members and, therefore, a sense of accomplishment, increasing intrinsic satisfaction and favorably influencing intention to stay.

Therefore, two suggestions are made herein. Shaheen et al. reported that increasing individuals' professional effectiveness significantly influences the individuals' sense of accomplishment and job satisfaction [47], and strategies that take advantage of this fact and improve job competency through training have been proven to help nursing assistants manage problematic behaviors relating to dementia, consequently increasing their job satisfaction [48]. Therefore, training that strengthens nursing assistants' job competencies to meet an organization's staffing needs is key to strengthening intention to stay [49,50].

Second, nursing assistants are compensated less well than those working in other medical industries. Typically, people in this profession have lower socioeconomic status, come from single-parent families, or are from an ethnic minority [51]. Furthermore, the stereotype of this type of work having a poor professional image, involving overly long work hours, and causing excessive stress is widespread in society (Chien, 2019). Therefore, increases in nursing assistants' extrinsic satisfaction, such as their salary, are urgently required; government agencies and long-term care facilities should establish systems for advancing or grading nursing assistants' competencies. Scholars reported that nursing assistants have less favorable opportunities and channels of promotion than those working in other sectors [52]. Therefore, if nursing assistants' competencies could be graded or a standard for advancement could be established, nursing assistants could continue to improve their professional abilities and facilities could employ the competency grading to decide upon salaries and compensation for different types of work and increase nursing assistants' extrinsic satisfaction. Lastly, organizations should take action to increase intrinsic job satisfaction, such as by providing greater psychological empowerment [53], increasing work autonomy [54], or increasing individuals' sense of accomplishment [9].

This study was subject to some research limitations. First, the number of respondents in this study was insufficient, and if sufficient resources are available in the future for a more extensive investigation, the study results would be more reliable. The cross-sectional nature of the study is its second main limitation. Although we used PLS to analyze the causal model between the latent variables, it is inappropriate to draw causal conclusions. Future studies should collect and analyze data employing longitudinal designs to provide evidence for reciprocal relations and longitudinal mediation and moderation effects. Finally, the current study discussed the mediating effects on nursing assistants' job competency and intention to stay using only two factors: intrinsic and extrinsic satisfaction. Aloisio et al. stated that support from leaders [6], work autonomy, organizational slack, and perceived psychological empowerment are strongly correlated with job satisfaction. Furthermore, Park et al. argued that work stress [55], the degree of work centrality, and self-efficacy have significant influences on long-term nursing assistants' job satisfaction. Future studies are suggested to further consider using these factors to investigate the moderating or mediating effects between job competency and intention to stay.

5. Conclusions

This study investigated the relationships between job competency and intrinsic and extrinsic job satisfaction. This study discovered that more competent employees have greater job satisfaction and thus a stronger intention to stay. Furthermore, this study found that intrinsic and extrinsic job satisfaction play a mediating role between job competency and intention to stay; more significantly, job competency was found to first influence extrinsic satisfaction and then, through extrinsic satisfaction, influence intrinsic satisfaction to ultimately affect nursing assistants' intention to stay. Concrete suggestions are provided to long-term care facilities seeking to retain their nursing assistants.

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Appendix A

Long-term care support and services

1. I can improve my knowledge of long-term care and continue to learn.
2. I can self-examine and improve the deficiencies for caring for the residents.
3. I participate in professional skills education and training for care services at least twice a year.
4. I will pay attention to long-term care policies and development trends.

Support daily living

1. My care skills are proficient and can ensure the quality of residents' care.
2. I can help and encourage residents to take in balanced nutrition (including tube-feeding diet).
3. I can assess the psychological condition of the residents and respond in a timely manner.
4. I can provide disease prevention and care for residents.
5. I can help maintain the personal hygiene of the residents.

Crisis prevention and conflict resolution

1. I can build a relationship of trust with residents or family members.
2. I can use communication skills to interact with peers or work partners.
3. I can respect the opinions of my employer.
4. I can express my thoughts appropriately.

Ethics

1. I will not do anything to harm the residents.
2. I will protect the privacy and dignity of the residents.

3. I take my due care responsibilities with all my heart.
4. I abide by work regulations and requirements.
5. I will respect the ideas and wishes of the residents.

Patient health and safety

1. I can assess the changes in the physiological condition of the residents and inform the healthcare personnel if necessary.
2. I will assist in the emergency response and handling of accidents (e.g., fires, natural disasters) to ensure the safety of residents.
3. I can assist in dealing with incidents (e.g., falls, slippage of pipes) and solve the problem correctly.

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Article

Factors Affecting the Competence of Nursing Assistants in Taiwan Long-Term Care Institutions

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Abstract: With the increasing number of people with disabilities caused by an aging global population, the need for long-term care is gradually increasing. Nursing assistants (NAs) are the primary providers of direct care services to older adults with disabilities, whose knowledge, skills, and beliefs affect the quality of care provided. This study aimed to investigate the influential factors affecting NAs' current competences. A total of 255 NAs' valid questionnaires were collected from 20 long-term care institutions in Taiwan through convenience sampling. The questionnaire comprised dimensions of demographics and care competence. The study results indicated that NAs had the greatest care competence in the domain of recognition of patient rights (4.64 ± 0.54 points). The multiple regression indicated that age, religion, job category, disability care experience, the receiving of performance bonuses, and the receiving of year-end bonuses significantly affected the level of care competence ($p < 0.05$). With the aforementioned findings, the results of this study serve as references for the government in employing long-term care NAs and developing management policies. Training programs for NAs should be developed to improve the quality of care provided to older adults with disabilities.

Keywords: care competence; nursing assistants; disabled elderly; long-term care

1. Introduction

An aging population is a serious problem of global concern. According to statistics from the United Nations, 9% of people worldwide were >65 years old in 2019, and this figure is projected to increase to 16% by 2050 [1]. Taiwan's society became an aged society in 2018, and it is estimated to become a super-aged society by 2026 [2]. Similar to other developed countries, Taiwan's low total fertility rate has transformed family structures in Taiwan. Consequently, care functions from familial support have declined, and this has, in turn, increased the long-term care (LTC) needs and social burden in Taiwan. Therefore, the promotion of LTC has become an urgent policy matter in Taiwan and many other countries.

LTC types in Europe and North America involve assisted living facilities, skilled nursing facilities, continuing-care retirement communities, medical foster care, and home health care. However, institutional LTC in Taiwan includes LTC institutions, retirement homes, and nursing homes. Nursing assistants (NAs) account for 66%–70% of care manpower but are engaged in 80–90% of care work [3–5]. Therefore, NAs are an indispensable source of manpower for LTC institutions. Low wages, lack of good benefits, heavy workload, and lack of promotion channels are all restrictions on the personal and professional development of NAs [6]. In addition, the care competence of NAs is highly correlated with LTC quality [7–10].

Studies have indicated the importance of professional health care knowledge, efficient interpersonal communication techniques, and moral responsibility in ensuring that the care services rendered to older adults by NAs are of satisfactory quality [11,12]. NAs' core care competences comprise knowledge on health care, care plan formulation, communication skills, cross-professional team care, safety, professional responsibilities, and ethics [13]. NAs are assistive personnel without formal academic certificates who must undergo training on body mechanics, nutrition, anatomy and physiology, cognitive impairments, mental health, infection control, and personal care skills [14,15]. A recent study indicated that NAs must possess the following care competences for professional and high-quality care: autonomy, daily functioning prevention of health problems, healthy aging and wellbeing, involvement of informal care, collaboration between professionals, and informal care [16]. However, a study indicated that education and training programs are not the primary determinants of NA care quality [17]. The development of leadership skills and services, including personal improvement, civic engagement, communication, and professionalism are also affecting factors [5]. By contrast, LTC institutional culture and LTC feedback to NAs regarding their work performance are the crucial determinants [18]. A recent study done in Australia reported that NAs did not improve in their care competences with experience; however, NAs with more than 5 years of work experience tended to exhibit a more positive work attitude [19].

As indicated in the aforementioned studies, the demand for NAs has been in increasing. NAs are the primary providers of direct care services to older adults with disabilities, and their knowledge, skills, and beliefs affect the quality of care provided. However, the literature on Asia has rarely explored the occupational competences of NAs. Therefore, the present study in Taiwan investigated (1) which critical care competences NAs must possess in providing care to individuals with disabilities and (2) the main factors affecting these care competences of NAs.

2. Materials and Methods

2.1. Study Design

This cross-sectional study identified prospective participants from 20 assisted living residences, retirement homes, and nursing homes through convenience sampling; these institutions were situated in Northern Taiwan (7 institutions), Central Taiwan (7 institutions), Southern Taiwan (4 institutions), and Taiwan's outlying islands (2 institutions). Questionnaires were distributed in July 2019 to prospective participants. This study protocol was approved by the Institutional Review Board of China Medical University Hospital, Taiwan (CMUH107-REC2-166), with accreditation by the international association accreditation research protection programs (AAHRPP).

2.2. Sample and Setting

Participants had to satisfy the following inclusion criteria: they had to be (a) individuals with NA training qualifications obtained in Taiwan, (b) NAs who had cared for five or more older adults with disabilities, (c) NAs with >6 months of experience in caring for older adults with disabilities, and (d) lucid individuals who could complete the questionnaire and communicate in either Mandarin Chinese or Taiwanese Hokkien. Both Mandarin Chinese and Taiwanese Hokkien are native languages in Taiwan. Thus, there was no need for language translation in the study. In total, 269 NAs completed the questionnaire, and 255 of them provided valid questionnaires, for a response rate of 95%.

2.3. Measures

This study used structured questionnaires to collect data. NAs responded to the questionnaires independently. The demographic variables comprised sex, age, monthly salary, bonus, nationality, marital status, level of education, previous disability care experience, religion, education level, college major, nationality, job category, employment type, years of experience, and average hours worked daily. Care competence-related data were collected using the Perceived Caring Ability Assessment Scale of Nurse-Aides in Long-Term Care Facilities developed by Tsai (2013), who approved this study's use of the scale [20]. This scale comprises six dimensions and 50 items. All items were scored on a 5-point Likert scale, with 1 representing strongly disagree and 5 representing strongly agree. The dimensions (and the number of items in them) are as follows: assistance in daily activities (13), medical professionalism (14), mental and spiritual care (14), professional ethics acknowledgment (4), health education and literacy (3), and recognition of patient rights (2). The Cronbach's alpha of each dimension was between 0.81 and 0.96. After an expert validity analysis conducted by 10 experts, the content validity index of the scale was noted to be 0.92–0.95.

2.4. Statistical Analysis

Descriptive statistics were used to summarize distributions of NAs' characteristics, including demographics, the types and characteristics of their workplaces, and the score of care competence. The differences between NAs' demographics, the types and characteristics of their workplaces, and care competences were examined using a t test and analysis of variance (ANOVA). According to the sample size and related experts and scholars in Taiwan, the years of experience were categorized into <1, ≥1 and <3, ≥3 and <5, ≥5 and <10, and ≥10 years. The monthly salary of the study was divided into four groups according to the payroll bracket table of the National Health Insurance Administration, Taiwan. Moreover, after all other relevant variables were controlled for, and multiple regression was conducted to determine the crucial factors affecting NAs' competences in caring for older adults with disabilities. IBM SPSS Statistics for Windows version 22.0 (IBM Corp., Armonk, NY, USA) was used to conduct statistical analysis. Statistical significance in this study was defined as $p < 0.05$.

3. Results

Table 1 presents the data on the participating NAs' demographic characteristics and overall care competence level. The majority were female (86.3%) and married (60.8%). For the age variable, most participants were in the 31–40 year old group (28.6%), followed by the 41–50 year old group (25.1%). The ≥61 year old group was the smallest (7.5%). For level of education, 78% of the participants graduated from high school or above. Only 29.4% of the participants graduated in a health-related major. For job category, most of the participants worked in nursing homes (56.9%). Almost all of them were full-time workers (95.3%). The proportion of participants with 5 years of experience or longer reached 45.4%. Most of the participants worked an average of 8–12 h daily (76.9%). Only 39.6% of the participants had previous disability care experience. Among the participants, 69.4% had a monthly salary reaching NT$27,001 or above; 65.5% had been receiving work performance bonuses, and 78.8% had been receiving year-end bonuses. In terms of care competence, the participants with an age of 51–60 years, a native-Taiwanese nationality, 5 years of experience or more, previous disability care experience, work performance bonuses, and year-end bonuses exhibited greater care competences. The results reached statistical significance ($p < 0.05$).

Table 2 depicts the importance of NAs' care competence domains to care for individuals with disabilities. The recognition of patient rights was the most important domain, followed by health education and literacy, professional ethics acknowledgment, assistance in daily activities, medical professionalism, and mental and spiritual care.

Table 1. The overall competence level of disability nursing assistants.

Variables	**Overall Competence Level (*N* = 255)**						***p*-Value**
	N	**%**	**Score**				
			Sum	**Mean**	**±**	**SD**	
Age (year)							0.03
20–30	41	16.1	166.5	4.06	±	0.47	
31–40	73	28.6	287.8	3.94	±	0.49	
41–50	64	25.1	256.7	4.01	±	0.44	
51–60	58	22.7	244.0	4.21	±	0.44	
≥61	19	7.5	77.2	4.06	±	0.43	
Sex							0.07
Male	35	13.7	137.0	3.91	±	0.54	
Female	220	86.3	895.2	4.07	±	0.45	
Marital status							0.76
Married	155	60.8	630.0	4.06	±	0.48	
Single	82	32.2	329.4	4.02	±	0.47	
Divorced/separated	18	7	72.7	4.04	±	0.30	
Religion							0.25
None	59	23.1	233.5	3.96	±	0.43	
Buddhism	76	29.8	309.8	4.08	±	0.42	
Christianity/Catholicism	58	22.7	240.1	4.14	±	0.52	
Taoism	60	23.5	241.1	4.02	±	0.50	
Other	2	0.9	7.7	3.85	±	0.04	
Level of education							0.78
Elementary or lower	12	4.7	48.5	4.04	±	0.34	
Middle school	44	17.3	175.2	3.98	±	0.43	
High school	91	35.7	367.0	4.03	±	0.44	
Trade/Technical college	60	23.5	245.7	4.09	±	0.55	
University or above	48	18.8	195.8	4.08	±	0.45	
Graduated with majors							0.36
Healthcare-related	75	29.4	306.7	4.09	±	0.47	
Else	180	70.6	725.5	4.03	±	0.46	
Nationality							0.03
Native	234	91.8	951.5	4.07	±	0.46	
Non-native	21	8.2	80.7	3.84	±	0.49	
Job category							0.87
Retirement home	18	7.1	72.2	4.01	±	0.48	
Assisted living	49	19.2	199.6	4.07	±	0.42	
Long-term care	11	4.3	44.4	4.04	±	0.45	
Adult day-care	16	6.3	65.0	4.07	±	0.44	
Nursing home	145	56.9	588.5	4.06	±	0.50	
Home care	16	6.2	62.5	3.90	±	0.29	
Employment type							0.06
Full-time	243	95.3	986.5	4.06	±	0.46	
Part-time	12	4.7	45.6	3.80	±	0.44	
Average daily work hours							0.54
Less than 4 h	3	1.2	11.2	3.72	±	0.31	
4–7 h	50	19.6	200.7	4.01	±	0.42	
8–12 h	196	76.9	795.4	4.06	±	0.48	
12 h or more	6	2.3	24.9	4.15	±	0.42	

Table 1. *Cont.*

Variables	**Overall Competence Level (N = 255)**						
	N	**%**	**Score**				***p*-Value**
			Sum	**Mean**	**±**	**SD**	
Years of experience							<0.01
<1 yr	31	12.2	121.5	3.92	±	0.47	
≥1 and <3 yrs	56	22.0	217.0	3.87	±	0.45	
≥3 and <5 yrs	52	20.4	211.3	4.06	±	0.44	
≥5 and <10 yrs	63	24.7	259.7	4.12	±	0.48	
≥10 yrs	53	20.7	222.6	4.20	±	0.43	
Previous disability care experience							<0.001
Yes	101	39.6	421.5	4.17	±	0.44	
No	154	60.4	610.7	3.97	±	0.47	
Monthly salary (NTD)							0.13
22,001–27,000	78	30.6	311.6	3.99	±	0.44	
27,001–32,000	84	32.9	336.8	4.01	±	0.48	
32,001–37,000	76	29.8	315.7	4.15	±	0.46	
≥37,001	17	6.7	68.1	4.00	±	0.49	
Performance bonus							<0.01
Yes	167	65.5	686.3	4.11	±	0.47	
No	88	34.5	345.9	3.93	±	0.43	
Year-end bonus							0.04
Yes	201	78.8	820.0	4.08	±	0.47	
No	54	21.2	212.2	3.93	±	0.44	

Table 2. Domains of competency level in disability nursing assistants.

Domain	**Mean**	**SD**	**Rank**
Assistance in daily activities	4.30	0.52	4
Medical professionalism	4.30	0.55	4
Mental and spiritual care	3.91	0.62	6
Professional ethics acknowledgment	4.42	0.75	3
Health education and literacy	4.62	0.52	2
Recognition of patient rights	4.64	0.54	1

Table 3 presents the multiple regression results, which indicate the crucial factors affecting NAs' competences in caring for older adults with disabilities in each domain. Relative to NAs aged 20–30 years, NAs aged 51–60 years had significantly greater care competence in the domains of assistance in daily activities ($\beta = 0.22$, $p < 0.01$), medical professionalism ($\beta = 0.18$, $p = 0.02$), and mental and spiritual care ($\beta = 0.25$, $p < 0.01$). Furthermore, compared with NAs without religion, NAs with the religion of Christianity/Catholicism ($\beta = 0.26$, $p < 0.001$) and Taoism ($\beta = 0.20$, $p < 0.01$) had greater care competence in the domain of recognition of patient rights. In the domain of professional ethics acknowledgment, NAs working in assisted living residences ($\beta = 0.23$, $p = 0.04$) and adult day-care centers ($\beta = 0.20$, $p = 0.04$) exhibited greater care competence compared with NAs working in retirement homes. NAs with ≥5 and <10 years of experience ($\beta = -0.21$, $p = 0.02$) and ≥10 years of experience ($\beta = -0.19$, $p = 0.04$) exhibited lower care competence.

Table 3. Factors affecting competency level in different domains in disability nursing assistants.

Variables	**Assistance in Daily Activities**		**Medical Professionalism**		**Mental and Spiritual Care**		**Professional Ethics Acknowledgment**		**Health Education and Literacy**		**Recognition of Patient Rights**	
	β	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**
Age (year)												
20–30 (ref.)												
31–40	0.02	0.77	−0.04	0.66	−0.04	0.64	−0.08	0.30	−0.02	0.78	−0.01	0.87
41–50	0.07	0.39	0.04	0.57	0.02	0.78	−0.08	0.32	0.06	0.42	0.01	0.96
51–60	0.22	<0.01	0.18	0.02	0.25	<0.01	0.08	0.26	0.15	0.06	0.15	0.06
≥61	0.02	0.77	0.01	0.92	0.09	0.17	−0.11	0.11	0.08	0.24	0.06	0.37
Religion												
None (ref.)												
Buddhism	0.07	0.35	0.10	0.19	0.07	0.43	0.01	0.96	0.03	0.72	0.01	0.99
Christianity/Catholicism	0.09	0.24	0.01	0.58	0.04	0.64	0.05	0.48	0.09	0.23	0.26	<0.001
Taoism	0.16	0.05	0.13	0.10	0.15	0.05	0.06	0.43	0.15	0.05	0.20	<0.01
Other	0.13	0.05	0.12	0.06	0.16	<0.01	0.08	0.24	0.08	0.23	0.15	0.02
Level of education												
Elementary or lower (ref.)												
Middle school	0.06	0.58	−0.05	0.67	0.05	0.65	−0.07	0.78	−0.07	0.52	−0.09	0.44
High school	0.05	0.70	−0.03	0.86	0.08	0.55	−0.26	0.24	−0.03	0.81	−0.09	0.50
Trade/Technical college	0.03	0.82	−0.13	0.27	0.00	0.99	0.02	0.93	−0.05	0.66	0.02	0.84
University or above	−0.10	0.45	−0.17	0.18	−0.05	0.72	−0.09	0.69	−0.15	0.24	−0.19	0.14
Graduated with majors Healthcare-related (ref.)												
Else	0.04	0.54	0.06	0.35	0.07	0.25	−0.10	0.10	0.02	0.75	0.04	0.48
Nationality												
Native (ref.)												
Non-native	0.02	0.81	0.03	0.64	0.08	0.21	0.04	0.55	0.01	0.94	0.03	0.59
Job category												
Retirement home (ref.)												
Assisted living	0.04	0.71	0.10	0.39	0.13	0.23	0.23	0.04	0.02	0.84	0.10	0.36
Long-term care	−0.05	0.54	−0.06	0.50	−0.01	0.93	0.08	0.36	−0.10	0.25	−0.07	0.44
Adult day-care	0.04	0.70	0.10	0.30	0.01	0.87	0.20	0.04	0.02	0.80	0.09	0.30
Nursing home	0.07	0.59	0.14	0.29	0.03	0.80	0.22	0.09	−0.10	0.43	0.11	0.38
Home care	−0.02	0.81	0.06	0.53	0.10	0.26	0.14	0.11	−0.01	0.91	0.09	0.34

Table 3. *Cont.*

Variables	Assistance in Daily Activities		Medical Professionalism		Mental and Spiritual Care		Professional Ethics Acknowledgment		Health Education and Literacy		Recognition of Patient Rights	
	β	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**	**β**	***p*-Value**
Employment type												
Full-time (ref.)												
Part-time	−0.05	0.43	−0.06	0.38	0.03	0.64	0.03	0.67	−0.03	0.61	−0.02	0.75
Years of experience												
<1 yr (ref.)												
≥1 and <3 yrs	−0.02	0.84	−0.02	0.86	−0.08	0.39	−0.14	0.13	0.10	0.39	−0.08	0.38
≥3 and <5 yrs	0.08	0.40	0.10	0.29	−0.02	0.86	−0.09	0.31	−0.04	0.74	−0.12	0.19
≥5 and <10 yrs	0.03	0.71	0.03	0.76	−0.09	0.36	−0.21	0.02	−0.09	0.45	−0.11	0.25
≥10 yrs	0.11	0.17	0.08	0.35	0.02	0.77	−0.19	0.04	−0.07	0.64	−0.08	0.30
Previous disability care experience												
No (ref.)												
Yes	0.18	<0.001	0.18	<0.001	0.23	<0.001	0.09	0.17	0.12	0.05	0.16	<0.01
Monthly salary (NTD)												
22,001–27,000 (ref.)												
27,001–32,000	0.08	0.33	0.12	0.12	0.05	0.56	−0.04	0.63	−0.06	0.47	−0.03	0.74
32,001–37,000	0.05	0.50	0.09	0.27	−0.02	0.76	−0.10	0.19	−0.03	0.75	0.00	0.98
≥37,001	0.03	0.63	0.02	0.75	−0.01	0.92	−0.02	0.73	−0.04	0.59	−0.01	0.87
Performance bonus												
Yes (ref.)												
No	−0.13	0.19	−0.04	0.66	0.02	0.77	−0.13	0.04	−0.08	0.18	−0.08	0.23
Year-end bonus												
Yes (ref.)												
No	−0.08	0.40	−0.02	0.82	0.02	0.81	−0.16	0.05	−0.18	0.03	−0.11	0.08

NAs with previous disability care experience exhibited greater care competence levels in the domains of assistance in daily activities (β = 0.18, $p < 0.001$), medical professionalism (β = 0.18, $p < 0.001$), mental and spiritual care (β = 0.23, $p < 0.001$), and recognition of patient rights (β = 0.16, $p < 0.01$). Relative to those who did, NAs who were not receiving performance bonuses had lower care competence in the domain of professional ethics acknowledgment (β = –0.13, $p = 0.04$), and NAs who were not receiving year-end bonuses had lower health education and literacy (β = –0.18, $p = 0.03$).

4. Discussion

With the increasing number of people with disabilities caused by an aging global population, the need for long-term care is gradually increasing. NAs are the primary providers of direct care services to older adults with disabilities, and their knowledge, skills, and beliefs affect the quality of care provided. This study investigated (1) which care competences are crucial for NAs in caring for people with disabilities and (2) the main factors influencing these care competences. The results of the study indicate that NAs' care competence was greatest in the domain of recognition of patient rights, followed by health education and literacy, but poorest in the domain of mental and spiritual care. The NA's age, level of education, disability care experience, receiving performance bonuses, and receiving of year-end bonuses were correlated with their care competence.

Among the participating NAs who were taking care of older adults with disabilities, most were married women with a high school education or above. These demographic characteristics are similar to those noted in studies conducted outside of Taiwan [21]. However, this study's participating NAs were mostly 31–60 years old and were thus older than their overseas counterparts. This is possibly because most of the NAs in Taiwan are those who made a mid-career change from hospital caring to LTC. Compared with hospital caring work, LTC work is more stable [22,23].

NAs had the greatest care competence in recognition of patient rights, followed by health education and literacy, whereas mental and spiritual care was the lowest. This is attributable to the emphasis, by the Taiwanese LTC policies and by assessments of LTC institutions, on 1) care recipients' perspectives in requirements of older adult care quality and 2) the delaying of disability in care services. However, in Taiwan, patients bear the cost of LTC institutions' services, which are not covered by public health insurance. The ratio of NAs and care recipients in LTC institutions are on the high side to reduce the cost of long-term care. The daytime care ratio of NAs to care recipients ranges from 1:10 to 1:15, and the night-shift care ratio ranges from 1:25 to 1:30. Considering these labor constraints, the patient rights, daily activities, and health education competence are prioritized to the neglect of mental and spiritual care. Moreover, the education and training of mental and spiritual care among the training programs for NAs in Taiwan should be strengthened. Studies have also suggested that NA education and training should emphasize older adults' social and health care needs in the domains of autonomy, daily functioning, prevention of health problems, healthy aging, and collaboration with health care professionals [16,24]. The results of this study indicate that there is still room for improvement regarding the training programs of mental and spiritual care for NAs in Taiwan.

The participating NAs who were aged 51–60 years and who had disability care experience tended to have greater care competence in the domains of assistance in daily activities, medical professionalism, and mental and spiritual care. In general, more experienced LTC personnel provide better care [25,26]. A Norwegian study interviewed nurses in a nursing home; it indicated that the hospital admission rate among care recipients was influenced by the nursing home's human resources, personnel deployment, and workers' care competence [27]. NA care behavior affects the care recipient's mental health [28–30]. More experienced NAs were found to be more emotionally competent [31]. Compared with their counterparts without care experience, NAs with care experience are more able to provide physiological, psychological, and spiritual care centered on care recipients, thereby improving their care quality. The participating NAs in this study who were receiving performance and year-end bonuses had greater care competence. This result is consistent with those of previous studies demonstrating that incentive policies increase NAs' work satisfaction and care competence [32].

In Taiwan, there are currently about 30,000 NAs working in retirement centers and nursing home institutions in Taiwan. The nursing care training and qualification requirements of NAs are mostly 90 h (50 h core courses established by the Ministry of Health and Welfare of the Taiwan government, including training on body mechanics, nutrition, anatomy and physiology, cognitive impairments, mental health, infection control, hospice care, and personal care skills, etc.) and a 40 h practice course (10 h of demonstrations and 30 h of clinical practice). Taiwan's Ministry of Education, following the government's promotion of its long-term care program 1.0 starting in 2007, has facilitated NA training in colleges and universities. As of 2018, there are about 6530 graduates. However, the salary of NAs in Taiwan is relatively low (32,000 NTD/month or 1150 USD/Month), and institutions have difficulty retaining graduates, with only about 20 to 30% of graduates remaining in the elderly and disability care industry. Of the NAs in Taiwan (about 30,000 in 2019) more than 97% are qualified through the 90 h of training required under the Ministry of Health and Welfare Taiwan (MOHW). NA training courses include lectures, implementation, and clinical practice. Current training courses focus on physical care services. However, NAs simultaneously play the roles of caregiver, companion, and communicator in their provision of comprehensive physical and spiritual care to older adults. The Taiwanese government and related professional organizations should refer to European countries such as Denmark and Finland to nurture NAs or increase the number of theoretical and practical training hours for NAs as done in France, the UK, Australia, and Canada. They can also consider the Netherlands, the UK, and South Korea, where professional grading systems are implemented to enhance the care competence of NAs [33]. In addition to education and training, the professional acknowledgment and welfare of NAs in Taiwan are lower than those in other countries. Therefore, adequate incentives should be provided to increase the care competences of NAs. This study's limitation lies in its use of convenience sampling, for reasons of limitations in time and resources. Although convenience sampling yields poorly generalizable results, the results are somewhat representative of Taiwan because the participants were from LTC institutions from many parts of Taiwan, specifically, Northern Taiwan, Central Taiwan, Southern Taiwan, and Taiwan's outlying islands. The results of this study serve as references for the government in the recruitment of NAs for LTC and management policy development. Training programs for NAs should be developed to improve the quality of care provided to older adults with disabilities.

5. Conclusions

NA care competence was greatest in the domain of recognition of patient rights, followed by health education and literacy, but poorest in the domain of mental and spiritual care. The NA's age, level of education, disability care experience, the receiving of performance bonuses, and the receiving of year-end bonuses were correlated with their care competence. The results of this study serve as references for the government in employing long-term care NAs and developing management policies. Training programs for NAs should be developed to improve the quality of care provided to older adults with disabilities. Future research could possibly seek to explore the difference between NAs receiving formal school education and those receiving the MOHW "Nursing Assistant training program" in the competence of disabled care in order to consider adjusting NA education and training content or duration.

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Article

A Cross-Sectional Study on the Impacts of Perceived Job Value, Job Maintenance, and Social Support on Burnout among Long-Term Care Staff in Hawaii

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Abstract: Extensive research has demonstrated the factors that influence burnout among social service employees, yet few studies have explored burnout among long-term care staff in Hawaii. This study aimed to examine the impact of job value, job maintenance, and social support on burnout of staff in long-term care settings in Hawaii, USA. This cross-sectional study included 170 long-term care staff, aged 20 to 75 years, in Hawaii. Hierarchical regression was employed to explore the relationships between the key independent variables and burnout. The results indicate that staff with a higher level of perceived job value, those who expressed a willingness to continue working in the same job, and those with strong social support from supervisors or peers are less likely to experience burnout. Interventions aimed at decreasing the level of burnout among long-term care staff in Hawaii may be more effective through culturally tailored programs aimed to increase the levels of job value, job maintenance, and social support.

Keywords: burnout; job value; job maintenance; social support; care worker

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1. Introduction

With rapid population aging, the importance of long-term care is growing in most countries affiliated with the Organization for Economic Co-operation and Development (OECD). In 2005, long-term care expenditures accounted for slightly more than 1% of the GDP of all OECD countries, but this number is expected to reach between 2% and 4% by 2050 [1]. Interest in long-term care is expected to grow even more. On the contrary, long-term care is labor-intensive, and its burden is increasing; thus, attracting long-term care staff is becoming more difficult. To respond to the increasing demand for long-term care, investment in policies to utilize the available labor force more efficiently is essential. In particular, the importance of non-financial benefits has recently emerged [2].

The shortage of long-term care staff is one problem occurring in many countries. In particular, the field's high turnover rate is often pointed out as a cause of the shortage of staff, while job dissatisfaction and burnout are identified as predictors of turnover among long-term care staff [3].

The older population in the US, including Hawaii, has been growing rapidly. Between 2015 and 2018, the proportion of the state's population aged 65 years and older increased from 22.6% to 24.2%, and the percentage of individuals aged 85 and older increased from 2.7% to 3.2% [4]. Given these demographic trends, the demand for long-term care services in Hawaii is expected to grow exponentially over the next few years.

Older people often experience chronically complex health conditions that require long-term treatment. With the increased demand for long-term care derived from the longer average life expectancy and aging population, the workload of staff is increasing. At the same time, the mental stress experienced by staff has attracted attention, and studies from multiple fields have been conducted to identify ways of reducing their mental burden.

Therefore, this study examined the factors affecting burnout to develop practical measures for increasing job satisfaction and lowering turnover rates among staff in Hawaii.

1.1. Burnout

Burnout refers to the process in which energy related to a job is drained and leads to feelings of helplessness and cynicism in an individual; it largely comprises the sub-concepts of emotional burnout, depersonalization, and lack of personal achievement [5]. The term burnout refers to these and other aspects of job-related stress, which were identified in the 1970s among volunteers of the American Mental Health Center who had lost their motivation to care adequately for clients [6]. In particular, burnout is a negative phenomenon frequently seen in human service professionals, such as doctors, nurses, teachers, counselors, and social workers [7].

If burnout persists, it negatively affects physical and psychological well-being. For example, burnout causes disorders like anxiety and depression, decreases job satisfaction and job commitment, diminishes work motivation and productivity, and increases turnover and retirement intentions [8]. Additionally, individuals with a lack of emotional empathy due to burnout might be more inclined to tolerate the abuse of those in their care [9].

As mentioned earlier, research suggests that people who provide care services are more likely to experience burnout. Additionally, as the demand for care increases alongside the aging population, researchers' interest in exploring burnout issues has become more urgent. Maslach et al. [5] classified the factors related to burnout into personal and situational factors. Personal factors include demographic characteristics, personality, and work attitude. Situational factors are classified into job-related characteristics, occupational-related characteristics, and organizational characteristics. Many burnout-related studies have utilized these factors originally identified by Maslach et al. [5].

In summary, if burnout persists for an extended period among those who provide care services, they might experience exhaustion and a decrease in motivation to work, which might deteriorate the quality of the services provided and result in abusive behavior toward patients. Therefore, to develop practical support measures for reducing the burnout of staff, we examined factors affecting their burnout.

1.2. Theoretical Background

Among the research models that hypothesize the cause of burnout, the job demands–resources model can be applied as a theory that provides major implications for this study. This theory was proposed by Demerouti et al. [10] as a model of job burnout, applicable to various occupation groups, and was based on the theory of resource conservation [11]. Job resources, referred to herein, are all job-contextual functions that effectively respond to job demands required by the organization, contribute to reducing negative effects (such as job-related stress), and ultimately play a functional role in achieving job goals [10]. For example, they may include a number of individual job-related factors, such as participation in the decision-making process related to the job, diversification of job-related skills, and feedback on the degree of autonomy in performance, along with interpersonal factors, such as cooperative relationships with colleagues and supervisors, and organizational atmosphere [12].

Based on the job demands–resources model, it is assumed that as a variable that affects employees' burnout, employees' attitude toward their job—such as high job value, willingness to maintain their job and their relationship with co-workers—is an influential factor [13]. When an organization member experiences a depletion or shortage of job resources, they experience exhaustion due to a decrease in job performance and personal motivation toward achievement.

The direct influences of job attitudes and circumstances (namely, job value and social support) on burnout are well known. There are several studies that show that as the years of service increase, burnout decreases; however, there is a scarcity of studies exploring the inverse causal relationship, which establishes that a decrease in the number of years of service may lead to increased burnout [12,13].

As mentioned above, excessive job factors induce stress in staff; furthermore, they manifest as burnout, which consequently can negatively affect organizational effectiveness [14]. In particular, this study is focused on the existing job demands–resources model, but expands the scope to factors related to favorable work performance environments such as social support and internal motivations such as job value and service providers. According to the results of previous studies, even if job factors negatively impact staff, burnout is likely to decrease when social support is high; internal motivations such as job value and job maintenance are also likely to reduce burnout. Therefore, our analysis could contribute to broadening the scope of application of the job demands–resources model and thereby contribute toward finding ways to reduce burnout.

1.3. Literature Review

1.3.1. Job Value and Burnout

Job value and burnout generally have an inverse relationship: individuals who have a positive emotional outlook regarding their jobs tend to experience a lower level of burnout. For example, in a study on social workers, the higher the value that social workers assigned to their jobs, the lower their levels of burnout were [15]. Similarly, a higher level of burnout was associated with a lack of occupational identity among occupational therapists [16]. Among staff, higher job values have been observed to contribute to a reduction in burnout [17]. In addition, high vocational awareness has been associated with a lower level of burnout among employees in other service sectors [18].

The aforementioned studies suggest that the level of burnout decreases as human service professionals perceive their jobs more positively. Several factors contribute to the positive perception of one's job, including social reputation and related benefits. Nevertheless, there is a lack of research that has analyzed the effects of individual attributes of job perception on burnout. Therefore, this study focused on and examined the perception of Hawaiian long-term care staff of the social value of their job and its various attributes.

1.3.2. Job Maintenance and Burnout

In a study that examined the relationship between job maintenance and burnout, poor work environment factors, such as long working hours and a lack of regular rest hours, increased burnout among welfare facility workers [14]. Similarly, another study found that job stress and job satisfaction had a significant effect on burnout among nurses [19]. Yet, another study showed a significant relationship between job satisfaction and burnout among counselors. Additionally, many human service professionals continue to work in their respective jobs despite their burnout potential, which provides additional evidence of a relationship between job satisfaction and burnout [20]. Conversely, if job satisfaction decreases and the level of attachment and immersion also declines, workers' willingness to continue working in the same job also decreases [21]. Therefore, research indicating that as job satisfaction decreases burnout increases, highlights the necessity of examining the long-term impact of the human service profession on workers' burnout. Therefore, this study also aimed to verify the impact of being a long-term care provider, on burnout.

1.3.3. Social Support and Burnout

All resources that satisfy one's physical, material, and emotional needs can be collectively referred to as social support, which reduces the harmful effects of stress, as well as psychological and social burdens [22,23]. Social support also plays a positive role in reducing the burnout of workers by helping them cope with stressful situations [24,25]. Research indicates that social support is a major factor that alleviates burnout by acting as a buffer between stress factors and tension [19,26]. One of the most important forms of social support that individuals have is their network of relationships with others. Studies conducted with social workers indicate that sufficient social support reduces burnout [27–29].

Prior studies have demonstrated that social support affects individuals' experiences of burnout. Additionally, the level of burnout varies among care providers who undergo the same level of stress. Therefore, this study examined the association between different factors (such as job-related social support and the long-term will of caregivers) and burnout, as this notion has not yet been adequately explored.

1.3.4. Purpose of the Study and Hypotheses

This study aims to examine the relationships between job value, job maintenance, social support, and burnout among long-term care staff in Hawaii, USA. The hypotheses (Figure 1) for the current study are as follows.

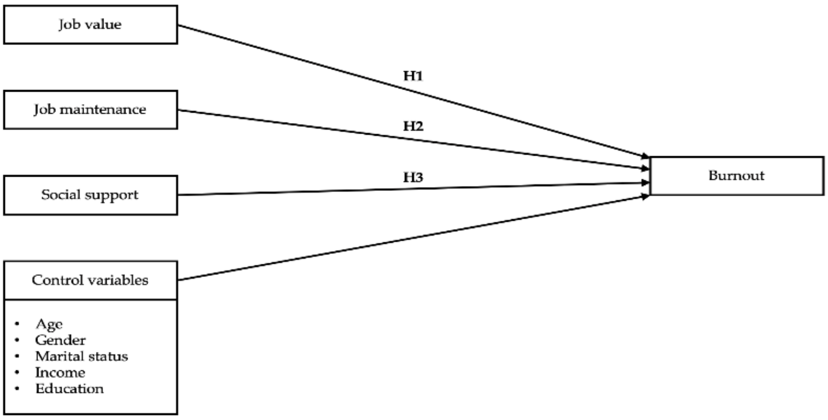

Figure 1. The hypothesized model.

Hypothesis 1 (H1). *Job value is correlated with burnout among long-term care staff in Hawaii.*

Hypothesis 2 (H2). *Job maintenance has an influence on burnout among long-term care staff in Hawaii.*

Hypothesis 3 (H3). *Social support is associated with burnout among long-term care staff in Hawaii.*

2. Method

2.1. Design, Study Site, and Participants

The study used a cross-sectional survey design with data collected from a convenience sample of 192 long-term care staff in Hawaii, US. The study sample was recruited from 23 long-term care agencies such as nursing homes, adult day care centers, and independent living facilities. Participants in the study were professionals working in long-term care facilities, including nurses, nursing assistants, social workers, physical therapists, and occupational therapists. Staff working at long-term care institutions in Hawaii include social workers, physical therapists, and occupational therapists, as well as nurses and nursing assistants. Social workers play a role in social care and case management, and therapists also play an important role in rehabilitation and dementia management at long-term care institutions. The research team first contacted program directors of long-term care centers and explained the purpose and procedure of the study to obtain their consent for participation. Once agency-wide consent was obtained, the authors identified potential research participants at each agency, obtained informed consent, and distributed self-administered questionnaires for completion. Of the 192 responses obtained, the data from 170 questionnaires were used (22 questionnaires were discarded due to missing data and incomplete responses), representing an acceptance rate of 88.5%. Each participant received USD 5 as compensation.

2.2. Data Measures

2.2.1. Burnout

To measure burnout, the study used the Maslach Burnout Inventory (MBI). The MBI was developed by Maslach and Jackson [30]; it comprises three domains (depersonalization, attainment of personal fulfillment, and emotional exhaustion) and 17 items. Participants answered items using a 5-point Likert scale (1 = *almost always*, 2 = *sometimes*, 3 = *every once in a while*, 4 = *rarely*, and 5 = *never*). High scores indicated a high risk of burnout. The only survey item that required inverted calculation due to inverted response values was the attainment of personal fulfillment. The internal consistency reliability (Cronbach's alpha) for the MBI in this study was 0.91. In addition, confirmatory factor analysis (CFA) was conducted to verify the factor structure of a set of observed items. The CFA produced a chi-square of 5.61 (p = 0.47), a root mean square error of approximation (RMSEA) of 0.03, a comparative fit index (CFI) of 0.91, and a Tucker-Lewis index (TLI) of 0.92, all indicating the measure's reasonably good fit.

2.2.2. Job Value

To measure the level of job value, we used the following item: "How much do you think your current job is valued by society?" Participants responded to the item on a 4-point Likert scale (*very much, somewhat, not much,* and *not at all*). A low score indicated that the participant perceived his or her job as highly valuable.

2.2.3. Job Maintenance

To measure the possibility of participants maintaining their current job, we utilized the following item: "How long would you like to stay in your current workplace?" Participants responded to the item on a 4-point Likert scale (*I would like to quit my job right now, I would like to quit my job but not now, I would like to stay here for the time being*, and *I would like to stay here as long as possible*). A high score indicated a high level of job maintenance.

2.2.4. Social Support

Social support was measured using the Social Support Measurement Tool by Poulin and Walter [31]. This 18-item scale contains five items to measure instrumental support from supervisors, six items to measure emotional support from supervisors, and seven items to measure emotional support from peers. Participants responded to the items using a 4-point Likert scale (*very agreeable, agreeable, almost not agreeable,* and *not agreeable*). A higher score meant stronger social support. In this study, the internal consistency reliability (Cronbach's alpha) for social support was 0.89. Moreover, CFA analysis produced a chi-square of 7.24 (p = 0.23), an RMSEA of 0.01, a CFI of 0.94, and a TLI of 0.97, all indicating the variable's good fit.

2.2.5. Background Information

Sociodemographic variables were included in this study as follows: age (in years), gender (1 = female), marital status (1 = married), income (continuous variable), and education (continuous variable).

This study addressed the issue of common method bias. Usually, the concern is that when the same method is used to measure multiple constructs, it may result in spurious method-specific variance that can bias observed relationships between the measured constructs [32]. In order to reduce common method bias, this study used two methods. By adding a time delay, thereby increasing temporality of the items, the study could reduce participants' tendency to use previous answers to inform subsequent answers. In addition, ambiguous items increase participants' reliance on their systematic response tendencies as they are unable to rely on the content of the ambiguous item [33]. The study reduced ambiguity by keeping questions as simple and specific as possible.

2.3. Ethical Considerations

The authors clearly informed potential participants that their participation was voluntary, that the study adhered to a rigorous protocol for research ethics (guaranteeing participants' anonymity and confidentiality), and that collected data were to be used for research purposes only. The study design was approved by the Institutional Review Board of the University of Hawaii (CHS #22473) on 9 October 2014.

2.4. Data Analysis

There were three procedures for data analysis. First, the study used descriptive statistics to explain the main study variables in terms of frequencies, percentages, and means. Next, the study used bivariate analysis (Pearson's correlation) to examine the correlational relationships between the independent variables and the dependent variable. Finally, the study performed a robust hierarchical regression analysis with the outlier down-weighting algorithm using STATA version 13.0 software. Four sets of independent variables were regressed on burnout in successive order as follows: (1) sociodemographic characteristics, (2) job value, (3) job maintenance, and (4) social support. Additionally, variance inflation factors were assessed to determine multicollinearity.

To investigate burnout, we first added the sociodemographic variables as a group (age, gender, marital status, education, and income) to control how these factors affect the dependent variable (burnout). Through a hierarchical regression analysis, the change in the R-squared value at each step provided insight into the predictive power of each cluster while controlling the variables in the previous model. To overcome this problem, a robust regression procedure was used to repeatedly reduce or correct outliers.

3. Results

3.1. Sample Characteristics

Demographic characteristics of the sample and descriptive data of the following study variables are shown in Table 1: age (range, mean age), gender ratio, marital status ratio, educational level spectrum, average monthly income, the mean scores of job value, job maintenance, social support, and burnout level.

Table 1. Participants' characteristics.

Characteristic	Descriptive Statistic	%
Age		
Range	20–75	
M (SD)	40.18 (12.41)	
Gender (*n*)		
Male	30	17.65
Female	140	82.35
Marital status (*n*)		
Single (unmarried/widowed/divorced)	98	57.65
Married	72	42.35
Education (*n*)		
Elementary	16	9.41
Middle school	18	10.95
High school	15	8.82
College	48	28.24
Graduate school	73	42.94
Monthly income (dollars)		
Range	USD 400– USD 6500	
M (SD)	4383.90 (1058.97)	
Job value		
Range	1–3	
M (SD)	1.48 (0.66)	

Table 1. *Cont.*

Characteristic	Descriptive Statistic	%
Job maintenance		
Range	1–4	
M (SD)	3.33 (0.73)	
Social support		
Range	0–54	
M (SD)	41.45 (9.93)	
Burnout		
Range	0–46	
M (SD)	17.04 (9.05)	

3.2. Bivariate Correlations with Burnout

Imputed correlations between variables from the predicted model are shown in Table 2. Since no correlation coefficient values were over 0.06, multicollinearity was considered nonexistent among the study variables [34]. There was a significant positive correlation between job value ($r = 0.38$, $p < 0.01$) and burnout, indicating that increased negative job value was related to higher levels of burnout. Moreover, there were significant negative correlations between job maintenance ($r = -0.49$, $p < 0.01$), social support ($r = -0.33$, $p < 0.01$), and burnout, indicating that a longer intended stay in the current job and increased levels of social support were associated with lower levels of burnout.

Table 2. Correlations among study variables.

	1	2	3	4	5	6	7	8
1. Age	-							
2. Gender	−0.00							
3. Marital status	−0.24 **	−0.04						
4. Education	0.24 **	0.02	−0.09					
5. Income	0.13	0.04	−0.15 *	0.18 *				
6. Job value	0.01	0.03	−0.05	−0.05	0.07			
7. Job maintenance	0.05	−0.06	0.06	−0.12	−0.04	−0.28 **		
8. Social support	−0.00	−0.04	0.13	0.12	0.11	−0.25 **	0.20 **	
9. Burnout	−0.05	0.13	0.03	−0.12	−0.05	0.38 **	−0.49 **	−0.33 **

* $p < 0.05$. ** $p < 0.01$.

3.3. Hierarchical Regression

A hierarchical regression analysis was conducted to examine the impact of job value, job maintenance, and social support on burnout, controlling for the selected demographic variables. Table 3 displays the results of the analysis for the four models. Model 1 included participants' age, gender, marital status, education, and income; it explained 4% of the total variation in burnout. Of the five demographic predictors, only gender had a significant relationship with burnout ($p < 0.05$). Job value, included in Model 2, explained 18% of the total variation and was positively associated with the level of burnout ($p < 0.01$). Job maintenance was added in Model 3 and explained 35% of the total variance in burnout ($p < 0.01$). Finally, by adding social support to Model 4, it explained 39% of the total variance in burnout. Interestingly, in Model 3, education was a significant variable at the p-level < 0.05; however, it was not significant in Model 4. In Model 4, the effect of social support was large, therefore the influence of education was reduced. It can be seen that the level of burnout changes depending on the degree of social support regardless of the educational background. In summary, the results indicated that perceived job value was positively associated with burnout, whereas both job maintenance and social support were negatively associated with burnout.

Table 3. Standardized coefficients from robust hierarchical regression on burnout.

Variables	Model 1		Model 2		Model 3		Model 4	
	β	*t*	β	*t*	β	*t*	β	*t*
Age	−0.01	−0.19	−0.02	−0.37	0.01	0.24	0.01	0.17
Gender	0.14	2.04 *	0.12	1.92	0.10	1.85	0.10	1.81
Marital status	−0.00	−0.02	0.02	0.28	0.04	0.69	0.07	1.06
Education	−0.13	−1.52	−0.09	−1.10	−0.15	−2.04 *	−0.13	−1.75
Income	−0.04	−0.74	−0.07	−1.05	−0.07	−1.62	−0.04	−1.05
Job value			0.37	4.80 **	0.25	3.78 **	0.20	3.17 **
Job maintenance					−0.43	−5.77 **	−0.39	−4.87 **
Social support							−0.21	−2.74 **
R^2	0.04		0.18		0.35		0.39	
R^2 change			0.13 **		0.17 **		0.04 **	
Adjusted R^2	0.06		0.21		0.37		0.41	
F	1.43 **		5.49 **		10.52 **		10.98 **	

* $p < 0.05$, ** $p < 0.01$.

4. Discussion

This study examined the association between burnout and job value, job maintenance, and social support among 170 long-term care staff in Hawaii, US. Several implications for clinicians are provided below based on the major findings of the study.

This study found that job value was negatively associated with burnout among long-term care staff, which supports our first hypothesis. In other words, care staff with a higher perception of job value are more likely to experience a low level of burnout. This is consistent with the findings of earlier research [15–18]. Long-term care service jobs are often seen as undesirable and difficult, characterized by long work hours, requiring minimal skills, providing low wages, and having high labor intensity [35]. As a result, treatment for long-term care staff tends to be poor, despite the considerable physical, mental, and emotional burden associated with their job, while financial compensation is commensurate with that of a low-quality job. If long-term care staff feel they are not appreciated, their job satisfaction and pride in their work decrease, while stress and burnout are likely to increase.

Efforts are required at the individual, institutional, and government/social levels to increase the extent to which staff value their jobs in long-term care settings. First, staff themselves must recognize that their work helps maintain the human dignity of older adults and the socially disadvantaged. It should be recognized that their assistance as official caregivers does not only increase the independence and life satisfaction of older clients, but also eases families' care burden and helps family caregivers maintain their social life. Second, it is necessary to provide education and training programs for the professional development of long-term care staff at the institutional level. Specifically, staff should be provided with job training opportunities that require complex skills (such as body care, physical therapy, and rehabilitation), thereby enabling care work to gain acceptance as a viable career choice. In particular, there is a need to expand specialized education on dementia in line with the increasing number of patients with dementia [27]. Additionally, wages and treatment of workers should also be improved to mitigate the negative image of care work. Third, support for long-term care staff should be strengthened at the governmental and societal level. An institutional mechanism is needed to increase the budget support of the central government and to develop policies to improve the treatment of workers by local governments. In particular, it is necessary to actively consider the introduction of public long-term care insurance and to make efforts to facilitate the care of older adults from a public policy standpoint.

This study found a significant negative relationship between job maintenance and burnout among long-term care staff, confirming our second hypothesis. In other words, staff who expressed a willingness to continue working in the same job are more likely to have a low level of burnout. This finding is consistent with earlier research [14,19–21]. Having a willingness to work longer means that you are proud and satisfied with your work, and that you are rewarded for your job. Research generally shows that the more employees express a willingness to change their job, the more likely it is that they are unsatisfied with their current job, experience higher levels of stress, and have a higher level of burnout [36]. Thus, it is necessary to improve the work environment, foster the organizational culture of the organization, and adjust the work intensity so staff can stay at their jobs in the long-term.

Additionally, our study revealed that social support was significantly correlated with burnout among staff at long-term care agencies, thus supporting our third hypothesis. Specifically, staff with strong social support from supervisors or peers are less likely to experience burnout; this is consistent with earlier research [19,22–29].

The job demands–resources model posits that burnout is influenced by individual job-related factors, such as participation in the decision-making process related to the job, diversification of job-related skills, and feedback on the degree of autonomous performance, but also interpersonal factors, such as social support and cooperative relationships with colleagues and supervisors [12]. Our findings are in concordance with the aforementioned model.

Long-term care staff play a role in helping older people who experience difficulties with activities of daily living as well as instrumental activities of daily living during working hours. Due to the deterioration in physical functioning and cognitive ability of older adults, it is sometimes difficult to communicate with them; consequently, job stress in staff is higher in such cases. In this situation, if the relationship between staff and their supervisor is not productive, the workers' level of satisfaction with their work will be lower. Conversely, if staff communicate frequently with their supervisors and receive emotional support from them, their mental stress will be reduced. Additionally, if a supervisor provides good supervision and allows staff to discuss their job-related difficulties, the care worker will have a more organized work environment. If relationships with colleagues involve understanding and listening to each other, and staff receive emotional support in a caring attitude, their work life will be easier and more productive. Likewise, staff who receive social support from their supervisor or colleagues will have a lower level of burnout resulting from reduced job stress. In addition, to strengthen the social support for staff, a line of dialogue must be established between staff and supervisors, to allow them the opportunity to communicate openly with each other through meetings and employee training, thereby creating an open organizational culture for solving problems.

This study has a few limitations. First, the study used cross-sectional survey data, which limits our ability to identify causality and time order. Accordingly, future research needs to examine causal relationships among the variables because social support, job value, and job maintenance are time-varying variables, which means they may improve or deteriorate over time. Second, because the participants were recruited from territories in Hawaii from various long-term care facilities (based on non-probability convenience sampling), the findings cannot be generalized to other contexts. Future studies need to recruit study participants from various geographic locations and broaden the applicability of the survey. Third, it is necessary to diversify the questions used in the survey. For example, job value was measured using only one question. Therefore, it is necessary to further subdivide the construct and measure job value as is perceived by the staff themselves and by their family members and acquaintances. Additionally, consideration should be given to including other variables that affect burnout (e.g., physical health, mental health, and job satisfaction) so that it is possible to provide practical policy implications for dealing with burnout by addressing a wider range of influencing factors. Finally, the study did not examine the group differences among staff (e.g., nurses, nursing assistants, social workers, physical therapists, occupational therapists) because the majority of study participants in this study were nurses or nursing assistants and other staff groups are quite small to carry out comparisons. For future study, it is recommended to include an extended number of staff besides the nursing workers.

5. Conclusions

The present study contributes toward an understanding of the effect of job value, job maintenance, and social support on burnout by examining the understudied group of long-term care staff in Hawaii. The higher the value of a worker′s job, the more rewarding and positive it will be. Moreover, as workers remain longer in their position, the relationship with their clients will deepen and close relationships will be formed. Additionally, mutual support between workers and supervisors will increase job satisfaction and reduce work stress, which will eventually improve the quality of services provided to clients.

Even though previous studies indicate that job value, job maintenance, and social support are significantly associated with the level of burnout, there are limited studies on burnout among staff at long-term care settings in Hawaii. In particular, the relationship between burnout and job value, job maintenance, and social support has not been examined in the previous literature. This study fills the gap by emphasizing the significance of a culturally specific approach. Interventions aimed at decreasing the level of burnout among long-term care staff in Hawaii may be more effective if the levels of job value, job maintenance, and social support are increased through culturally tailored programs. It is necessary to develop a community-friendly and emotional value-oriented program that considers the cultural characteristics of Hawaii. In particular, practitioners can help attenuate burnout among long-term care staff by informing the leaders of long-term care facilities about the importance of job value and social support, to ensure improved quality of care.

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Article

Personal and Work-Related Factors Associated with Good Care for Institutionalized Older Adults

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Abstract: Despite efforts to promote good care, many institutionalized older adults (IOA) experience elevated neglectful conditions and reduced person-centered care approaches. Based on the job demand–control model, this study aimed to analyze the relationship between nursing home professionals' personal and organizational factors and good care provided to institutionalized older people. Data was collected through a self-administered survey completed by 208 nursing home staff members. Three dimensions of personal factors (i.e., personal accomplishment, depersonalization, and negative old age stereotypes) were significant predictors of good care. Depersonalization and negative old age stereotypes were negatively associated with IOA, and both good care and personal accomplishment were positively associated with good care in nursing homes. Only one work-related factor (i.e., management support) was positively associated with good care. Personal factors may play a significant role in good care. Management support offers a promising mechanism to promote good care among nursing home professionals. The findings support the need to change the focus on entirely completing care tasks to providing good care of residents in nursing homes that promotes management support, personal accomplishment, personalization and positive old age consideration, attitudes, and behaviors. Policies and interventions should be developed to address in a more humanized way.

Keywords: elder abuse; good treatment; humanization; institutions; long-term care; mistreatment; nursing homes; staff; person-centered treatment; residential aged care

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1. Introduction

Residents in nursing homes often have many physical and cognitive problems, and the occurrence of dementia is quite frequent [1]. Most studies found that 50% of IOA have dementia [2]. Nursing homes can be a difficult environment for professionals because of the complex health and cognitive status of the residents. Family caregivers experience high levels of anxiety and depression [3]. In most occasions, family caregivers decide to institutionalize their older relative after a period of deep reflection and various consultations with specialists [4].

The poor pay and working conditions of care workers such as overwhelming workloads, lack of respect, and lack of support are well-documented, especially for nursing assistants [5–7]. These issues present challenges to provide good care in nursing homes. Kayser-Jones (1990) suggested a conceptual framework about quality of care in long-term institutions and described four essential aspects: personalization, humanization, no infantilization, and no victimization [8]. Quality of care among nursing staff and residents is a crucial issue to promote good care. Good care for IOA not only implies avoiding abuse (no victimization) but also promoting person-centered care (personalization, humanization, and no infantilization) [9]. Good care not only focuses on avoiding abuse. It also promotes good daily care practices, such as respect, humanization, and ethical values [10,11]. Consequently, good care includes avoiding elder abuse but is not only this, and good care also includes person centered care but it is more than this too.

1.1. Person-Centered Care

While the traditional long-term care model is focused on tasks and professional-directed (institution-centered perspective), the person-centered care perspective targets older people's preferences and needs. [12]. It reflects the move from a biomedical approach based on clinical quality and quality of care to a biopsychological approach based on people´s quality of life and quality of care. The latter consists of a humanistic perspective that has been extensively used in gerontology settings in the last few decades.

Person-centered care affirms that the person should be the focus of care delivery and not their disease, frailty, deficits, nor their illnesses [13]. This perspective recognizes the importance of considering older adults, their family and staffs' well-being and quality of life. However, different authors use the term person-centered care to refer to a variety of different concepts and there is no standard definition yet [12]. WE-THRIVE, an international consortium of long term care researchers, prioritized the following concepts within the person-centered care domain: relationship (among residents, professionals, and relatives), knowing the elder, paying attention to what is important for the person and providing a positive context in which the person can engage meaningfully. As can be observed, this consortium enhances the importance of setting caregiving goals that ensure residents´ quality of life. Considering this, there is an important international debate about what the construct good care refers to [14].

Person-centered care has found positive outcomes in nursing home staff, including organizational and personal factors. Some organizational conditions related with a higher person-centered care are a higher staff-to-resident ratio [14], a lower job turnover [14,15], better equipment and facilities [14,16], better organizational climate [17], and higher management support [12,14,18,19].

There are also individual factors related with a higher Person-Centered Care such as lower burnout [15,17,20,21], less work overload [15,21–23], higher intrinsic motivation [24], and less stereotypes towards ageing [14,20].

1.2. Elder Abuse

Different gerontologists have tried to develop theoretical models to explain a bad and good care approach. However, there is still no consensus. The difficulty in defining the causes of elder abuse in institutions and the factors associated with IOA´s good care has been pointed out [25].

Elder abuse is a common problem, commonly missed in the aging services network. It is often viewed as a 'hidden issue' or 'inner affair'. In fact, elder abuse is an interpersonal violence less reported than other types of violence conducted in institutions. It is a violation of human rights that not only affects the victims but also the relatives and society in its totality. Research regarding elder abuse is still in its infancy [26,27].

Only a few studies deal with elder abuse in residential care since the trailblazing research of Pillemer and Moore (1989) [28]. Some reasons why older people are more vulnerable to suffer elder abuse in institutions are not being able to report the abuse because of their cognitive or physical difficulties, being worried about the negative consequences that may take place if they report the abuse (e.g., revenge) or feeling hopeless and believing that no one would help them [29,30]. Staff may be reluctant to admit their own or colleagues abuses for fears of reprisal [31] and they tended to condone abusive behaviors toward elderly residents [32]. Therefore, IOA and staff members are unable or unwilling to seek help.

The direction of the abuse is varied: resident-to-staff, residents-to-residents, family-to-residents, and staff-to-residents. The last one is the most prevalent. However, a resident who experiences resident-to-resident abuse may become more vulnerable to suffer abuse by a staff member or vice versa [29]. Furthermore, studies from United States of America and

European countries elder abuse is more likely to take place in a shared living environment, specifically for physical and financial abuse [33].

Ho et al. (2017), in the first meta-analysis on the global prevalence of community and institutional elder abuse estimated a prevalence of 10%. Nevertheless, this study mixed abuse in community-dwelling older people and IOA abuse [34]. Yon et al. (2019) analyzed only nine studies finding the physical and psychological abuse as the most prevalent types based on data provided by the nursing home staff. Although caution should be taken when self-reported elder abuse data is used, nearly 64% of nursing home staff acknowledges that they have abused IOA. This review estimates that there is a 33.4% prevalence of psychological abuse, 14.1% of physical abuse, 13.8% of financial abuse, 11.6% of neglect, and 1.9% of sexual abuse. All of these percentages are higher than those experienced by community-dwelling older adults [26]. However, Pillemer et al.(2016, p. 195) affirm that the prevalence of IOA abuse is not covered because of "the lack of research in this area; no reliable prevalence studies have been conducted of such mistreatment in nursing homes or other long-term care facilities" [33].

There are only a few studies that have analyzed the risk factors of elder abuse in nursing homes, and the research conducted to date on this topic is inconclusive [35]. More research analyzing the underlying risk factors is needed considering the different levels of the ecological framework. Literature has supported the role played by organizational and personal factors in elder abuse perpetrated by staff working in nursing homes. Some organizational conditions related with higher abuse are poorer working condition, particularly staffing shortages, time pressures, and lack of equipment [36–40], as well as lower management support, and a lack of guidance and support; a service isolated within the organization [38]. Regarding individual factors, burnout is a strong predictor of abuse [28,36,39,41]. Nursing home staff often rated work overload perception as a reason for abuse and neglect [39,40]. Abusers did not feel sufficiently motivated [37] and showed more negative attitudes towards residents [28,41].

1.3. Good Care

The WHO global strategy and action plan on ageing and health (2016–2020) stresses the need to provide a better long-term care to prevent elder abuse [42]. The European roadmap on healthy ageing (2012–2020) also includes strategies to improve the quality of services in nursing homes [43]. Furthermore, the European Commission suggested that desired good care levels include not only encouraging quality but also counteracting elderly abuse. Governments have the responsibility to protect vulnerable IOA and set the framework underpinning oversight of good care. Monitoring nursing homes quality has been growing in importance but needs further development. Good care implies, on the one hand, effectiveness and care safety, and on the other, patient-centeredness, responsiveness, and care coordination [11]. Professionals should work multidisciplinary and must be trained in good practices and the promotion of good care. Good care implies humanization, no infantilization, respect, and IOA empowerment.

Good care for IOA implies humanization. Dehumanization is a subtle form of mistreatment that violates basic human rights and it is even more devastating than depersonalization. Humanization follows when IOA are treated sensitively and amicably. Humane care recognizes the human attributes such as compassion, understanding and kindness. Humanization promotes sensitivity to IOA needs, especially to those with high dependency levels. Interactions are personal, where individuals are spoken to rather than spoken at [8].

Good care for IOA also implies the absence of infantilization, establishing an 'adult–adult' relationship instead of a 'parent–child' one among nursing home staff and older adults. IOA must be treated as adults, taking their life-long accomplishments into consideration. This includes such behaviors as avoiding scolding incontinent IOA, addressing IOA in respectful terms and dressing them in adult attire. Non-infantilization increases independency, role, and status. It also promotes and maintains a sense of dignity and self-worth. Because of the vulnerability of many IOA, there is a high risk of conducting paternalist practices in nursing homes. Being especially significant those practices related to infantilization [8].

Good care for IOA is related to respect [6,44]. Nursing home professionals' practice implies respect for intrinsic dignity, worth, and uniqueness of each person. Respect enhances a person's sense of dignity and pride in nursing homes [8,44,45].

The nursing–IOA interaction is positive and respectful. Nursing home staff culture promotes the interest in paying attention to and understanding older people's deepest needs [46]. The staff also respected the family's wishes [47]. Privacy and space are necessary so that IOA can have time with their relatives and bring closure to their lives. IOA and their families want and deserve respect and dignity [48]. Disrespect is linked, to a violation of human rights such as dignity, privacy, or autonomy [29].

Good care for IOA is related to empowerment [6]. The resident empowerment approach is well suited to helping IOA make self-selected changes. Empowerment is related with meaning, competence, and self-determination. Therefore, listening to residents empower them [49]. As a result, older people feel more meaningful, confident, and satisfied [45].

Drawing upon the job demand-control (JDC) model [50], which highlights the relevance of demands (stressors that are present in the work environment, i.e., work-related factors) and control (the potential of workers of regulating their tasks and behavior at work, i.e., personal factors), these being resources for understanding the differences in job impact between individuals, the present study aims to answer the following main research question: What is the relationship of nursing home good care with the position in the facility, work stressors (better organizational conditions and more management support) and personal variables? The hypotheses were the following: (1) team technicians (i.e., psychologists, physiotherapists, social workers, occupational therapists, nurses) will show better good care than nursing assistants; (2) The lower the levels of turnover and ratios, the more adequate the equipment and facilities, and the higher the management support, the more they will hold good care attitudes and behaviors; and (3) those professionals with less burnout, work overload, stereotypes towards ageing and more intrinsic motivation, will have a greater tendency to develop good care in nursing homes.

2. Materials and Methods

2.1. Sample and Data Collection

We used a cross-sectional design study. A convenience sample of nursing home professionals participated. Before gathering data, the Institutional Review Board of CEU San Pablo University approved the study. We contacted several nursing homes to recruit participants. They were required to be working as a front-line care nursing home professional (staff directly involved in care). The inclusion criterion of being directly involved in care was selected because they have a close daily interaction with residents and are the largest group of professionals in nursing homes [7]. The survey was self-administered. However, trained interviewers (i.e., psychology postgraduate students and the authors of this study) assisted participants in case they needed help. Before completing the survey, interviewers explained the aims of the study, the types of questions and response options, data confidentiality, and their rights. All participants signed the informed consent. A total of 231 nursing home professionals participated in the study. Twenty-one participants did not meet the inclusion criteria (being a front-line care nursing home professional) and two participants did not complete the questionnaires and were excluded. The final sample included 208 nursing home staff members directly involved in care.

2.2. Measures

Questionnaires collected information on sociodemographic outcomes and the good care of the nursing home staff, as well as assessed perceived personal and work-related factors in their caregiving experiences. The sociodemographic information included was age, sex, marital status, highest education qualification attained, position in facility (nursing assistants versus interdisciplinary team technicians), nursing home equipment and facilities, non-consistent assignment of staff (turnover), and staff-to-resident ratio.

Good care was assessed using the good care scale in nursing homes (GCS-NH) [51]. Initially, this instrument was composed of 32 items (reverse-scored and direct scored) grouped in four dimensions: humanization (9 items; bonding, connection, tenderness and closeness), non-infantilization (10 items; consideration of older people as adults, avoiding overprotection), respect (7 items; respect and avoid stigmatization by staff), and empowerment (6 items; promotion of older people´s decision-making and choices and control over their lives). The items are scored on a five-point Likert scale (from 0 = nothing to 4 = a lot). This scale is based on the perspective of centered care by including practices in line with avoiding mistreatment and power relationships as well as providing individualized care, considering older people's singularity. This scale is focused on protecting from disrespect (violation of human rights such as dignity, privacy, or autonomy). Internal consistency for this scale in this study was 0.714 (Cronbach's α).

Burnout (personal variable) was assessed using the Maslach Burnout Inventory (MBI) [52]. It is a 22-item measure grouped in three subscales: emotional exhaustion (EE), depersonalization (DP), and personal accomplishment (PA). Research conducted in nursing homes and other healthcare contexts has extensively supported its validity and reliability [52,53]. Participants had to indicate the frequency they experienced 22 statements of 'job-related' feelings on a seven-point Likert scale ranging from 0 ('never experienced such a feeling') to 6 ('experience such feelings every day'). The EE domain has nine items, the DP domain five items, and the PA domain eight items. High levels of EE and DP scores, and low levels of PA are associated with more burnout. Subscales internal consistency were as following: 0.866 for the EE scale, 0.728 for the DP scale, and 0.736 for the PA scale (Cronbach's α). Internal consistency for this scale in this study was 0.710 (Cronbach's α).

Professional quality of life was assessed using the PQL-35 Questionnaire [54]. It is a 35-item measure of the professional quality of life with three domains: work overload (WO), intrinsic motivation (IM), and management support (MS). This questionnaire is based on Karasek´s demand-control model formulated [50]. Professional quality of life was related to the balance between work demands and the perceived ability to carry them out. WO and IM are personal variables and MS is a work-related variable. Professional quality of life was assessed in a 10-point scale from 1 ('none) to 10 ('a lot'). The WO domain has 11 items, the IM domain has 9 items, and the MS domain 13 items. The final item that measures global quality of life and the item that measures ability to disconnect from work were excluded in line with previous studies [55,56]. Subscales internal consistency were as following: 0.845 for the WO scale, 0.815 for the IM scale and 0.918 for the MS scale (Cronbach's α). Internal consistency for this scale in this study was 0.765 (Cronbach's α).

Negative old age stereotypes (personal variable) were assessed using the Negative Stereotypes Towards Ageing Questionnaire [57]. This scale has 15 items. Response options range from 1 ('strongly disagree') to 4 ('strongly agree'). Higher scores show high levels of negative stereotypes towards older people. In the present study we found a global internal consistency index for this scale of 0.897 (Cronbach's α)

2.3. Data Analysis

Hierarchical multiple regression was used to assess the contribution of position in facility indicators; personal and work-related factors to IOA good care scores. Variables were entered into the regression equation in three blocks: position in facility (nursing assistants versus interdisciplinary team technicians) was entered first, followed by four work-related factors and then followed by six personal factors, using the SPSS software (version 24, IBM Corp. Armonk, NY, USA). We controlled the effects of position in facilities (nursing assistants versus interdisciplinary team technicians) by entering them in the first step of the hierarchical multiple regression analysis.

3. Results

3.1. Sample Characteristics

Participants were 208 staff members at 11 different nursing homes in Spain (about 19 professionals at each institution). As shown in Table 1, the mean age of participants was 39.28 years. Most participants were female, nursing assistants and had at least a high school degree and a little less than half were married.

Table 1. Sample characteristics (N = 208).

Variables	M (SD)/*n* (%)
Age, M (SD)	39.28 (11.85)
Gender (% male)	28 (13.5%)
Marital status (% married)	89 (42.8%)
Education (% Lower than high school diploma)	41 (19.7%)
Position in facility	
Nursing assistants (IOA care providers)	149 (71.6%)
Interdisciplinary team technicians	59 (28.4%)
Nursing home equipment and facilities (% adequate)	151 (72.6%)
Non-consistent assignment of staff (turnover) (% yes)	166 (79.8%)
Staff-to-resident ratio (% adequate)	51 (24.5%)
Good care, M (SD)	58 (9.30)
Professional quality of life, M (SD)	
Management support	6.05 (1.71)
Work overload	4.84 (1.96)
Intrinsic motivation	8.63 (0.98)
Burnout, M (SD)	
Emotional exhaustion	10.78 (10.35)
Depersonalization	5.03 (4.83)
Personal accomplishment	40.52 (7.52)
Negative old age stereotypes, M (SD)	33.23 (8.10)

Data are presented as mean (SD), or *n* (%). Professional quality of life = Professional quality of life, PQL-35 Questionnaire; Burnout = Maslach Burnout Inventory; Negative old age stereotypes = Negative Stereotypes Towards Ageing Questionnaire; Good Care = Good Care Scale in Nursing Homes.

Regarding organizational factors, the mean score for management support was 6.05. Overall, about 72.6% of respondents considered adequate nursing home equipment and facilities but only 24.5% considered adequate staff-to-resident ratios. In terms of non-consistent assignment of staff, almost 80% of participants experienced turnover.

Regarding individual or personal factors, the mean score for the burnout dimension was 10.78 for emotional exhaustion, 5.03 for depersonalization, and 40.52 for personal accomplishment. Applying the cut points, only the mean score of personal accomplishment implies high levels of this dimension. The mean score of 4.84 for work overload and 8.63 for intrinsic motivation, on a 1–10 scale, indicates a relatively high tendency to experience intrinsic motivation. Mean scores for negative old age stereotypes and good care indicated a medium level of experienced stereotypes and good care behaviors and attitudes.

3.2. Role of Organizational and Personal Factors on Good Care

The hierarchical regression results are displayed in Table 2. In step one, position in facility explained 6.1% of the variance (Adjusted R^2) in good care. Position in facility and organizational factors in step two accounted for 20% of the variance (Adjusted R^2); an increase of 14% from step one. In the final step, position in facility, organizational and personal factors explained 31.1% of the variance (Adjusted R2); an increase of 11% from step two.

Table 2. Hierarchical regression analysis examining the associations between assessed variables and good care

Variables	Step 1			Step 2			Step 3		
	B	SE	B	B	SE	B	B	SE	B
Position in facility (0 = Nursing assistants)	7.111	1.931	0.256 ***	3.447	1.929	0.124	0.932	1.975	0.034
Staff-to-resident ratio (1= adequate)				0.957	1.975	0.034	0.773	2.235	0.027
Turnover) (1= yes)				0.783	2.174	0.024	0.997	2.080	0.031
Nursing home equipment and facilities (1 = adequate)				1.607	2.033	0.059	0.696	1.929	0.025
Management support				0.208	0.043	0.372 ***	0.145	0.052	0.259 **
Work overload							0.005	0.054	0.008
Intrinsic motivation							−0.042	0.110	−0.030
Emotional exhaustion							0.016	0.117	0.013
Depersonalization							−0.478	0.215	−0.186 *
Personal accomplishment							0.400	0.114	0.243 **
Negative old age stereotypes, M (SD)							−0.370	0.101	−0.242 ***
Change in adjusted R^2	0.061 ***			0.139 ***			0.111 ***		

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Higher levels of management support were related to higher levels of good care ($\beta = 0.259$, $p \leq 0.01$). Similarly, personal accomplishment was positively associated with good care ($\beta = 0.243$, $p \leq 0.001$). Higher depersonalization was associated with lower levels of good care ($\beta = -0.186$, $p \leq 0.05$). Additionally, higher negative old age stereotypes was significantly related to lower levels of good care ($\beta = -0.242$, $p \leq 0.001$).

4. Discussion

We aimed to examine the association between personal and work-related factors and the good care provided to residents by nursing home staff. As predicted, many personal or individual factors were related to good care levels in the expected directions. Nevertheless, only one work-related variable was positively related to good care: management support.

Good care models [8,9] were linked with the job demand–control model because they highlight the relevance of demands (work-related factors) and control (personal factors) as factors that seem responsible for good care, avoiding elder abuse and promoting person-centered care. Our results confirm the relevance of demands and control for good care.

Our findings also show that personal variables can have significant effects on good care. Previous studies have supported the negative effects of personal variables on person-centered care [15,17,20,21] and on risk of abuse [28,39]. The novelty of this study lies in the more in-depth description of the potentially harmful effects of personal variables on abuse and the potentially beneficial effects on person-centered care to an under-studied variable; good care. In this regard, this study stresses the importance of promoting personal variables and, more specifically, good care within the nursing home staff.

An interesting finding was that lower depersonalization and higher personal accomplishment predicted IOA good care, whereas emotional exhaustion did not. This result may be related to the importance of connectedness and empathy in nursing homes. Personal accomplishment is connected with empathy, attitudes, and behavior towards IOA care. Professionals reporting more personal accomplishment also showed more staff–resident interactions [58,59]. Depersonalization was negatively related to willingness to help [59].

Moreover, our results agree with a previous study in which only some burnout factors were predictive of person-centered Care [17]. Also, some good care trainings among professional caregivers in nursing homes had no effect on emotional exhaustion [19,21].

Supporting our hypothesis, a negative association between old age stereotypes and good care was observed. Lower levels of old age stereotypes were found to be associated with reporting higher levels of good care among the assessed individual factors. In line with these results, other studies have shown a use of stereotypes in disrespect or generally treated older adults [45], that may be related to a less effective IOA abuse recognition ability among nursing home professionals [35], and that involves more nursing home mistreatment [41]. Furthermore, there is evidence for a dysfunctional nursing home caregiving type, named rough handling care, in which professionals behave impatiently, ignoring and treating IOA as objects, or even threatening them. Moreover, nurses´ negative stereotypes affect negatively the delivery of IOA care [30]. Because of the important role played by professionals´ negative self-perceptions of aging explaining good care in this study, it should be considered as a key dimension. Given that negative stereotypes can reduce the potential IOA good care, more research and interventions should be developed among front-line professionals working in nursing homes. Institutions supporting continued education and care about reducing nursing staff´s negative old-age stereotypes, have the potential to impact on IOA good care and ameliorate ageism.

Furthermore, management support (i.e., being thanked for a job well-done; receiving support in the form of feedback on work performance) is the only work-related factor analyzed significantly associated with good care. Consistent with previous research, supporting capacities of supervisors towards their subordinates, plays a role of major importance [19]. Sufficient support for professionals and colleagues should be guaranteed in a friendly and reinforcing work atmosphere [18]. Practically, our results support the notion that researchers, chairs, supervisors, and nursing home professionals may need to focus on social support. Collective support (managerial and coworker social support) may provide the individual with more opportunities to perceive improved control, thereby improving good care.

Most nursing assistants take this employment because of not finding a job in their original occupation [32]. Workplace stress can be especially problematic for nursing aides or nursing assistants [32,60]. Contrary to our hypothesis, there were no differences on the good care ratings on the GCS-NH among positions in facilities. No association was found between good care and both being a nursing assistant or being a technician in the last step of the regression analysis. The correlation of good care with being a nursing assistant is no longer significant when work-related and personal resources are considered. These results may be explained by mediation effects. For example, being a technician may lead to receiving higher management support, and higher personal resources (i.e., more personal accomplishment and less depersonalization, and negative old age stereotypes). Previous studies have found less management support in nursing assistants [60]. Nursing assistants experienced higher levels of burnout and negative stereotypes [32,60] that may be related to less effective good care ability, involving less use of humanization, no infantilization, respect, and empowerment strategies.

This is one of the first studies to analyze the impact of personal and work-related resources on IOA good care. However, the different effects of management support, depersonalization, personal accomplishment, and negative old age stereotypes on good care for IOA should be studied further.

The results of the present study should be interpreted in light of its limitation involved in cross-sectional designs. We cannot make causal inferences because a cross-sectional study can only test associations between the variables. Further longitudinal research is needed to analyze this model of IOA good care. Moreover, intervention studies targeting work-related and personal resources might help to determine causality between work-related and personal resources and good care.

In addition to the cross-sectional design, this study has the following limitations. First, regarding the data-collection method through a self-reported survey, social desirability may have affected nursing staff´s answers by showing what the employer expects them to respond instead of their true feelings or impressions. Second, our findings cannot be generalized because of the use of a non-probability sample. A more representative sample of nursing home professionals should be included in future studies to provide a more complex view of good care, thereby advancing our knowledge. Third, data on residents and their relatives' impressions were not collected. Future studies could be based on our results and go further by examining residents' and their relatives' concepts about nursing home professionals' good care. Fourth, even though the regression model explained 31% of good care, this means that there are still additional factors influencing the IAO good staff that remain to be explored.

5. Conclusions

Despite these limitations, this study provides relevant information about the effect of personal and work-related variables on good care in front-line care nursing home professionals. In summary, in addition to management support, some personal issues—such as personal accomplishment, depersonalization, and negative old age stereotypes—seem to be relevant for explaining good care for IOA at nursing homes.

Good care seems to be related to work related factors and personal resources that may have to do with a negative view of aging, such as perceiving older adults as less capable, and with burnout feelings and management support. The data from this study suggests that it is not mainly work-related factors themselves but having positive perceptions of aging and less burnout perceptions that are related to good care for IOA. Nursing staff with positive perceptions of aging develop a better IOA care. Furthermore, nursing staff with engagement—characterized by energy, implication or commitment, and efficiency—may be regarded as the opposite to burnout, and seem to be more connected to IOA good care.

Policymakers and practitioners could consider the following aspects. First, promoting good care in nursing homes should begin by working on personal variables. The aim would be reducing staff burnout, a highly prevalent variable in nursing assistants working in long-term facilities for older people [32]. Professionals´ burnout should be sanctioned at the policy levels. Increasing the levels of personal accomplishment, and improving personalization attitudes may contribute to tackling burnout, which may, in turn, influence their good care to the residents. Second, modifying professionals´ attitudes towards older people can prevent negative old-age stereotypes. Burnout and negative stereotypes are modifiable through support, education, supervision, and other well-established means. Third, management support is a key point when changing the organization in the nursing home. It is also essential to assess the effect of these changes in IOA good care. Each nursing home should have clear policies to report and promote good care for its residents. Person-centered care and good care are wide constructs with relevant joint points. However, they are not exactly the same [61]. Good care is everyone's business [44]. The theory of 'doing good care' involves anticipatory caring, and momentary caring [62]. Good care conveys to IOA that they are important. Individually, each good care behavior could have a positive impact. Collectively, they have the potential to result in a sense of strengths, optimism, and self-esteem [45]. Good care is both value reinforcing (it allows nursing home professionals to support the value of personhood) and an ethical expression (it is good to work with residents who are dependent and fragile). The essential test of this care is recognizing the uniqueness of the other. All of this, assuming that a holistic approach considers also factors associated with quality of life in IOA (control and autonomy, pleasure, and self-realization) [63].

The recent COVID-19 pandemic has shown the importance of having a well-organized health system, enough flexible to adapt to the people´s needs not only to respond to emerging threats, but also to cope with chronic diseases. COVID-19 outbreak had a limited impact on older adults' psychological wellbeing [64]. However, IOA do not have usually an alternative home (the long-term center is their home), making the nursing homes an essential service and a priority for the whole of society. The preventive measurements of the lockdown of residences, sectorization of spaces, and isolation of residents has affected to good care during COVID-19 outbreak. The present study highlights the influence of nursing staff personal factors (a positive perception of aging and personal accomplishment and personalization) on good care. Nursing staff with lower levels of old age stereotypes and depersonalization will probably inform residents, and their relatives, with understandable language, answer all questions, and repeat information when necessary, about the emergency of exceptional situations and the existing COVID's protocols (i.e., regarding referrals to health services, test for COVID-19, visit conditions). Furthermore, nursing staff with higher levels of personal accomplishment will probably discover new forms of working during COVID-19 outbreak (i.e., identify circuits in nursing homes that allow the development of routines basic mobility for IOA; guarantee the monitoring of educational and social work activities to the IOA). Nevertheless, more research is needed on this topic.

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Setting Priorities to Inform Assessment of Care Homes' Readiness to Participate in Healthcare Innovation: A Systematic Mapping Review and Consensus Process

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Abstract: Organisational context is known to impact on the successful implementation of healthcare initiatives in care homes. We undertook a systematic mapping review to examine whether researchers have considered organisational context when planning, conducting, and reporting the implementation of healthcare innovations in care homes. Review data were mapped against the Alberta Context Tool, which was designed to assess organizational context in care homes. The review included 56 papers. No studies involved a systematic assessment of organisational context prior to implementation, but many provided post hoc explanations of how organisational context affected the success or otherwise of the innovation. Factors identified to explain a lack of success included poor senior staff engagement, non-alignment with care home culture, limited staff capacity to engage, and low levels of participation from health professionals such as general practitioners (GPs). Thirty-five stakeholders participated in workshops to discuss findings and develop questions for assessing care home readiness to participate in innovations. Ten questions were developed to initiate conversations between innovators and care home staff to support research and implementation. This framework can help researchers initiate discussions about health-related innovation. This will begin to address the gap between implementation theory and practice.

Keywords: long-term care; organisational; context older people; care homes

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1. Introduction

In England, there are almost three times as many care home places as there are beds in the acute hospital sector, and one in six people aged 85 or over are living permanently in a care home [1]. Care home residents have complex healthcare needs due to multiple comorbidities (including dementia) yet do not always have access to the healthcare services that they would have if they were living in their own home [2]. In the UK, most care homes do not have registered nursing staff on site [3].

There is a growing recognition of the need for care home specific evidence that informs and improves healthcare of older people in these settings [4,5]. How improvements to healthcare for residents in care homes are implemented depends on a range of factors, including institutional and sectoral priorities, leadership styles, communication patterns, staff interest, and the quality of pre-existing relationships between staff and visiting healthcare professionals [6–8]. Understanding from the outset how the organisational context and culture of a care home influences readiness to participate in change is important. It has the potential to shape how healthcare professionals and care home staff plan their work together and explain the variability of uptake of new initiatives across the sector.

Implementation science recognises that differences in context influence innovation and implementation [9]. Context is a broad concept, and multiple implementation frameworks have operationalised the individual, organisational, and environmental factors involved [10,11]. Despite the rapid growth in implementation science in the healthcare sector in general, there is limited knowledge regarding how context affects innovation and implementation in care homes [12,13]. This is especially relevant when implementation involves practitioners from different types of organisations (public and private, health, and social care), with overlapping but distinct priorities, beliefs, and values.

A Canadian programme of work (Alberta Context Tool© (ACT)) has linked assessment of the organisational context of care with a care home's capacity to embed new ways of working and caring into its everyday practice [14,15]. This has been done by studying different elements of organisational context, such as leadership styles and communication patterns and their impact on implementation of innovative models of care [16]. The aim of our study was to draw on this work to explore in more detail how the organisational context of the care home, and its constituent elements, might shape care home capacity and readiness to engage alongside health services in innovative approaches to care delivery. We aimed to identify the extent to which researchers have considered organisational contextual factors when planning and reporting the implementation of healthcare interventions in care homes. Organisations involved in innovation in care homes might then use these results to measure and better understand their local care home organisational contexts before attempting to implement changes.

2. Methods

The study had two phases. Phase 1 was a systematic mapping review of care home research. A mapping review is based on the concept that published articles not only represent findings but indirectly represent activity related to the finding [17,18]—in this case, the impact of organisational context on implementation. We used the domain headings of the Alberta Context Tool to assess whether care home studies reported any pre or post hoc consideration of the impact of organisational context on readiness to engage in healthcare innovations. Phase 2 consisted of two consensus workshops where findings were reviewed using nominal group technique and stakeholders identified possible questions that practitioners could use to assess care home readiness.

2.1. Phase 1 Systematic Mapping of The Literature

2.1.1. Inclusion Criteria

We included Randomised Controlled Trials (RCTs) and process evaluations in three main areas: telehealth (video consultation and remote monitoring); integrated working between care home staff and visiting healthcare professionals; and comprehensive assessment and care planning, for example by general practitioners (GPs). The reason for including these areas was that they had been selected by commissioners in the English National Health Service (NHS) as priorities for improving care home residents' contact with the healthcare system. This was part of a broader strategic plan for system-wide change in NHS England [19], where interventions were piloted in six geographically disparate health economies identified as 'Vanguard sites' (known as the New Care Model Vanguard sites for Enhanced Health in Care Homes) [20].

In addition, we included RCTs, process evaluations, and qualitative studies that had reported on how context had informed uptake and implementation but whose intervention differed from those three areas of care.

2.1.2. Search Strategy

We searched PubMed and CINAHL for records published between 2009 and July 2016. The search was updated in June 2018. The search strategy (see Table 1) involved broad terms based on those used in a previous mapping review of care home research [4]. Non RCTs, such as process evaluations and qualitative studies, were identified from personal knowledge and from lateral searches, such as citation and keyword searches on Google Scholar.

Table 1. Search terms for the mapping review.

PubMed.
"nursing home" OR "residential facilities" OR "homes for the aged" (MESH) OR nursing homes (TI/AB], care home [TI/AB] OR residential care [TI/AB] AND "randomised controlled trial" OR "randomized controlled trial" (MESH)
CINAHL
"nursing homes" OR "residential facilities" OR "skilled nursing facilities"

2.1.3. Data Extraction and Analysis

Search results were downloaded into bibliographic software, and duplicates were deleted. Two authors independently screened the first 20 titles and abstracts to check for agreement (R.S., C.R.). The data extracted included information on study aims/research questions, interventions (including how care home staff were involved), participants, setting, type and size of care home, country, and information applicable to organisational context. The focus of data extraction was on factors related to implementation rather than the effectiveness of the intervention. The data was extracted by one of the following authors (R.S., C.R., M.H.) with 20% checked by a second author (F.B.). Disagreements relating to inclusion or data extraction were resolved by discussion with a third author (C.G. or F.B.).

We mapped the extent to which studies reported on implementation factors outlined in the Alberta Context Tool [21]. The rationale for choosing this particular tool is that it focuses on constructs related to organisation, addresses context assessment in long-term care facilities similar to English care homes, has been used in long-term care research, and draws upon the theoretical work of the Promoting Action on Research Implementation in Health Services (PARIHS) framework [22]. The ACT includes eight dimensions that are comprised of 10 contextual concepts: (1) leadership, (2) culture, (3) evaluation, (4) social capital, (5) structural and electronic resources, (6) formal interactions, (7) informal interactions, (8) organisational slack—staffing, (9) organisational slack—space, and (10) organisational slack—time [14,15]. For the analysis, the data were mapped against the ACT framework to determine if the study assessed care home contextual factors in planning or conducting the study and/or reported on the potential impact of factors on the implementation of the intervention.

2.2. Phase 2 Consensus Workshops

In phase 2, we tested the findings of the review with key stakeholders working in sites that had received additional NHS funding to improve working between healthcare professionals and care homes [20]. We invited care home managers and frontline care home staff, care home researchers, NHS commissioners, and providers of services to care homes to consensus workshops in two areas in England (Nottingham and London). Invitations were sent via the leads for each Vanguard site. Care home staff and managers who responded were self-selecting and were recruited on the basis of their interest in the topic rather than their representativeness. However, to be eligible, participants had to have direct experience working with NHS services and care homes. Before attending the half-day workshop, participants were sent a briefing document outlining the background to the research and the aims of the meeting. To structure the discussion at each workshop and rank the importance of the findings, we used the nominal group technique. This is a process that promotes the generation of ideas and enables the participation of all group members. The process involves four stages: (1) the generation of ideas, (2) recording of ideas, (3) discussing of ideas, and (4) prioritising of ideas [23]. To begin with, review findings were presented using the ACT headings to structure the discussion, and participants were asked whether findings resonated with their experiences. Research team members and participants recorded group discussions on index cards and flipcharts. Initial discussions resulted in 21 characteristics likely to affect care home readiness to participate in NHS-led service improvements. Using the nominal group technique [23], participants ranked these in order of importance. Thirty-five participants attended the two workshops (Table 2). Findings from the two phases were synthesised by members of the team (C.G., F.B., R.S., J.L., A.G.), and the key themes or ideas were expressed as questions. These questions were developed by the researchers and were not tested further with participants.

Table 2. Workshop participants.

Workshop	Participants	
London workshop n=21 + 3 facilitators	Care home manager	3
	Care home representative organisation/charity	4
	NHS physician/nurse/therapist working with care homes	6
	NHS manager/commissioner	3
	Care home researchers	5
Nottingham n=14 + 2 facilitators	Care home manager	1
	Care home representative organisation/charity	3
	NHS physician/nurse/therapist working with care homes	4
	NHS commissioner/manager	4
	Care home researchers	2
Total participants		35

3. Results

3.1. Systematic Mapping

Fifty-six papers from 48 studies met our inclusion criteria (Figure 1). These included 36 RCTs [24–59] and 20 process evaluations or qualitative explorations of implementation [60–79]. We found studies from 10 countries: the United Kingdom (13), the United States (11), Australia (8), the Netherlands (5), Norway (3), Belgium, New Zealand, Canada (all 2), China (1), and France (1). An overview of the types of interventions and the domains of the ACT covered can be seen in Table 3. For further details of individual studies, see Supplementary Materials S1.

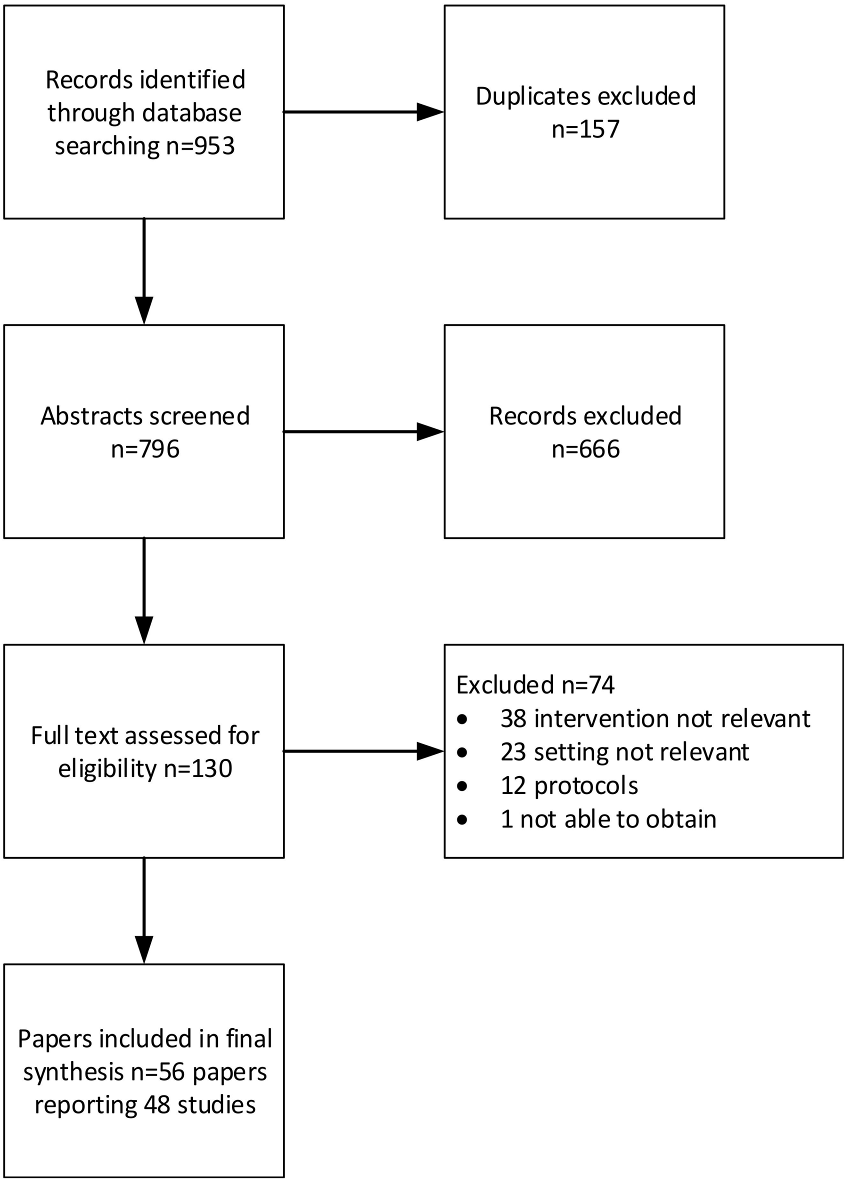

Figure 1. Selection of studies for inclusion in the mapping review.

Table 3. Types of interventions and frequency with which Alberta Context Tool (ACT) domains were considered.

Type of Intervention	N of Papers	Citations
Integrated working between care home staff and visiting health professionals	24	[24,25,27,28,32,35,36,38,39,42–45,47,50,58,60,63–66,69,78,79]
Comprehensive assessment and care planning	8	[44–46,48–51,64–66,77]
Telehealth	3	[31,33,41]
Other type of intervention (but provides detail on organisational context)	27	[26,28,32–35,38,39,44,47–49,54,58,60–62,67,68,70–73,75]
Domain of ACT	**Considered in paper (n=)**	**Citations**
Leadership	40	[24,25,27–31,34,36,38,40,42–50,52–56,58–60,62–64,66–69,72,73,75,77,78]
Culture	32	[24,27,34,36,37,42,45,46,48,49,52–55,58,59,62–64,66–70,72–76,78]
Evaluation	12	[25,39,40,44–46,48–51,64,66]
Social capital	13	[25,31,49,59,64–66,68–70,72,76,77]
Informal interactions	11	[30,49,55,57,59,60,64,65,67,72,77]
Formal interactions	30	[27–31,34,38,42,45,46,48–52,55,61,63–66,68–70,72,73,76–79]
Structural/electronic resources	22	[25,30,31,41,42,44–46,48–53,55,57,61,64–66,72,77]
Organisational slack—staff	36	[24,26,27,29,30,34,36,38,42,45,47–50,52–54,56–61,63–68,73–78]
Organisational slack—space	6	[33,51,66,68,70,71]
Organisational slack—time	30	[24,27–30,34,37–39,45,47,49–53,55,56,58,59,61,65,66,68,70–73,77,78]

None of the papers included a structured and comprehensive assessment of context that considered all the domains of the ACT. However, one study [48] used the PRECIS-2 tool [80] to evaluate implementation of their pragmatic randomised controlled trial, and another used the findings of an RCT in nursing homes to develop a tool to assess and manage the challenges facing complex organisational interventions [74]. However, the latter framework focuses on issues that arise during a study rather than anticipating and planning for them in the study design and set-up.

The most commonly considered areas of organisational context were leadership, culture, formal interactions, and staff availability. Where contextual assessment did feature, it was most frequently used as an unstructured post-hoc exploration of why an intervention had or had not worked. Detailed mapping of individual studies against the domains are shown in Tables S1 and S2.

3.1.1. Leadership

Most papers reviewed (n=40) noted that care home leadership influenced the uptake of a given innovation. Studies cited the importance of leadership from care home managers and/or senior direct-care staff [29,38,53,54,64,77] and from staff acting as clinical champions or persuasive leaders. Some studies attempted to address leadership issues prospectively through early engagement with care home managers [30,34,36,38,45,66,77] and/or the appointment of clinical champions [26,29,44,45,48–50,63,64]. However, in many cases, engagement appeared superficial or limited. Examples where more sustained engagement was built into the trial design include the MARQUE study [45] and the WHELD study [44,64]. In the former, researchers held regular supervision and troubleshooting meetings with care home managers, and in the latter, champions were given sustained support and coaching aimed at building their confidence. This engagement process appeared to contribute to sustained delivery of the intervention.

A number of studies focused almost exclusively on the negative impact of a lack of leadership [38,42,43,53,68,72,78]. Issues cited included poor role clarity, managers' resistance to change, delegation of responsibilities to staff without the skill or authority to implement change, turnover of managers, and insufficient management attention to the innovation. Whilst these are well known to affect implementation, they had generally not been addressed as part of the innovation's development.

3.1.2. Culture

Positive cultural attributes were identified as those factors that gave time and resources to staff education, reinforcement of learning, and quality improvement [43,45,52,54,64–67]. Feedback on progress encouraged a sense of shared ownership of a given change [53]. Uptake was more likely when an intervention was acceptable to healthcare professionals, residents, and staff; when it fitted with existing care home routines; and when there were opportunities for ongoing consultation with staff [36,45,60,69,70]. Some studies attempted to proactively address the impact of culture, for example by involving stakeholders, such as care homes staff, in the development of the intervention [36,63,74].

Culture negatively affected uptake when the systems of care and required staffing levels were incompatible with those proposed by healthcare professionals or if care home staff felt that the proposed change implied a criticism of current practices [24,38,55,61]. Practices within the care home that specifically worked against the successful uptake of initiatives were the following: a task-focused approach to care, a preoccupation with risk reduction, or staff with a limited skill set working with residents who had advanced dementia [34,37,62,68,71,73,75]. Studies highlighted the importance of managerial support to change perceptions about what constituted real work. For example, supporting people so that they felt comfortable to sit and talk with residents rather than engaging in task-based care [49].

3.1.3. Evaluation

Care homes' use of data to assess performance and achieve outcomes was discussed in terms of staff's familiarity with gathering data and how they used information to inform quality improvement, specifically whether care homes easily provide information about residents' characteristics, document their participation and health-related outcomes, or provide information about relatives' involvement in care [30,54,60,71–73,76]. One study noted the related challenges of synthesising data from the multiple data sources within a care home [55]. Other studies described the benefits of engaging in pre-intervention work or adapting to current processes to ensure consistent documentation of care [40,79].

3.1.4. Social Capital

Social capital recognises the existing resources and support networks, both formal and informal, available to a care home to deliver care. It helps to explain why care homes with similar populations may be more or less resilient and responsive to change. This domain was not explored in most of the research reviewed, although some studies reflected on how homes' connections, particularly with external services, affected implementation of care initiatives [27,31,69,70,72,76]. Specifically, absent or poor connections with general practitioners (community physicians), secondary care (hospitals), and professional or academic organisations were important in affecting how care homes worked with visiting healthcare practitioners. Two studies reported on the advantages of having clinicians working with care homes to support interventions to improve the quality of care [25,36].

3.1.5. Informal and Formal Interactions

Low GP participation or resistance from GPs [29,34,47,61,63,69,77–79,81], limited opportunities for formal communications in multidisciplinary team meetings [27,28,60,72,73], and poor communication within the organisation [55,68,73] were factors reported to be barriers to implementation. One study recognised the need in future work to address how group dynamics and peer pressure facilitates (or not) the adoption of the intervention and the possible benefits of preparatory coaching to build staff confidence in their practices [30]. Indeed, approaches that fostered a combination of formal and informal interactions, for example through regular meetings, coaching, interactive approaches, and good communication of information, were all identified as facilitators [30,38,52,67,77]. This included interactions between care home staff, between staff and external health professionals, and between staff and researchers.

3.1.6. Structural/Electronic Resources

Studies showed that when care homes experienced system changes or reorganisation, uptake of new interventions was limited [25]. Some studies did acknowledge the impact of this; for example, one study excluded care homes in which major innovation projects had recently been implemented [30]. Care home record keeping systems, and limited access to computers could have a negative impact on the collection of outcome data or participation in the study [49,51,53,72]. Some studies provided support or training to staff to improve recordkeeping or the use of IT in the care home [48,64,66]. In the WHELD study, recordkeeping for the research influenced the wider practice of the care home and led to an overall improvement in documentation [64]. This appeared to be because staff were actively engaged in the project and because the research enabled them to see the connection between care home practice and outcomes [64].

3.1.7. Organisational Slack

The biggest issue, identified by almost all studies (n = 43), was staff availability and capacity. This was expressed in four ways: staff workload, staff turnover, staff skills, and whether an innovation was seen as a priority by the care home. Some studies suggested that funding for staff time to deliver an intervention or attend training might ease the problem of staff availability [29,42,45,53,63,68,75]. Making time to build relationships, to agree how to work together, and to establish if the intervention was relevant to the care home was also important [27,41,56,59,60,64]. Space was less frequently mentioned as an issue, although two studies reported that the physical structure of the home could be challenging [68,71], for example making it difficult to maintain residents' privacy during research interviews [71].

3.2. Consensus Workshops

Participants at the consensus workshops recognised and validated the review findings. They found it challenging, however, to articulate how they would quantify these different aspects of care home context or assess how they affected readiness to participate, implement, and sustain innovation. For example, participants endorsed the importance of having enough time to get to know each other to build a shared agenda and mutually beneficial working relationships but were unsure how this is achieved or how many resources are required.

Similarly, everyone identified leadership approaches in the care home as key. They struggled, however, to unpack what type of leader was important, whether the level of managerial involvement was significant, or how staff turnover and availability might affect uptake of the interventions. Fewer still, despite personal experience in instituting healthcare change in and with care homes, had considered how the internal systems of the care home and surrounding networks of care affected uptake or whether the priorities of the NHS always aligned with those of the care homes.

Evidence showing that it was frequently difficult to engage healthcare professionals with different care home innovations resonated with participants at both workshops. Participants also noted that there was little information on what was required to ensure that visiting healthcare professionals were ready to work with care homes and limited evidence about how healthcare practitioners' prior knowledge and experience of working in care homes affected implementation. They observed that studies seldom considered if an innovation was wanted or needed by the care home and that they usually failed to partner with care home staff in planning innovation from the outset.

Workshop discussions identified 21 characteristics likely to affect care home readiness. When asked to rank them, participants identified the following as most important: having a capable and confident manager, alignment of priorities and staff buy-in, engagement with a care quality vision, evidence of a culture of change, and receptiveness of manager and senior staff to engage in change.

The findings were then developed by the research team into a series of questions (Table 4). These questions were designed to provide a framework to promote conversations between researchers, practitioners, and commissioners when considering innovation in care homes.

Table 4. Set of questions combining review findings with the workshop priorities.

	Set of Questions Combining Review Findings with the Workshop Priorities
1	Does this intervention align with care home priorities?
2	What evidence is there of senior management interest and enthusiasm for this intervention at the organisational and unit level? Are they willing and able to take an ongoing leadership role in supporting the proposed change?
3	Do care home staff have enough 'slack and flexibility' to accommodate the change into their current workload? Will it be recognised as core to their work?
4	How is change discussed (formally and informally) in the care home setting? Who needs to be involved in decision-making about what is being proposed and how it is implemented?
5	What are the recent changes or health-related projects this care home has been involved with?
6	Is there a champion in both the care home and in the linked NHS service with protected time to facilitate change?
7	What are the pre-existing relationships between NHS services and care home staff and networks of care and support around the care home (e.g., general practitioners (GPs), visiting specialists, links with local hospital)?
8	Could the intervention appear judgmental by signalling in a negative way that the care home needs to change?
9	How well do existing care home training programmes and work schedules fit with what is proposed?
10	Will care home staff have to collect and enter new data or are they held in existing systems?

4. Discussion

To identify and map the contextual influences that affect successful implementation of healthcare interventions in care homes, we conducted a review of 56 care home papers and undertook workshops involving 35 participants. Both the review and the workshops offered evidence of how context influenced implementation but less knowledge of how to achieve context 'readiness'. The most commonly cited components of organisational context were leadership, care home culture, formal interactions, and organisational slack. The review demonstrated that researchers are aware of how context affects uptake of healthcare innovation in care home settings. Despite this, organisational context was generally used to explain problems with implementation post hoc, rather than being planned pre hoc as part of the study design.

Leadership, care home culture, and staff capacity to engage in and prioritise innovations are well recognised as important influences on uptake of innovation [82,83]. Given this, it is disappointing that, in many studies, these well-documented challenges are presented as findings, rather than being used to inform the study design. Overall, there were little data on what is required prior to innovation in terms of research design, involvement of staff, and the resources required. More recent trials in care homes [44,45] have provided accounts of how care home context was addressed in setting up the study and delivering the intervention. For example, the WHELD study highlighted the importance of understanding the experiences of care home staff, engaging them as active members of the research team, and supporting them to develop skills and take ownership of the intervention [64,65].

A clear message from the workshops, and from the review, was that it takes time to develop relationships that support effective collaborations between visiting healthcare professionals and care homes. These findings are supported by a recent realist evaluation of health service delivery to care home residents in the English NHS [84]. This study found that service integration between the NHS and care homes was dependent on time, and support from commissioners to develop relational working. It is also suggested that a long preparatory period, consultation with a range of frontline staff and care home residents [83], and co-design of interventions could improve implementation [85].

Very few studies provided the opportunity for care home staff to comment on the relevance of research or the experience of participation. Further, residents' and relatives' voices are also largely missing from this study. This is, in part, because they were absent in the papers reviewed. It is a significant limitation that so little can be said about how residents and their representatives influence the planning and uptake of healthcare interventions.

5. Limitations

It is possible that the time limits incorporated in our search strategy meant that we missed relevant studies on care home context. In addition, we did not include study protocols, which might have provided more information about researchers' plans to address organisational context. Previous mapping reviews of trials conducted in care homes have not, however, revealed significant volumes of implementation literature in the sector that would have been likely to change our findings [4]. The ACT framework provided a useful tool for mapping organisational context. However, we found some overlaps between domains, for example organisational slack around staff and time. We conducted only two workshops with self-selected participants; thus, the consensus rankings need further refinement and testing with a wider audience.

6. Conclusions

Care home context and readiness for change is an important factor for the successful implementation of healthcare initiatives. Approaches to measuring context, such as the ACT, have been applied to individual research studies. Drawing on the findings of this article, there is a clear case to persevere with structural assessment of care home context in research. This requires a systematic approach to assessment at the beginning of an innovation or intervention. This synthesis and stakeholder engagement led to the development of questions that can be used to help researchers, practitioners, and commissioners begin conversations about the measures needed to bring care homes to a state of readiness for successful implementation of healthcare initiatives. Ultimately, asking these questions consistently across diverse care home settings will inform the development of a shared, core set of context assessment tools to support healthcare interventions in care homes in England and elsewhere.

Supplementary Materials: The following are available online at http://www.mdpi.com/1660-4601/17/3/987/s1, Table S1: Table of included studies, Table S2: Summary of the ACT domains and linked evidence from the mapping review.

Author Contributions: C.G., F.B., K.C., A.L.G., T.D., and J.M. conceived of the study and developed the protocol. CG led the study. R.S., M.H., F.B., C.G., and J.L. extracted data and participated in the synthesis process. C.G., R.S., A.L.G., and J.L. conducted the stakeholder groups. All the authors were involved in interpretation of the results. F.B., C.G., and J.M. wrote the paper. All the authors critically reviewed the paper. All authors have read and agreed to the published version of the manuscript.

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Improving the Quality of Care in Care Homes Using the Quality Improvement Collaborative Approach: Lessons Learnt from Six Projects Conducted in the UK and The Netherlands

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Abstract: The Breakthrough Series Quality Improvement Collaborative (QIC) initiative is a well-developed and widely used approach, but most of what we know about it has come from healthcare settings. In this article, those leading QICs to improve care in care homes provide detailed accounts of six QICs and share their learning of applying the QIC approach in the care home sector. Overall, five care home-specific lessons were learnt: (i) plan for the resources needed to support collaborative teams with collecting, processing, and interpreting data; (ii) create encouraging and safe working environments to help collaborative team members feel valued; (iii) recruit collaborative teams, QIC leads, and facilitators who have established relationships with care homes; (iv) regularly check project ideas are aligned with team members' job roles, responsibilities, and priorities; and (v) work flexibly and accept that planned activities may need adapting as the project progresses. These insights are targeted at teams delivering QICs in care homes. These insights demonstrate the need to consider the care home context when applying improvement tools and techniques in this setting.

Keywords: Quality Improvement Collaborative; Quality Improvement; Implementation Science; residential facilities; older people

1. Introduction

The rising number of older people is a global phenomenon [1]. One option for older people who are not able to live independently is to live in a long-term care facility, such as a nursing home. An internationally agreed definition of nursing homes is provided by Sanford et al., defining these as facilities that "(i) provide 24-h functional support for people who require assistance with activities of daily living and have identified health needs, (ii) may or may not be staffed with health care professionals, (iii) provide long-term care and/or rehabilitation as part of hospital avoidance or to facilitate early hospital discharges (iv) do not function as a hospital ward and are not hospital based, and (v) may play a role in providing palliative and/or hospice care at end of life" [2]. There are differences between countries in the way that facilities operate, the way that care is financed, how quality of care is regulated, and in the mix and type of professionals employed [3]. For instance, nursing homes in the Netherlands employ a mix of health care professionals and care workers, and in the UK, nursing homes employ Registered Nurses and care workers (with wider healthcare input received from community services). On the other hand, residential homes (referred to as care homes in the Netherlands) in both the UK and the Netherlands employ care workers to provide direct care and healthcare professional input is received from community services. The general characteristics of residents living in nursing and residential homes, however, are similar [4]. In this article, we use the general term "care homes" to refer to both nursing and residential homes.

In the UK, the quality of care across the sector varies [5] and several initiatives dedicated to improving the quality and safety of care have been introduced in recent years. Since 2013, 15 regional Academic Health Science Networks (AHSN) across England have supported projects focused on improving quality and safety in care homes [6]. In 2016, National Health Service (NHS) England commissioned the Enhanced Health in Care Home Vanguards, an initiative to implement a suite of evidence-based interventions in care homes located in six areas of England [7]. In the Netherlands, national initiatives focused on improving quality of care in care homes were supported by the Dutch National Care for Frail Elderly Persons Programme, which took place from 2007 to 2016, and comprised a series of Quality Improvement (QI) initiatives and studies clustered around eight academic medical centres [8].

An approach used in several of these initiatives is the Quality Improvement Collaborative (QIC) intervention [9]. Various versions of the QIC intervention exist. One of the most prominent is the Breakthrough Series Collaborative, as developed by the Institute for Healthcare Improvement (IHI) [10,11]. A QIC based on the Breakthrough Series model is a multifaceted intervention that typically lasts 6–15 months [12] and generally includes five essential features: (1) a team of clinical and QI experts bring clinical and QI knowledge and lead the QIC; (2) local multi-professional teams take part and form the collaborative; (3) the collaborative focuses on a specific topic; (4) participants engage in structured activities; and (5) they use the IHI's Model for Improvement to guide change [13]. The Model for Improvement is a framework used to guide improvement projects where goals are set and a process called the Plan–Do–Study–Act (PDSA) cycle is used to test the impact of changes [14]. A PDSA cycle is a cyclical process of planning change (plan), actioning plans (do), observing and reflecting on the result (study), and modifying plans to address what has been learnt (act) [14]. Previously, collaboratives have been studied mainly in hospital settings [9]. The recent use of QICs with care homes in the UK and the Netherlands provides an opportunity to examine and learn whether and how this approach works in this setting.

A recent scoping review conducted by Chadborn et al. highlighted that while there is a body of evidence around QI strategies used in the care home setting, without detailed descriptions of how strategies are applied, the extent to which others can replicate and learn from them is limited [15]. The aims of this paper are firstly to provide detailed descriptions of six QIC projects carried out in care home settings in two countries, and secondly, to share insights and learning from these projects.

2. Method

Representatives of teams delivering QIC interventions were identified through our networks and UK national organisations including the British Geriatrics Society, AHSNs, the Health Foundation Q Network, and Health Services Research UK. Representatives attended an initial face-to-face meeting where detailed descriptions of each QIC intervention were presented and structured using the Template for Intervention Description and Replication (TIDieR) standardised reporting template [16]. This was followed by a series of face-to-face, electronic, and telephone meetings where the TIDieR framework descriptions were used to elicit discussion about lessons learned during conduct of the QICs. The focus was to find lessons that applied across more than one QIC initiative and those specific to the care home setting, as opposed to generic lessons that might apply to QICs conducted in other contexts. A list of lessons learnt is provided and each is summarised, outlining the challenges faced and the ways that these were addressed. The learning is targeted at teams leading and facilitating QICs in care homes.

3. Results

3.1. QICs in the Care Home Setting

The insights in this article are based on six QIC projects. Five were conducted in the UK and one in the Netherlands:

1. The Proactive Healthcare of Older People in Care Homes collaborative (PEACH);
2. Safer Care Homes;
3. Promoting Safer Provision of Care for Elderly Residents Collaborative (PROSPER);
4. The Safer Provision and Caring Excellence (SPACE) Programme;
5. The Medical care Optimalisation Care home Implementation (Medische zorg Optimalisatie Verzorgingshuizen Implementatie Traject)—MOVIT project;
6. The South Sefton Care Home Innovation Programme (CHIP).

Projects took place in five areas of England (Nottinghamshire, Salford, Essex, Walsall and Wolverhampton, and Bootle) and one area in the Netherlands (Leiden). The earliest project started in 2009 (MOVIT), the most recent started in 2017 (Safer Care Homes), and the length of completed programmes ranged from 13 months (Safer Care Homes) to 42 months (MOVIT), with one project still ongoing since 2014 (PROSPER). Projects' specific aims varied. The PROSPER, Safer Care Homes, and SPACE QICs focused on improving safety and reducing avoidable harms. The PEACH QIC aimed to improve healthcare and used Comprehensive Geriatric Assessment (CGA) as a template to guide discussions. The MOVIT project aimed to improve fragmentation of medical care and the CHIP QIC focused on reducing ambulance conveyances.

3.2. Descriptions of the Quality Improvement Collaborative Initiatives

Detailed descriptions of each QIC are provided in Tables 1–6, broadly following the TIDieR template, with the addition of information on evaluation activities undertaken for each project.

Table 1. Description of the PEACH Quality Improvement Collaborative.

Brief Name	**The PEACH Collaborative**
Why	The aim was to improve healthcare for care home residents, and CGA was used to guide discussions.
Where	Nottinghamshire, UK. Collaborative shared learning events were carried out at a university location, and in between events (action periods), teams met in local care homes and at local Clinical Commissioning Group (organisations which plan and purchase healthcare services) locations.
Who provided	The PEACH collaborative was delivered by a team comprising a locally known clinical academic geriatrician, a nurse leader with expertise in appreciative inquiry to promote quality of life in care homes, a Health Foundation QI Fellow, and a researcher with interest in improvement science. The overall PEACH programme was funded by The Dunhill Medical Trust (grant number FOP1/0115). The collaborative shared learning events were funded by the East Midlands AHSN Patient Safety Collaborative (https://www.emahsn.org.uk/our-work/patient-safety).
Recipients	The collaborative took place across a region which has four distinct sites, and a team formed in each site. In each site, the person responsible for planning and purchasing healthcare services (commonly referred to as "commissioners" in the UK) for older people recruited a team. Teams were multidisciplinary and included general practitioners (GP), nurses, therapists, geriatricians, pharmacists, dementia specialists, care coordinators, care home workers/managers, and voluntary sector staff. Members of the public with experience of care homes were also recruited to teams. The configuration of teams varied and depended on local resource and staff availability.
How	Face-to-face meetings.
When and how much	18 months (September 2016 to February 2018), with four collaborative shared learning events that took place approximately every 6 months.
What (materials and procedures)	Collaborative shared learning events: The events included: • Allocated time for teams to discuss and reflect on their local needs and priorities. • Allocated time for teams to brainstorm and develop QI plans. • Sessions for each team to present and share their project ideas, progress, and experiences of the improvement journey, describing challenges, successes, and lessons learnt around how to overcome barriers. • Educational/learning sessions (described below). • Networking opportunities. Educational/learning sessions: the events included educational elements, with training delivered on: • QI techniques: setting SMART (Specific, Measurable, Achievable, Realistic, Timebound) objectives and testing change ideas using a PDSA approach. An educational game using "Mr Potato Head" was carried out to demonstrate the PDSA approach, teaching teams how to set goals, and test change ideas • CGA and using this approach to care for older people.

Table 1. *Cont.*

	Action period group meetings: during action periods (the time in between each shared learning event), teams met at their own site locations to review and progress their improvement projects. Coaching: a Health Foundation-trained QI fellow on the team (JB) provided coaching and mentoring to individual teams, both at shared learning events and also during the action periods. Signposting teams to relevant contacts and resources: when collaborative teams faced challenges, the improvement team helped by signposting to relevant contacts and resources. Newsletter: provided project updates (i.e., meeting dates) and team stories describing progress with QI projects. Shared through email, with approximately three newsletters per year. Administrative support: the project improvement team provided the collaborative teams with administration support during action periods, for example, arranging meetings and circulating meeting agendas/minutes. Support with data collection: the collaborative intervention was one component of a programme of work which included work packages orientated around evaluating the activity of the QIC, collecting data around health care service use, and care home resident wellbeing. Collaborative teams were offered support with data collection and evaluation.
Tailoring	Shared learning events included features designed to create a safe working environment and reduce effects of perceived hierarchy amongst teams: • Ice breaker activities to enhance relationship building. • Time was spent at the beginning asking teams to consider items to add to a list of "ground rules", for example, (i) no question is a silly question, (ii) everyone listen when someone is speaking, (iii) mobile phones on silent. Team members were asked to comply with these rules throughout the events. • All activities maintained an appreciative enquiry approach, using positive and encouraging language, e.g., asking teams to focus on what is working well and why, envisaging how things could be, and identifying how to work together to make it happen. GPs and care home staff were provided with backfill payment for their time taken to attend events as they are independent sector workers and only able to attend meetings if adequate staff cover is arranged to cover workload.
Modifications to the programme	The original plans included carrying out conference calls as another way to meet and discuss progress with improvement work. The conference calls would take place during action periods and involve each collaborative team with the improvement team. One conference call was carried out and not repeated as face-to-face meetings were more effective for reviewing and discussing project progress.
How well	Over the course of the project 34 (out of 44) NHS and care home staff attended at least 2 (out of 4) collaborative meetings.
Project evaluation	• Process evaluation to understand how the QIC approach works, for whom, and in what ways when used to implement and deliver CGA in care homes. This evaluation uses a realist methodology; a detailed research protocol is available elsewhere [17]. • QI project evaluation to examine the impact on resident and service outcomes. A combination of interrupted times series, stepped wedge cluster design, and quasi experimental approaches were used, and are described in more detail by Usman et al. [18].

Table 2. Description of the Safer Care Homes Quality Improvement Collaborative.

Brief Name	**Safer Care Homes**
Why	The aim was to reduce medication errors, falls with harm, and pressure ulcers.
Where	Salford, UK. Collaborative shared learning events were held at a local centre for QI (http://www.haelo.org.uk/about-us/), and in between events (action periods), the collaborative met during peer exchange visits carried out at care home locations.
Who provided	The Safer Care Homes collaborative was delivered by a local organisation called Haelo: an innovation and improvement science centre based in Salford, and commissioned by Salford Clinical Commissioning Group. The Safer Care Homes collaborative was delivered by a team including an executive sponsor (Safer Salford board representative), a consultant geriatrician, a QI lead, a programme facilitator, and a data analyst (measurement support).
Recipients	Nine care homes (mix of residential and nursing) took part and collaborative members comprised care home managers and senior/junior care workers from each participating care home.
How	Face-to-face meetings.
When and how much	13 months (January 2017–January 2018), with four half-day collaborative shared learning events that took place quarterly, and monthly peer exchange visits.
What (materials and procedures)	In September 2016, a local expert panel met to set the aims of the Safer Care Homes collaborative. The panel included commissioners, general practitioners, community geriatricians, safeguarding leads, pharmacy leads, and care home representatives. A driver diagram was developed which set out the aims and objectives of the collaborative. Collaborative shared learning events included: • Sessions for each care home to present and share their project ideas, progress, and experiences of the improvement journey, describing challenges, successes, and lessons learnt around how to overcome barriers. • The improvement team presented analysed data from care homes to the whole collaborative. • Allocated time for each care home to examine and reflect on data, and develop action plans. • The improvement team encouraged care homes to generate and test ideas that were aimed at reducing falls, pressure ulcers, and medication errors. • Educational sessions (described below). • Networking opportunities. Educational sessions: each event included educational elements, with training delivered on • QI methodology. • Influence of the care home on harm reduction. Coaching, data collection, and project evaluation: members of the improvement team visited care homes weekly to provide additional support with QI training and provided each home with data dashboards constructed from data submitted from the home. Peer support and exchange visits: collaborative members visited other care homes part of the collaborative as another way to share and exchange knowledge and experiences. This helped to develop a support network between the care homes. Awards and celebrating good work: at the summit event, care home members were recognised for their achievements with awards. All received an award for completing the programme, with additional awards agreed by the improvement team for "most improved", "most innovative PDSA", and "best use of improvement methodology".

Table 2. *Cont.*

Tailoring	After the programme was completed, the improvement team adapted the model for improvement for a care home audience. This is called the "six steps to improvement" and is based on the learning and feedback from participants. This is available online at: https://safersalford.org/wp-content/uploads/2018/07/6-steps-to-improvement-30.04.18.pdf.
Modifications to the programme	Establishing a baseline number of falls with harm and medication errors was difficult, and for this reason, the improvement team worked closely with care homes to provide support with data collection and analysis. Initially, the improvement team planned that care homes would come up with their own innovative change ideas to test; however, the care homes preferred the improvement team to provide ideas based on evidence. One example of a change idea used to improve rate of falls is "pimp my zimmer", an intervention where resident walking aids are personalised and decorated to help residents recognise and use their own walking aid, and also allow staff to recognise when a resident is using the incorrect walking aid (https://safersalford.org/case-study-pimp-my-zimmer/). Part-way through the collaborative period, it was recognised that care homes valued time to share and learn from one another and so "peer exchange visits" (exchange visits hosted in participating care homes) were introduced to enhance shared learning, exchange ideas, and develop support networks. Education and training on the influence of care home on harm reduction was introduced to help care homes see they can influence the reduction in harm, e.g., changing the belief that falls were either inevitable or caused by factors external to the homes. Although the focus of the collaborative was to reduce falls, pressure ulcers, and medication errors, the majority of the homes focused on reducing falls during the collaborative. Focus on medication errors was introduced later during the collaborative. This occurred after one care home joined the collaborative part way through and showed an interest in this outcome. Following this, other care homes also started to show an interest in this outcome.
How well	Collaborative shared learning event attendance was not assessed.
Project evaluation	Success of individual change ideas was evaluated using data dashboards. Each care home was able to see the impact of each intervention, which informed ongoing tests of change. Improvement in QI knowledge was evaluated through a comparative improvement knowledge survey, performed at the start of the breakthrough series, after each shared learning event, and at the summit event. Qualitative data were collected to reflect the impact of shared learning and collaboration between each care home (https://safersalford.org/safer-care-homes-summit-2/).

Table 3. Description of the PROSPER Quality Improvement Collaborative.

Brief Name	**PROSPER**
Why	The aim is to reduce the number of harmful events (e.g., falls, pressure ulcers, and urinary tract infections) and improve the safety culture of teams.
Where	Essex, UK. Collaborative shared learning events were held in Chelmsford. Champion study days were held at five localities across Essex (Tendring, Colchester, Chelmsford, Basildon, and Harlow). Care home support visits were held at care home locations.

Table 3. *Cont.*

Who provided	The PROSPER collaborative was delivered by a team comprising a project manager and support officers with QI expertise (employed at Essex County Council), and community health practitioners with clinical expertise in falls, pressure ulcers, or urinary tract infections. The collaborative shared learning events were originally funded by the Health Foundation and have been sustained with Essex County Council and Better Care Fund funding.
Recipients	160 care homes (mix of residential and nursing) for older people, and 21 residential care homes for Learning Disability/Autism/Physical Sensory Impairment. The collaborative members comprised care home managers/deputies, senior/junior care workers, and domestic, kitchen, and maintenance staff from each participating care home.
How	Face-to-face meetings.
When and how much	An ongoing programme since 2014 consisting of two collaborative shared learning events per year, monthly care home support visits from members of the improvement team for the first 3 months (visits thereafter dependant on progress), and 10 champion study days a year.
What (materials and procedures)	Collaborative shared learning events: • Teams present and share their project ideas, progress, and experiences of the improvement journey, describing challenges, successes, and lessons learnt around how to overcome barriers. • Invited speakers deliver training (described below). • Networking opportunities. Education and training: • A PROSPER toolkit: paper and online (https://www.livingwellessex.org/quality/quality-innovation/prosper/prosper-toolkits/) resources to help care homes carry out quality improvement, comprising: i. SMART (Specific, Measurable, Achievable, Realistic, and Timebound) aim setting posters. ii. Driver diagram templates to help collaborative teams explain what is needed to achieve goals (primary and secondary drivers). iii. Worksheets to record small tests of change using the PDSA cycle approach. iv. Data collection tools to measure the number of falls, newly acquired pressure ulcers, urinary tract infections, and hospital admissions each month. v. "Safety Cross", a visual and colour coded data collection tool to display in care homes. The cross is split into days, and care staff use a colour code, using "green" for zero falls and "red" to indicate resident falls. vi. An online mapping function allows care homes to input data online, and this then generates runtime charts to show progress over time. vii. Tools for teams to carry out "Root Cause Analysis". • Invited speakers at collaborative shared events deliver training on relevant topics. Speakers included falls prevention specialists, occupational therapists, community health practitioners, community dental nurses, and continence/barrier cream suppliers. Speakers delivered training on pressure ulcers, falls, nutrition/hydration, infection control, catheter care, oral healthcare, manual handling and equipment, and urinary tract infections.

Table 3. *Cont.*

	Champion Study Days: intended for care staff who have taken the lead on implementing change in care homes. Domestics, kitchen, and maintenance staff also attended and received: 1. Goody bags including: champion badge, double compact mirrors to check heels for pressure ulcers, keyrings, smoothie recipes, and toilet bowl sensor lights (Night my Light). 2. Additional training on a range of subjects, e.g., falls prevention, infection control, nutrition/hydration, dementia, and pressure ulcers. 3. Other training delivered in a hands-on and "fun" way. For example, making smoothies and frozen banana penguins to give staff ideas on boosting nutrition hydration for care home residents and using an ageing simulation suit during falls prevention training for staff to experience the physical aspects of frailty. Care home support visits: the improvement team visit care homes to enhance engagement and provide QI expertise and advice. Support with data collection and interpretation: monthly mapping runtime charts were provided to the homes from the improvement team based on data provided by the home. Runtime charts were discussed at care home support visits. Signposting: the improvement team helped by signposting care homes to relevant contacts, resources, and training. Monthly newsletter: sharing team progress, fun facts, and top tips (reinforcing methodology) through email and via the online care provider hub (https://www.livingwellessex.org/latest-news/prosper-newsletter/). Recognition of good practice: the PDSA worksheets, capturing care home QI activity, are provided as evidence to regulators who provide recognition in inspection reports.
Tailoring	The improvement team engage in ongoing discussions with collaborative participants and use their feedback to adapt tools. For example, data collection tools were modified with care home staff feedback to be simpler and less onerous to complete.
Modifications to the programme	Training around QI methodology included care home relevant examples, with driver diagrams and PDSA worksheet examples to help participants understand the concept of small changes. The community of practice events were adapted to allow more time for sharing of ideas and sharing care home experiences of their QI projects. More details around modifications made to the PROSPER intervention are reported by Marshall et al. [19].
How well	Collaborative shared learning event attendance was not assessed.
Project evaluation	Detailed reporting on the factors which helped/hindered the implementation of the PROSPER intervention components, changes made in care homes as a result (e.g., safety culture and safety processes), and resident and cost related outcomes are described in detail elsewhere by Marshall et al. [20] and UCL Partners Academic Health Science Partnership (https://www.livingwellessex.org/media/571025/prosper-final-evaluation-report.pdf).

Table 4. Description of the SPACE Quality Improvement Collaborative.

Brief Name	**The SPACE Programme**
Why	The aim was to promote a culture of continuous QI with potential to reduce avoidable harms in participating care homes.
Where	Walsall and Wolverhampton, West Midlands, UK. Mix of regional shared learning events organised by Walsall and Wolverhampton Clinical Commissioning Groups and delivery of training and ongoing support by SPACE programme facilitators in individual care homes.
Who provided	The intervention was delivered by two full-time facilitators (one in Walsall, one in Wolverhampton) with experience in QI. Appreciative Inquiry workshops to support positive safety culture were delivered by an external provider (https://www.appreciatingpeople.co.uk). The programme was funded by the West Midlands AHSN Patient Safety Collaborative (https://www.wmahsn.org).
Recipient	29 care homes: 11 nursing homes in Walsall (691 resident capacity) and 17 nursing homes and 1 residential home in Wolverhampton (1191 resident capacity). Collaborative members comprised care home managers, senior/junior nursing and care staff, staff in domestic, administrative, and maintenance roles, and activity coordinators.
How	Face-to-face meetings.
When and how much	24 months (December 2016 to December 2018) with eight half or full day collaborative shared learning events (four in Walsall and four in Wolverhampton). Monthly training in participating care homes attended by managers and staff, focusing on specific topics (described below). One to one coaching and support provided by facilitators throughout the programme (each home visited approx. weekly/fortnightly).
What (materials and procedures)	Collaborative shared learning events: • Networking opportunities for attendees: exhibition stalls promoting resources related to harm free care (e.g., tissue viability) and stalls run by regional/national training providers (e.g., My Home Life, Skills for Care, Age UK). • Skills development via group training and breakout sessions on harm-specific and general QI topics (e.g., PDSA cycles). • Invited speakers gave overviews of national/regional challenges faced by the sector and facilitators presented on SPACE progress. • Care homes presented QI projects, sharing success factors, barriers and how they were overcome, and sharing of their "improvement journey". Education and training: training was delivered by the facilitators or by relevant specialist teams through small groups or large training workshops attended by staff from several care homes. Training delivered on: • Leadership and culture: emphasised the importance of engaging stakeholders, leading/managing change, safety culture, and human factors training. • Measurement for improvement: Model for Improvement Driver Diagrams were used to conceptualise QI and design projects. Based on SMART aims, choice and measurement of outcomes, and how improvement effectiveness can be tested using PDSA cycles. • Communication and handover: focus on improving handovers between staff at shift change to support positive safety culture, e.g., developing safety boards to highlight key risks visually and minimise risk of errors and harms. • Workforce development: training attendees asked to identify their learning from each session and describe how they would cascade that learning to colleagues once back at work to facilitate changes in care home practice.

Table 4. *Cont.*

	Support from facilitators: programme facilitators visited each home to provide ad hoc support and one-to-one QI coaching. This included reviewing PDSA data on specific QI projects and co-developing action plans, signposting towards relevant resources or external training opportunities, helping with data collection and interpretation, risk and harm monitoring, and providing regular data run charts to capture trends over time. Facilitators also supported homes to provide evidence to the Care Quality Commission (CQC) regulators, and address issues such as staffing and resistance to change. Recognition/sharing of best practice: • Bi-monthly newsletters to highlight achievements, share learning, notify about forthcoming training events, and signpost to useful resources. Care home managers and staff also provided content (e.g., photos and articles describing events held at their home). • Annual awards ceremony and "celebrating success" forum as part of the shared learning events, to recognise and reward innovative practice. • Bi-monthly forums led by programme facilitators, attended by care home managers. Designed to build relationships, develop shared purpose, provide peer support, and share best practice. Programme sustainability: resource toolkit and best practice guidelines developed. Facilitator role in Wolverhampton integrated into the CCQ Quality Nurse Advisor (QNA) role, and quality assurance officers trained in QI. In Walsall, QI nurses undertake joint quality visits with the local authority.
Tailoring	• Shared learning events carried out using Appreciative Inquiry principles, focusing on what works well and human factors to understand errors. • Events included ice-breaker activities to enhance relationship building between teams and across care homes. • Programme elements aligned with local and national priorities and best practice, e.g., CQC domains of care and hospital avoidance. • Flexible design and delivery of care home-based training, integrating lessons learned from incidents, mapping exercises to encourage staff groups (maintenance, domestic etc.) to identify their own contribution towards particular aims. • Training events designed to elicit a "commitment to act" from attendees and cascade learning to others to improve practice.
Modifications to the programme	Training flexibility: one-to-one coaching support with managers, small group training in the care home, larger workshop with staff from multiple care homes, and larger collaborative events to disseminate and share learning. Responsiveness: training was modified on an ongoing basis to respond to feedback and focused on topics identified as areas of interest. Adaptation: release of care home staff to attend training was challenging. Events were linked with specialist clinical training available from clinical partners, e.g., falls, tissue viability, and dementia. Underpinning theories: inclusion in year 2 of human factors principles, increased focus on oral care QI activity linked to chest infection reduction, and improving recognition and management of deteriorating care home residents. Co-design: emphasis on co-design of QI interventions between facilitators and managers/staff. Workforce development: workforce development and promoting opportunities for career advancement were offered.
How well	Collaborative shared learning event attendance was not assessed.
Project evaluation	Process and outcome evaluation was undertaken to assess programme design, implementation, and staff/service outcomes. Methods included care home manager and staff surveys, interviews with care home staff and key informants, quantitative analysis of pre and post implementation avoidable harms data, and observations of QI programme activities and training. The final SPACE evaluation is reported by Damery et al. [21].

Table 5. Description of the MOVIT Quality Improvement Collaborative.

Brief Name	**The MOVIT Programme**
Why	The aim was to reduce fragmentation of medical care and ensure care meets the increasing complex medical needs of residents.
Where	Leiden, the Netherlands. Regional meetings were held at a university location and teams also met locally in their care home locations.
Who provided	The MOVIT collaborative was led by a local general practitioner and team members included a professor of primary care at Leiden University Medical Centre, a project manager, a postdoctoral researcher with experience in geriatrics, and a liaison member of staff from a local GP organisation. The project was funded by the Dutch Ministry of Health via the National Programme on Elderly care.
Recipient	29 local teams were formed (serving 33 residential homes). Each comprised general practitioners, community pharmacists, elderly care physicians, and nursing home staff.
How	Face to face meetings.
When and how much	42 months (2009–2013) with 10 regional educational meetings that took place 2–3 times per year, and in between, regional teams met in their locations and received QI coaching.
What (materials and procedures)	Forming communities of practice: the regional project team actively identified and approached care providers of local residential homes (general practitioners, nursing staff, elderly care physicians, and pharmacists) and formed teams. Once formed, each team agreed a focus which reflected local needs around improving integrated care and translating this into an improvement plan. Collaborative shared learning events: • Teams shared project ideas, progress, and experiences of the improvement journey, describing challenges, successes, and lessons learnt around how to overcome barriers. • Allocated time for education sessions (described below). • Networking opportunities. Educational sessions: • Education sessions aimed to inspire teams and provide relevant clinical evidence-based knowledge. • Sessions target improvement project topics and activities. Consensus and guideline development: the teams developed and implemented regional guidelines on a variety of topics: geriatric assessment, patient-based interdisciplinary meetings, medication management and distribution, wound treatment, and advanced care planning. Implementation and sustainability: • Managers and governors of the organisations and financial and regulatory institutions were involved to consider future sustainability. • Promoting sustainability by developing financial constructions for the participating professionals and organisations within regional and national frameworks.

Table 5. *Cont.*

	Newsletter: team success stories were shared using a project newsletter, shared through email, approximately every 6 months. Evaluation: the MOVIT project team included a research nurse who helped (to a limited degree) with collecting data to monitor and evaluate improvement project outcomes and study the QI process. QI coaching: each team received coaching from a GP trained in QI and with special interest in elderly care. There were approximately seven GPs providing coaching to teams. Coaches met regularly (every 6 months) to coordinate and exchange experiences.
Tailoring	The project team took a flexible approach, adapting and tailoring implementation activities to respond to the obstacles encountered.
Modifications to the programme	Government policy moved towards phasing out residential care during the project; as a result, collaborative teams adapted and worked on transporting care from the institutional context to that in the community. As a result, teams were expanded to include domestic and social care providers and related stakeholders.
How well	Collaborative shared learning event attendance was not assessed.
Project evaluation	A structured process description and analyses were performed to better understand the relation between the project activities, identify relevant contextual factors, and examine the fidelity and quality of the implementation [22]. General satisfaction and satisfaction with GP care were compared pre and post MOVIT implementation using a repeated cross-sectional study [23].

Table 6. Description of the South Sefton Care Home Innovation Program (CHIP) Quality Improvement Collaborative.

Brief Name	**CHIP**
Why	The aim was to reduce ambulance conveyances by 1/3 over 12 months from April 2015.
Where	Bootle, UK. The collaborative shared learning events were carried out at a neutral location (a hotel), and in between events (action periods), collaborative members continued to meet in their care home locations.
Who provided	The CHIP programme was led by two local general practitioners, and team members provided support with administration and with data collection and evaluation support. The project was funded by South Sefton Clinical Commissioning Group.
Recipient	31 care homes (both part residential and nursing homes) took part. The collaborative members comprised care home managers, senior and junior care staff, and over the course of the project, members from wider healthcare organisations provided input into improvement projects, such as community geriatricians, community matrons, pharmacists, palliative care specialists, voluntary organisations, tele-video equipment providers, and informatics.
How	Face to face meetings.
When and how much	36 months (April 2015–April 2018) with collaborative shared learning events every 2–3 months.

Table 6. *Cont.*

What (materials and procedures)	Forming the CHIP collaborative: prior to starting the CHIP collaborative, audits and interviews were carried out in individual care homes to understand and establish their needs. The CHIP collaborative was then designed to meet care home stakeholder requirements. Collaborative shared learning events: • During events, each team was interviewed as a way of sharing progress, updates, and their experience of the improvement journey. • Eduational and training (described below). • Networking opportunities. Education and training: • Training in QI methodology and QI techniques simplified through the use of games e.g., demonstrating PDSA cycles with Mr Potato Head. • Training on how to use equipment being implemented in the care home, e.g., 24/7 tele-video in reach support. • Training on basic observations and use of protocols with Edge Hill University. • Awareness training from a variety of specialists. Care home teams were provided with support with data collection and interpretation: • BI-level time series analysis was carried out and presented to care homes in an easy to digest way. • Data were collected using data dashboards and monthly data trackers. Outcomes were focused on care outcomes and process measures at the care home level. Clinical support: • Development of clinical protocols (e.g., standardised protocols topics such as falls and urinary tract infections). • Relational coordination with care home matrons (care home matrons had easy and direct access to a community geriatrician, GPs, and other community specialist teams). • Advanced care planning led by community matrons (the matrons collated background information, populated care plans, liaised with the GP or community geriatrician to complete and sign off care plans. Mostly done in liaison with GPs, and more complex cases referred to the community geriatrician). CHIP dashboard with "star" status: each home was given an individual attainment plan and "star chart" that helped them to reflect on areas of focus to enable scale up. CHIP champions: each care home selected a "CHIP" champion (e.g., care home manager or care staff). Champions functioned as a CHIP advocate and acted as the point of communication to both the improvement team and care home. Each champion was celebrated and recognised (e.g., given a badge). Care home support visits: the improvement team visited care homes regularly to carry out both reactive and proactive care. Any issues that they needed further support for were dealt with by contacting the GP or community geriatrician. Newsletters: monthly newsletter provided through email.

Table 6. *Cont.*

Tailoring	At the beginning, the improvement team spent time describing the purpose of the collaborative and their role, placing emphasis on the point that the improvement team were not inspecting or judging the care homes. Every collaborative shared learning event started with ice-breaker activities and a recap of the CHIP vision. Efforts were made to ensure meetings were facilitated in a way that created a safe, non-judgemental, positive, and celebratory atmosphere.
Modifications over the course of the programme	QI training materials were simplified as most of the collaborative members had no previous awareness of QI terminology or techniques (for example, simplified PDSA cycle templates were created). At collaborative learning events, instead of collaborative teams carrying out presentations, they were interviewed 'on stage' as a way of sharing progress to the collaborative. The time, day, and duration of collaborative shared learning events were changed to make it easier for collaborative teams to attend.
How well	On average, each collaborate shared learning event was attended by 63% of care homes.
Project evaluation	The impact of the CHIP collaborative on emergency calls and conveyances to hospital was evaluated using frequency analysis; more details are reported by Giebel et al. [24]. The CHIP project has been cited as an example of good practice by the CQC: see https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf.

3.3. Delivering a QIC in the Care Home Sector: Lessons Learnt

Five "lessons learnt", specific to the care home sector and observed across more than one QIC initiative, were identified. These are listed in Box 1 and summarised below.

Box 1. Applying the QIC approach in the care home sector: what have we learnt?

1. Data are not always readily available in the care home sector; thus, sufficient resources are needed to support collaborative teams with:
    a. Collecting the data needed to test the impact of change. Data collection burden could be reduced by identifying ways that data collection might be incorporated into care home routine practice in an intuitive way (e.g., the Falls Safety Cross approach).
    b. Processing and interpreting data. Ensure data are presented in an accessible way, particularly for those who have not previously used data to evaluate change.
2. Make a conscious effort to create an encouraging and safe environment where collaborative members feel valued, connections are built in and across collaborative teams, and any perceived hierarchies between care home and healthcare staff are minimised. The following techniques help: (i) use appreciative language, (ii) celebrate achievement, (iii) facilitate ice-breaker activities, (iv) set ground rules, (v) reimburse care home staff time, and (vi) carry out small gestures, e.g., high quality catering at collaborative shared learning events.
3. Recruit collaborative teams and QIC lead/facilitators who have established and longstanding relationships, as these relationships are particularly important in enabling faster progress with QI in care homes.
4. People living in care homes receive input from multiple professionals employed across a mix of organisations. For this reason, lines of responsibility may be unclear, and there may be differences in what is considered a priority. Regularly check project ideas are agreed by team members to be: (i) within their job role and responsibility and (ii) a local priority.
5. The use of QICs in the care home setting has not been widely described and understanding around the types of activity that work well and which do not is limited. As we continue to generate learning in this area, it is important to work flexibly, accepting that activities may not go as planned and modifying planned activities if needed.

3.4. Plan for the Resource Needed to Support Collaborative Teams with Collecting, Processing, and Interpreting Data

Collaborative teams taking part in a QIC carry out projects where changes are made that aim to improve the quality of care, and PDSA cycles are used to test the impact of those changes. Data are an essential ingredient in assessing whether or not changes result in improvement. However, the data to inform PDSA cycles are not readily available in care homes in the same way as they are in health sector settings (Box 1, point 1a). Or, if data are available, the specific nature of the data might not match the specific aims of the QI projects. For example, collaborative teams in the Safer Care Homes collaborative faced challenges with establishing a baseline number of falls with harm and medication errors in care homes, and for this reason, the QIC facilitators worked closely with care homes to support data collection. Indeed, QIC facilitators were needed to provide support in all projects assessed in this paper. Collaborative team members provided data and the QIC facilitators then processed the data, constructing data dashboards and runtime charts. In some cases, QIC facilitators also helped with collecting data. In addition to this, the frontline staff taking part in the collaboratives may not have worked in this way before, where changes to care are made and data are used to evaluate the impact, and for this reason, QIC facilitators helped with interpreting data and reviewing PDSA cycles, arranging meetings where the data were interpreted and discussed.

A shared observation across projects was the importance of presenting data in an easy-to-digest way that enabled collaborative teams to review the impact of their changes (Box 1, point 1b). The level of support with data collection, processing, and interpretation required substantial resources from the QIC facilitators, which was not always anticipated during the planning phases of projects. To reduce data collection burden, the SPACE and PROSPER projects looked for ways that data could be collected within care home routine practice in an intuitive way. Both the SPACE and PROSPER projects used the Falls Safety Cross (for example, see https://www.livingwellessex.org/media/571058/falls-safety-cross.pdf), a data collection tool where care workers indicated the number of falls per resident on a prominent visual aide memoire display. This allowed falls-related data to be collated over time and allowed the data to be used to link to the improvement aim. Over time, care homes modified the Falls Safety Cross to also capture additional aspects of care quality such as incidents of challenging behaviour or resident hydration. An additional benefit for the care home was that the collection of data provided evidence of their safety culture, which was noted positively during inspections by the English regulator, the CQC.

3.5. Create Encouraging and Safe Working Environments

Care homes are heavily regulated, face negative public perceptions and stigma, and the majority of care homes are run by private companies (in the UK), and thus, there can be a sense of competitiveness between care home organisations. For these reasons, those working in care homes might be wary of and have reservations towards both those external to the care home sector (for example, academic researchers and those working in an NHS or commissioning role) and those from other care home organisations.

Across all QICs projects, conscious efforts were made to help create environments where participants felt safe and valued (Box 1, point 2). One technique was the use of appreciative language when asking collaborative teams for project progress updates. This could involve, for example, asking teams to focus on "*What worked well and why?*", "*How would you want things to be?*", "*How can we work together to make this happen?*", and "*What needs to be in place to make it happen more of the time?*". Phrasing questions carefully using appreciative language helped to focus on moving forward instead of focusing on barriers or problems. Another technique used by QIC facilitators was to create a celebratory atmosphere during shared learning events by congratulating collaborative teams, sharing positive stories. Ice-breaker activities helped to create an atmosphere of inclusivity and encourage connections amongst collaborative teams. Establishing agreed ways of working (e.g., listen to whoever is speaking, no question is a silly question, do not speak using acronyms) helped to create a safe environment and reduce perceived hierarchical imbalances, particularly where teams were mixed in seniority and/or professional status. In some projects, backfill payments were provided to care home staff to reimburse the cost of the time taken to attend meetings and help with arranging staff cover. Small gestures also helped to create an atmosphere where collaborative members' attendance and input was valued, such as providing high-quality catering at collaborative shared learning events. An observation across all projects was that over time, trust, relationships, and a sense of community developed where care homes started to work more collaboratively, openly sharing their ideas and learning and resources (e.g., training resources).

3.6. Seek Out Collaborative Teams and Leads/Facilitators with Existing and Longstanding Relationships

A shared observation across QIC projects was the time needed to establish teams, build trusting relationships, and develop and implement improvement projects should not be underestimated (Box 1, point 3). The MOVIT project's experience suggests that recruiting and forming collaborative teams takes at least one year, establishing team rapport and developing QI projects could take up to six months, and depending on the improvement projects, the time required to be able to notice effects could be a matter of years. The PEACH study recognised this and actively sought out collaborative teams where there were established relationships, enabling teams to "hit the ground running". Similarly, good working relationships between the collaborative members and the QIC leadership team also help with project progress. The Safer Care Homes project leads used their pre-existing relationships and recruited care homes known to the QIC leads and facilitators, and found faster progress where collaborative team members knew the facilitating staff. In projects where the QIC project facilitators were not known to the care homes taking part, it was found that progress became easier once trust was established and any previous disputes or misunderstandings resolved.

3.7. Clarify Collaborative Member Priorities and Lines of Responsibilities

The care home sector is distinctive in that there are multiple organisations and multiple and different health or social care professionals provide health- and care-related services to residents. When delivering a QIC project, those leading and facilitating need to ensure collaborative teams develop QI projects which are directly related to team member job roles and responsibilities, and in which team members believe their job role and responsibilities could have some influence (Box 1, point 4). For example, the Safer Care Homes project set out to reduce falls, pressure ulcers, and medication errors. In the initial stages, care home staff viewed the cause of these issues as external to the home, believing that pressure area damage was acquired during hospital admissions and not inside the care home. In this case, QIC leads sought to discuss the factors which affected resident safety both inside and outside the homes, and participants started to engage when they saw they had some influence. The variety and mix of health and social care professionals may also mean differences in perceived priorities. In a similar way, it is worth spending time checking collaborative teams are invested and view QI project topics as a priority. For example, in the MOVIT project, collaborative teams spent some time at the beginning of the project reflecting on and choosing project ideas that aligned with their priorities. This ensured collaborative teams worked on topics that mattered to them. Allowing teams to work on their local priorities helped to maintain the ownership and buy-in needed to implement change. Working in this way and allowing local priorities to take precedence might not be possible if projects are funded to achieve objectives focused on a predefined topic.

3.8. Work Flexibly and Modify Planned Activities Where Needed

The experience shared across projects is that whilst QIC facilitators may have had project activities planned, they often had to work flexibly and adapt activities in response to collaborative teams, adapting their activity plans as they went along (Box 1, point 5). This is true in all QICs, but particularly when working in care homes because processes and principles which work for community healthcare or hospital teams will need adaptation to work in this setting. For example, the CHIP project reduced original meeting durations to enable greater focus and maximum attendance, and the PEACH project changed the programme remit from one around Comprehensive Geriatric Assessment, which members found difficult to understand, to one around delivering holistic care to residents. More examples around how QICs projects were modified are provided in Tables 1–6. We suggest that project teams carry out initial pilot/set up phases. This would help to "test" planned activities, check feasibility, and examine potential modifications that might be needed. Initial pilot/set up phases would also help to build in the time needed to establish collaborative teams and build trusting relationships (Box 1, point 3).

4. Discussion

The extent of what we can learn from publicly available reports of QI in care homes is limited due to the lack of detailed reporting in this field [15]. This article helps to address this gap by providing detailed descriptions of how the QIC method has been applied and insight into the experiences of six projects using this methodology in care homes in the UK and the Netherlands. The insights described in this paper are also likely to be of value to those working in healthcare settings. While there is a wide-ranging QI evidence base, there is also a wide-ranging care home evidence base, with limited interaction between the two. Currently, insightful learning from each literature base has not yet been brought together, and thus, insights which may surprise experts in QI may not surprise those who are expert in care homes, and vice versa. Bringing insights and learning together in one paper is an important step forward.

One common observation across projects was that QIC leads and facilitators had not anticipated the extent of support collaborative teams would need with collecting, processing, and interpreting data. Use of baseline data and comparison groups to determine the effect of changes made to practice is rare in the care home sector, but of great importance to robust evaluation. It is important to take time establishing the data needed at the beginning of the project so its implementation and impacts can be properly monitored. The observation around data collection is perhaps unsurprising in countries where care home sector data are not routinely available and are held across different organisations. The collaborative nature of the QIC approach, though, could bring together key stakeholders from across organisations where data are held, and thus, help with accessing relevant data. This is an issue in countries as diverse as England, Austria, Portugal, and Brazil. In England, numerous ongoing research studies are focused on addressing this [25,26]. Countries such as the Netherlands and the United States have more consistent approaches to collecting care home quality benchmarking data [27,28].

Our other observations provide practical recommendations that are consistent with, and build upon, the wider care home literature. Previous findings show when dialogue with care homes is appreciative and focused on what is working well, this helps to develop practice in care homes [29]. Evidence also shows that working relationships in the care home sector are of particular importance, as successful innovations in care homes are established on a foundation of longstanding collaboration and trust [30]. In addition, previous evidence highlights how the lines of responsibility for those working in and with care homes are not always clear, as people living in care homes receive care from professionals working in different organisations. Thus, there can be uncertainty and dispute over roles and responsibilities for particular aspects of care [31].

Strengths and Limitations

A key limitation is that the learning described here reflects the experience and perspectives of those who led and facilitated QICs, and not the views of collaborative participants. The insights we present were developed through a relatively unstructured, discussion-based approach, though our use of the TIDieR framework enabled us to identify, present, and compare key points of similarity and difference across the cases. Some of our observations might be unsurprising to those working in care homes; however, we believe these care home-specific insights may not be fully appreciated by improvement practitioners who work outside the care home setting.

The main strength of our article is that it addresses a gap in the existing QI and care home evidence base. A recent review of QI strategies applied in care home settings included 65 studies, and reported that to date, the evidence in this field lacks comprehensive reporting, limiting the extent to which others can replicate and learn from existing work [15]. This paper makes a start in addressing this gap. To our knowledge, this article is the first to provide detailed descriptions of multiple QICs applied in the care home setting and describe learning from across these projects. Our detailed descriptions are structured using standardised reporting (the Template for Intervention Description and Replication—TIDieR). Reporting templates have not yet been used in the existing evidence base. Nevertheless, we have only begun to scratch the surface of learning from collaborative projects in care homes. We recommend that future research builds on this foundation by continuing to comprehensively describe how QICs are applied in this setting and conducting in-depth process evaluations to generate more learning about how to apply QIC methodologies in the care home sector.

5. Conclusions

As Marshall et al. put it, “frontline practice is messy, it is never possible to do things perfectly, and good improvers are always learning” [19]. The experiences described here illustrate that improvement tools and techniques cannot to be taken “off-the-shelf” and applied without adaptation to the local context [19]. Our detailed descriptions of how the QIC approach has been applied in care homes, and the practical lessons learnt, will enable future teams to progress more quickly. We recommend that teams leading QICs in this sector continue to share detailed descriptions, given the paucity of literature available on the topic to date.

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Article

Applying Intervention Mapping to Improve the Applicability of Precious Memories, an Intervention for Depressive Symptoms in Nursing Home Residents

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Abstract: Precious memories (PM) is a life review intervention for depression in older adults with no to mild cognitive decline that has been implemented in multiple nursing homes (NHs) in the Netherlands. Previous research suggested its relevance but questioned its applicability. Therefore, this research aimed to (1) investigate the applicability of PM, and (2) increase its applicability, if necessary. Intervention mapping (IM) was used to achieve these goals: process evaluation through semi-structured interviews with psychologists (n = 11) and clients (n = 2) to identify potential improvements for PM and to set an improvement goal (IM-step 1); three focus groups with stakeholders (n = 20) to specify behaviors necessary to reach the improvement goal (IM-step 2); and selection of behavior change techniques and applications to facilitate attainment of these behaviors (IM-step 3). Results showed that psychologists perceived a high drop-out rate, which was partly due to PM being provided to clients that did not belong to the target group. Although PM was generally considered relevant, psychologists articulated its longer-term effects should be improved. To improve PM's applicability, concrete maintenance strategies were developed aiming to maintain clients' well-being by stimulating positive contact with others. Future research must pilot, implement and evaluate these strategies.

Keywords: depression; nursing home; psychosocial intervention; applicability; implementation; life review therapy; intervention mapping; process evaluation; maintenance

1. Introduction

Depression is a common problem in nursing home (NH) residents. An extensive Dutch study [1] has demonstrated that approximately 41% of residents in NH units providing predominantly somatic care, and 52% of residents in dementia special care units showed signs of depression, with 17% and 23% respectively showing signs of severe depression. Depression is associated with adverse consequences in older adults, including poor general health, reduced quality of life and physical and mental functioning, and increased use of medication [2,3]. This illustrates the need for adequate treatment of depression in NH residents.

One treatment for depression in older adults is life review therapy, in which individuals reflect on their life experiences with a therapist [4]. Life review therapy aims to change negative reminiscence styles [5], which have been associated with depressive symptomatology [6]. A meta-analysis [7] concluded that life review therapy is effective in decreasing depressive symptoms at short-term follow-up, and that it might be a promising treatment for depression in older adults in primary care.

Besides negative reminiscence styles, depression has also been related to decreased memory-specificity; older adults with depressive symptoms retrieve fewer specific and more overgeneral memories than older adults without depression [8–10]. Additionally, individuals with depression seem to experience most difficulty in retrieving specific positive memories [11]. Specific memories are defined as memories tied to a specific time and place, whereas overgeneral memories only specify a life period and a general event [12]. Several studies have demonstrated that memory-specificity can be trained [13–15], and a meta-analysis [16] has concluded that increases in memory-specificity are associated with small to moderate improvements in depressive symptoms in (older) adults.

Precious memories (PM) is an intervention that combines life review therapy with training memory-specificity for positive events. PM is considered a life review therapy [17], because it systematically works through multiple life periods. Several studies have shown that PM can have significant beneficial effects on depressive symptoms [13,15,18,19], life satisfaction [13,15], and hopelessness [15] in older adults. Although PM was developed for use in the general older population, it has also been implemented in several NHs in the Netherlands as part of Act in Case of Depression—a comprehensive program for the detection and treatment of depression in NH residents [1].

However, a process evaluation of this program in a Dutch trial [20] showed that although PM was received positively by health care professionals, it was not often applied in daily practice. Therefore, it was suggested that its applicability—PM's usefulness and relevance—in the NH setting should be further investigated and that improvements might be needed. Furthermore, an effect study [19] of PM for depressive symptoms in NH residents showed that reductions in depressive symptoms and increases in memory-specificity were not maintained at eight-month follow-up. These results might also be explained by PM's potential limited applicability to the NH population. Therefore, the aims of this study are (1) to further investigate the applicability of PM in NH practice, and, subsequently, (2) to develop strategies to increase its applicability in this setting.

2. Materials and Methods

2.1. Design

The two aims of this study were addressed based on available evidence and theory, which is considered best practice by the Medical Research Council [21]. We chose intervention mapping (IM) [22,23] to systematically increase the applicability of PM. Although IM is predominantly used as a method to systematically develop new interventions, it might also help to adapt existing interventions to new settings and populations [24]. IM aims to provide guidelines for effective decision-making during the development and adaptation of an intervention, integrating theory, empirical findings, and information from the target population [24]. Six steps are described to develop and evaluate an intervention: (1) identification of potential improvements and setting an improvement goal ("needs assessment"); (2) defining behaviors and their determinants, needed to reach the improvement goal ("matrices of change objectives"); (3) selecting behavior change techniques and ways to apply them ("theory-based methods and practical applications"); (4) "program production"; (5) "adoption and implementation"; and (6) "evaluation planning" [24] (pp. 20–24). IM-step 1 was used to address the first aim, and IM-steps 2 and 3 to address the second aim of this study.

2.2. Intervention

PM has been applied in multiple NHs in the Netherlands and is considered relevant in NH residents with mild to moderate depressive symptoms having no to mild cognitive decline [19,25]. PM consists of five sessions, commonly provided by a trained psychologist. The first is an introductory session in which the psychologist (1) evaluates to what extent a client can be trained to retrieve specific, positive memories, (2) explains PM and sets therapeutic goals, and (3) identifies life phases that are appropriate for retrieving positive memories. This is followed by three sessions focusing on childhood, adolescence and adulthood, and a concluding session [25].

2.3. Procedure According to Intervention Mapping

Because we used IM to address the goals of this study, methods (and results) are described following those steps. An overview of the outcomes of each IM-step and methods to reach those outcomes can be found in Figure 1.

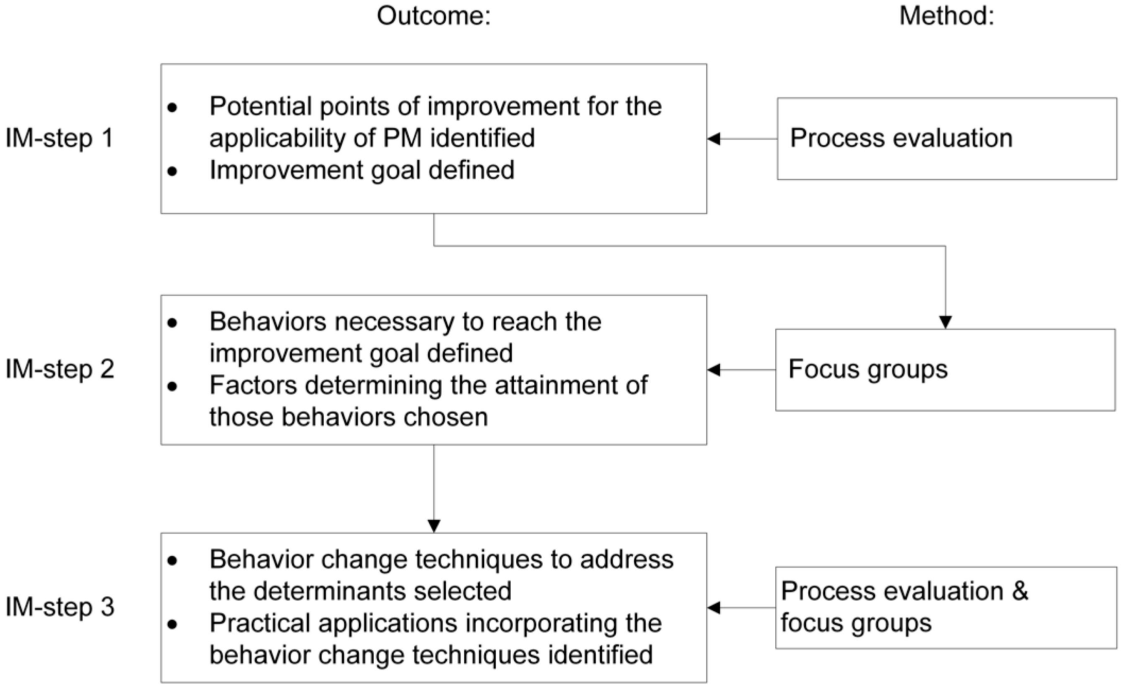

Figure 1. Overview of intervention mapping (IM)-steps, outcomes and methods to reach those outcomes.

2.3.1. IM-Step 1: Identification of Potential Improvements and Setting an Improvement Goal

Since previous research concluded that PM's applicability to the NH setting might be problematic [20], we investigated factors contributing to PM's applicability that could be improved. Because PM has already been applied in the NH setting, we had the opportunity to identify potential improvements based on a process evaluation of the current situation as experienced by stakeholders and to collect information on potential improvements. A process evaluation can provide insight into factors that diminish or increase the effects of an intervention [21], barriers and facilitators to implementation [20] and acceptability and feasibility of an intervention [26], and might therefore provide suggestions on how to optimize an intervention and its implementation strategies [21]. To this end, the framework of Leontjevas et al. [20] was used, which has successfully been applied in NH studies [27–29]. This framework distinguishes between first and second-order processes. First-order processes reflect (1) reach and sampling quality, describing selection procedures for the intervention and completion rates, and (2) intervention quality—which is defined as the extent to which components of PM are conducted according to the initial protocols and the extent to which PM is evaluated as relevant, clear, and feasible. Second-order process data provide insight into implementation strategies, and barriers and facilitators to implementation. Based on the outcomes of the process evaluation, the researchers (I.v.V., J.S., and D.L.G.) identified potential points of improvement. After choosing the most relevant one to focus on in this study, an improvement goal for PM was defined (Figure 1).

For data collection, we planned to conduct semi-structured interviews with a minimum of 10 psychologists who had followed the PM training and with 10 clients, and to stop conducting interviews if no new themes would arise after three consecutive interviews [30]. For psychologists, purposive sampling was used to increase data saturation [30], based on the year in which psychologists followed a PM training and the type of clients they worked with. Prior to the interview, psychologists completed an online questionnaire, covering demographic and occupational information, reach, relevance, feasibility, and barriers and facilitators (results are available in Table S1). The scores on the online questionnaire of a psychologist were used to further specify the content of the interview with that psychologist. Clients who had received PM were invited for semi-structured interviews through the contacted psychologists. The interviews were conducted by one of the researchers (I.v.V.).

We operationalized the elements of the process evaluation framework into topic guides based on other published process evaluations [27,29]. All interviews were transcribed and coded by the first author following a content analysis approach [31], meaning that codes were assigned inductively, as well as deductively, based on the process evaluation framework. After initial codes were assigned, categories were created. Subsequently, a tree diagram was developed depicting the relationships between codes and their categories, as agreed upon by the researchers (I.v.V., J.S. and D.L.G.). The qualitative data were manually coded in ATLAS.ti (version 7.1.5.).

2.3.2. IM-Step 2: Defining Behaviors and Their Determinants, Needed to Reach the Improvement Goals

We conducted three focus groups with psychologists and nursing staff who had experience with PM to define behaviors necessary to achieve the improvement goal of PM and factors determining the attainment of those behaviors (Figure 1).

In Focus Group 1, participants generated ideas on ways to address the most relevant point of improvement of PM. In Focus Group 2, generation was continued after which consensus was obtained on the best strategy to address this point using the nominal group technique [32]. Prior to this focus group, participants were asked to consider how to practically address the point of improvement. During the focus group, participants, first individually, wrote down ideas on how to address the improvement goal (silent generation). Secondly, participants named their ideas until all ideas were explained and discussed (round robin). Thirdly, the participants prioritized the ideas based on potential effects and feasibility (voting). Participants could also provide new strategies. In Focus Group 3, the strategy identified as most relevant in Focus Group 2 was discussed further to obtain specific information on its implementation in practice.

Focus group participants were recruited based on convenience sampling. The focus groups were conducted using topic guides. Using tape-based analysis [33], the content of the focus groups was arranged according to topic and summarized.

2.3.3. IM-Step 3: Selecting Behavior Change Techniques and Ways to Apply Them

To address the determinants of the behaviors needing change, behavior change techniques and practical applications were selected. Furthermore, specific conditions under which behavior change techniques are effective were specified (Figure 1).

Together with a clinical psychologist who provides training in PM, the researchers (I.v.V., J.S., and D.L.G.) selected the behavior change techniques and conditions under which these are effective based on behavior change theories [23,34,35], and chose applications based on the outcomes of the process evaluation and focus groups.

2.4. Ethical Approval

The local Medical Ethics Review Committee (CMO Region Arnhem-Nijmegen) reviewed the study and declared the study not burdensome to participants (number 2017–3854). The study was conducted in accordance with the Declaration of Helsinki and the applicable Dutch legislation. All participants signed an informed consent form before participation in the study.

3. Results

3.1. Participants

Face-to-face interviews were conducted with Dutch NH residents with depressive symptoms (Table 1). A third client was interviewed; however, because she seemed anxious, her data were not used. All interviews with psychologists (Table 2) were conducted in Dutch and by telephone, except for one interview which was conducted face-to-face because of participant preference. Characteristics of focus group participants are included in Table 2.

Table 1. Characteristics of client interviews.

Characteristic	Client 1	Client 2
Age	63	95
Sex	Male	Female
Length of nursing home (NH) stay (years)	2.5	1
Length interview (minutes)	44	29
Months between end of previous memories (PM) and study	3	4

Table 2. Characteristics of interviews with psychologists and focus group participants.

Participant Group	***n* (Female)**	**Mean Age (Range)**	**Profession**	**Work Experience in Elderly Care in Years (Range)**	**Years Between PM Training and Study**	**Type of Clients Participants Worked With**	**Length Interviews and Focus Groups in Minutes**
Interviews with psychologists	11 (11)	40.18 (29–54)	Psychologist ($n = 11$)	10.09 (5–18)	1 ($n = 8$), 2 ($n = 1$), 4 ($n = 2$)	Somatic ($n = 5$), cognitive ($n = 3$), both ($n = 2$), clients from primary care ($n = 1$)	$M = 69.91$ (13–99)
Focus Group 1	10 (9)	35.30 (25–56)	Psychologist ($n = 8$), clinical neuropsychologist ($n = 1$), psychological assistant ($n = 1$)	8.70 (0.5–24)	0.5 ($n = 8$), 4.5 ($n = 1$), 10 ($n = 1$)	Cognitive ($n = 5$), somatic ($n = 2$), both ($n = 2$), unknown ($n = 1$)	26
Focus Group 2	6 (6)	48.50 (27–60)	Psychologist ($n = 4$), nurse scientist ($n = 1$), nurse ($n = 1$)	16.50 (4–28)	4 ($n = 2$), 1 ($n = 1$), not trained ($n = 3$)	Both ($n = 3$), cognitive ($n = 1$)	106
Focus Group 3	4 (4)	52.25 (41–61)	Psychologist ($n = 4$)	17.13 (5.5–25)	8 ($n = 3$), 1 ($n = 1$)	Somatic ($n = 2$), both ($n = 2$)	49

Cognitive = clients with primarily cognitive impairments; somatic = clients with primarily somatic problems; both = clients with both cognitive impairments and somatic problems.

3.2. IM-Step 1: Identification of Potential Improvements and Setting an Improvement Goal

3.2.1. First-Order Process Evaluation

Reach: psychologists believed they proposed PM to less than half of the estimated indicated population, mainly because of time constraints for individual treatments, especially for clients with cognitive impairments.

Completion: psychologists reported multiple instances in which they applied PM to clients with moderate or severe cognitive impairments, which was an exclusion criterion for using PM. Furthermore, psychologists estimated that approximately two-thirds of the clients dropped out of therapy, which in their opinion was mainly due to clients' limited cognitive abilities, such as a limited attention span and an inability to (be trained to) retrieve specific, positive memories.

Intervention quality: PM was generally regarded as relevant by psychologists and as pleasant by clients, mainly because of its positive focus. Furthermore, some psychologists perceived positive effects on mood, even for clients with moderate or severe cognitive impairments, who were unable to remember the session's content and could not be trained to retrieve specific, positive memories. However, it was also reported that some clients with more severe cognitive impairments were still able to retrieve specific, positive memories, especially from childhood and adolescence. Nearly all interviewed psychologists would recommend the use of PM to other psychologists.

Although psychologists and clients perceived positive effects on mood during and in between sessions, they questioned longer-term effects of PM, due to the restricted trainability of clients. Both expressed that maintenance of the effects of PM should be improved and should be the improvement goal for PM. They reported that clients might only retrieve general memories directly after PM and might, therefore, need the help of others in maintenance. Accordingly, clients also expressed difficulties in retrieving memories by themselves. Incorporating the retrieved memories in mediative interventions (i.e., interventions delivered through others) was mentioned as a strategy for maintenance. Thus, although the interviewed psychologists considered providing PM a task for psychologists—because particular communication skills are necessary to reach specific, positive memories—the involvement of others was suggested for maintaining the effects.

3.2.2. Second-Order Process Evaluation

Barriers and facilitators: the PM training and protocol were reported as facilitators to implementation, whereas mentioned barriers were a lack of time and continuity because of changes within the organization and team, a medically oriented organizational culture, and a relatively low importance of PM within the organization. Furthermore, the attitude of close colleagues, such as other psychologists, could be a barrier if those had different priorities than implementing PM, or limited experience with PM.

3.2.3. Setting the Improvement Goal of PM

The process evaluation showed that it was indeed necessary to improve the applicability of PM to the NH setting and identified that (1) the reach of PM, (2) its low completion rates, and (3) its perceived low level of maintenance of effects must be improved. The first point primarily requires structural changes in the NH: allocating more time to individual treatments, which requires the involvement of the management of NHs and, potentially, health care insurance providers, which was therefore not addressed in this study. Regarding the second point of improvement, low completion rates may also stem from PM having been started in residents with more severe cognitive impairments whereas 'having no to mild cognitive impairment' was an inclusion criterion for PM. Decreased trainability of these clients was namely the most reported reason for dropout. The third point, maintenance of effects, emerged as the primary point of improvement from the interviews. Accompanied by the finding that reductions in depressive symptoms were not maintained at eight-month follow-up after applying PM to NH residents [19], we chose to set the improvement goal of PM to increase maintenance of the PM's effects. A model illustrating which behaviors and determinants contribute to the perceived low level of maintenance of PM’s effects (IM: logic model of the problem) is available in Figure S1.

3.3. IM-Step 2: Defining Behaviors and Their Determinants, Needed to Reach the Improvement Goal

3.3.1. Focus Groups

In Focus Group 1, participants generated ideas on ways to achieve maintenance of PM’s effects. Nursing staff and informal caregivers were regarded as individuals who could be practically involved in executing the maintenance strategies. The strategy identified for the transition between PM and maintenance was the psychologist discussing maintenance strategies with the client and informal caregiver at the end of PM, in regular care, or during family meetings.

In the Focus Group 2, participants continued the idea generation of Focus Group 1 and obtained consensus on the best idea. During the idea generation, participants discussed several issues concerning the goal and execution of the maintenance strategies. Firstly, they questioned whether the goal of maintenance should be to train memory-specificity; participants noted that this is not feasible for individuals with prominent cognitive impairments, which they regarded as a relevant target group for PM. Secondly, the positive nature of the conversations in the PM sessions, which results from retrieving positive memories, was thought to be beneficial to clients. Accordingly, participants found the goal of the maintenance strategies should be to provide clients with continued positive contact, allowing persons other than the psychologist, such as nursing staff, informal caregivers, family members and volunteers (henceforth referred to as ‘supporters’) to be involved in maintenance. The following aspects were considered prerequisites for maintenance:

- Psychologists should be in charge of PM, but maintenance could be coordinated by a nurse or family member;
- A maintenance plan should be included in clients’ dossiers and should include distinct maintenance advice for nursing staff;
- The PM protocol should include a checklist on what information to include in clients’ dossiers;
- The retrieved memories must be preserved after PM;
- Clients must be involved in the decision with whom to share which memories;
- Individuals involved in maintenance should have knowledge about the general principles of PM.

Due to limited time, it was not possible to group and vote on the generated ideas during the focus group. Therefore, after the focus group, the ideas were grouped by I.v.V. and D.L.G. Focus group participants were then asked by email to prioritize the strategies from least to most helpful, based on potential effects and feasibility. Table 3 shows the results.

Mediative interventions were identified as the best strategy for providing maintenance. Additionally, since creating a memory book or box (perceived as the second-best strategy) could also be considered a mediative intervention, this was also included in the discussion of Focus Group 3.

Participants of Focus Group 3 were asked how mediative interventions could be implemented in practice. Participants discussed that supporters could be involved in maintenance strategies aimed at providing positive contact with the client. They would need to be instructed and provided with ideas on topics to ask questions about, cues that helped to retrieve positive memories during PM, and with information about appropriate life periods to discuss.

Lastly, the transfer between the psychologist and those involved in maintenance was discussed. The maintenance plan should include information on which life periods the client enjoyed talking about and the positive memories the client retrieved. Furthermore, the psychologist should appoint a coordinator to evaluate maintenance, such as a family member or nurse.

Table 3. Prioritized options for maintenance strategies, from most (1) to least (7) helpful.

Priority	Options for Maintenance Strategies
1	Mediative interventions: (Temporarily) including retrieved memories in mediative interventions by (1) adapting stimuli in the environment of the client to the retrieved memories (e.g., memory walls, scents, and music), (2) having supporters help clients retrieve precious memories, or (3) providing the client with activities based on the retrieved memories.
2	Memory book or box: The memories retrieved during PM are processed into a memory book or box after PM.
3	Follow-up session: Providing a follow-up session after the end of PM to assess whether clients need more guidance to maintain the retrieval of specific, positive memories.
4	Mini PM-sessions: Using mini PM-sessions (i.e., booster sessions) after the end of PM to maintain the skill to retrieve specific, positive memories.
5	Diary/letter: Potentially with help, clients write up their retrieved memories in a diary or letter to themselves.
6	Embedding PM in other therapies: Including PM in other (psychological) therapies.
7	Group treatment: Clients who received PM can afterwards participate in a group treatment to maintain the skill to retrieve specific, positive memories.

3.3.2. Defining Behaviors and Their Determinants

As described, the goal of the maintenance strategies of PM was set to maintain clients' well-being by strengthening their positive contact with others. To address this goal, supporters help clients to retrieve positive memories, which provides clients with positive contact. Because the interview and focus group results showed that asking for specific, positive memories requires particular communication skills especially in a target group with cognitive impairments, we decided the most feasible strategy would be for others to support the retrieval of positive memories without explicitly focusing on the memories being specific. From the focus groups it followed that supporters need concrete guidelines on what topics to ask questions about. Therefore, they could create so-called memory products, such as life books, photo books/frames, and tool-boxes with objects, which connect to specific positive memories that came up during the PM sessions, facilitating the retrieval of positive memories.

Based on the interview and focus group results, we identified behaviors to reach the improvement goal. The following behaviors were defined, which describe how the maintenance strategies are organized:

1. After each PM session, with permission from the client, the psychologist reports the client's retrieved positive memories in the client's dossier;
2. After the five PM sessions, the psychologist and main nurse meet and develop a plan to improve positive contact with the client. They decide who is going to make what kind of memory product, who will help the client retrieve memories with the help of the product and when;
3. The psychologist and the main nurse together integrate helping the client retrieve memories as an activity in the pleasant activities plan of the client;
4. The psychologist instructs and practices the retrieval of positive memories with the supporter;
5. The supporter helps the client to retrieve memories at the—during the meeting decided—times with the help of the memory product;
6. The psychologist and main nurse evaluate (and adjust) the pleasant activities plan of the client as described in the Act in Case of Depression protocol;
7. The psychologist and main nurse implement PM (specifically the steps specified under 1–6).

Additionally, we chose attitudes, knowledge, self-efficacy, and outcome expectations as determinants of the behaviors needed to reach the improvement goal. The first column of Table 4 illustrates how these determinants can facilitate the attainment of one of the behaviors that must be performed to attain the improvement goal. A complete table of behaviors and their determinants (IM: Matrix of change objectives) can be found in Table S2.

Table 4. Explication of determinants, behavior-change techniques, applications and conditions for one of the behaviors * needed to reach the improvement goal.

Determinants of the Behavior *	Behavior Change Techniques	Application	Explanation (Conditions under Which Behavior Change Techniques are Effective in Bold)
Attitude: The psychologist believes it is important to report the positive memories.	Arguments [23] to convince the psychologist of the importance of reporting the positive memories.	PM training	Psychologists are informed that reporting the positive memories is necessary to create memory-products (**new information**). (Outcome expectation 1)
Knowledge (a) The psychologist knows why it is important to report the positive memories.	Providing information [23,34] about the expected outcome of this behavior.	PM training	The information is provided by the PM trainer.
(b) The psychologist knows how to report the positive memories.	Individualized [23] instruction [34,35] by providing a model [23,34,35] of the desired outcome.	PM training	Psychologists are instructed by the PM trainer (**appropriate model**) on how to report the positive memories and are shown an example of how to report them. Opportunity to ask questions (**responding to needs**).
Self-efficacy: The psychologist feels capable to report the positive memories.	Psychologists are verbally persuaded [23,34,35] about their capabilities. Guided practice [23,34] with feedback on performance [34,35].	PM training	Psychologists are persuaded by the PM trainer (**credible source**) why they are capable to report the memories. They practice and receive feedback on performance (**specific and individual**) from the PM trainer (**experienced person**) in the second PM training session.

* One of the behaviors needed to reach the improvement goal is "After each PM session, with permission from the client, the psychologist reports the client's retrieved positive memories in the client's dossier".

3.4. IM-step 3: Selecting Behavior Change Techniques and Ways to Apply Them

To address the determinants of the behaviors needing change, we selected behavior change techniques [23,34,35], conditions under which these techniques are effective and identified ways to deliver those techniques (applications) based on the process evaluation and focus group results. To ensure a fit between the person involved in the maintenance strategies and the applications, we chose different applications for individuals with different roles: the already existing PM training for psychologists, the Act in Case of Depression training and an e-learning for nursing staff (www.doenbijdepressie.nl); and newly developed coaching by the psychologist for nursing staff and supporters. Including the maintenance strategies in the existing training programs would be the most feasible and provides psychologists, nursing staff and supporters with the opportunity to practice the learned techniques and to receive feedback from the trainer. Through the newly developed coaching, the psychologists—who are used to providing psycho-education and coaching to nursing staff—can instruct the nursing staff and supporters on the maintenance strategies and practice these with them. The second, third and fourth column of Table 4 illustrate how and which behavior change techniques were chosen to address the determinants of each of the identified behaviors needed to reach the improvement goal, and consequently, how those behavior-change techniques should be applied. A complete table showing this for all identified behaviors can be found in Table S3. An overview of how the maintenance strategies are designed to increase quality of life (IM: logic model of change) is shown in Figure 2.

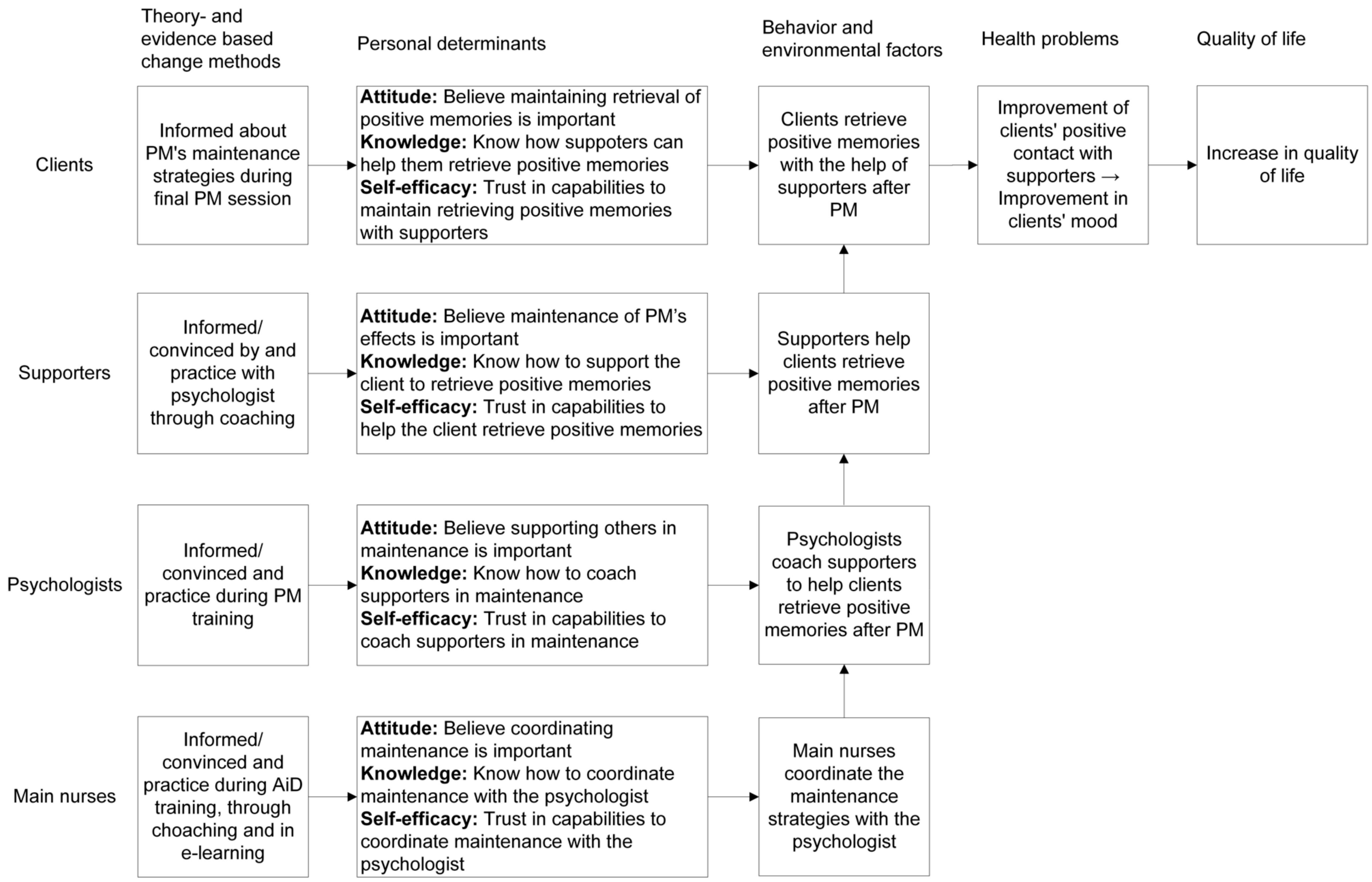

Figure 2. Logic model of change.

4. Discussion

This study's first aim was to investigate the applicability of PM in NH practice. The process evaluation showed that both the reach and completion rates of PM were low. Furthermore, PM was provided to clients with moderate or severe cognitive impairments, contrary to the inclusion criteria. Although PM was generally perceived as relevant and applicable, also in residents with cognitive impairments, its longer-term effects were questioned because of assumed limited trainability of clients, while maintaining PM effects was considered a primary improvement goal. Mentioned barriers to implementation were a lack of time and staff continuity, a medically oriented organizational culture, and a relatively low organizational priority of PM; facilitators were the PM training and protocol.

The second aim was to develop strategies to increase the applicability of PM in the NH setting. The strategies did not focus on PM itself, but regarded increasing maintenance of PM's effects. Using focus groups, the goal for maintenance was defined: improving clients' well-being by providing them with positive contact with others through helping them retrieve positive memories after PM ends. Subsequently, based on identified prerequisites for maintenance, maintenance strategies, including the formation of a maintenance plan, were suggested.

An important issue was that psychologists generally did not think their target population was capable of training memory-specificity, part of the supposed working mechanism of PM [13,15,18,19], because of cognitive impairments. In the original PM protocol, clients were assumed to continue retrieving specific, positive memories by themselves, after the intervention had ended. However, for clients with limited trainability, it is more difficult to retrieve specific, positive memories by themselves. Nonetheless, psychologists did perceive positive effects on clients' mood, which they hypothesized might be caused by the pleasant interactions clients have during sessions, which arise from the retrieval of general positive memories. Accordingly, we incorporated the positive contact with others through retrieving positive memories in the goal of maintenance strategies. A recent systematic review on the effects of life story books [36] found that these types of reminiscence activities can improve autobiographical memory, depression, mood, and quality of life in persons with dementia. Because the maintenance strategies of PM, similar to life story books, can support a person in retrieving positive memories, they might produce similar positive effects by providing clients with reminiscence.

Furthermore, maintenance strategies may account for decreased trainability of clients and, in this way, even increase the applicability of PM to clients with moderate or severe cognitive impairments and thereby also reduce drop out. However, further investigation should examine the applicability of specific aspects of PM to clients with more severe cognitive impairments, such as the questions psychologists use to probe for specific memories, the extent to which clients may deviate from life periods and the extent to which retrieved memories must be specific. Yet, PM was only delivered to less than half of the estimated indicated population because of limited time for individual treatments. Indeed, other NH studies also identified time restrictions as implementation barriers, e.g., [14,21]. This finding illustrates the need to improve the implementation of individual client therapies in the NH setting in general.

This study has a number of strengths. Firstly, the IM protocol was used to systematically evaluate and provide strategies for the improvement of PM. This provided transparency about the evaluation and improvement of PM creating important insights into workable maintenance strategies [24], especially since we integrated an extensive process evaluation in the first IM step. Furthermore, the involvement of the intervention's stakeholders in the development process, also embedded in IM, helped us to incorporate practically relevant issues [37] and is expected to increase the efficacy of the intervention [38].

Some limitations must also be acknowledged. Firstly, we aimed to use specific criteria for data saturation [30], but, because of time constraints, evaluating saturation after 10 interviews was not feasible. Nonetheless, Francis et al. [30] demonstrated that the use of purposive sampling could increase data saturation to between 86% to 92% after six interviews, suggesting that conducting 11 interviews with purposely sampled psychologists might have contributed to a satisfactory level of data saturation.

Furthermore, we could only use two interviews with clients, because it was not feasible to recruit clients without cognitive impairments who had been provided with PM relatively recently.

We originally planned to investigate the implementation strategies used by psychologists to implement the intervention. However, as psychologists in the first three interviews were unable to provide any information regarding these strategies, this topic was removed from the topic list. It is, however, important that individuals implementing an intervention know how to incorporate it into their tasks [39]. To address the found lack of knowledge about implementation strategies, we developed implementation strategies for the improvement goal.

Lastly, we aimed to influence the behavior of individuals directly involved in the maintenance strategies of PM. However, as the found barriers illustrate, when care organizations implement PM and its maintenance strategies, support at higher organizational levels must be obtained [39].

5. Conclusions

Individuals who have recovered from a depressive episode are at an increased risk of having another depressive episode in the future [40]. This illustrates the importance of investigating how the effects of psychotherapeutic interventions can be maintained. This research has contributed to this question by suggesting concrete strategies to maintain the effects of a specific intervention for depression in NH residents. In future research, the maintenance strategies of PM must be piloted, implemented, and evaluated on effects and processes (corresponding with IM-steps 4, 5 and 6, respectively). Furthermore, by strengthening PM, such a study may yield an alternative to mediative therapies in NHs, especially for residents with more severe cognitive impairments, thereby acknowledging that NH residents might still be able to receive individual therapies for depression.

Supplementary Materials: The following are available online at http://www.mdpi.com/1660-4601/16/24/5163/s1, Table S1: online questionnaire, Table S2: matrix of change objectives, Table S3: selected theory-based methods and applications addressing the determinants of behavior change, Figure S1: logic model of the problem.

Author Contributions: Conceptualization, I.v.V., J.S., G.J.W., R.L. and D.L.G.; data curation, I.v.V. and D.L.; formal analysis, I.v.V.; investigation, I.v.V.; methodology, I.v.V., J.S., R.L. and D.L.G.; project administration, I.v.V.; resources, J.S. and D.L.G.; supervision, J.S. and D.L.G.; validation, I.v.V., J.S. and D.L.G.; visualization, I.v.V., J.S. and D.L.G.; writing–original draft, I.v.V., J.S. and D.L.G.; writing–review and editing, I.v.V., J.S., G.J.W., R.L. and D.L.G.

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Conflicts of Interest: The authors declare no conflicts of interest.

Availability of Data and Material: The data that support the findings of this study are available from the corresponding author on request.

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Article

Nursing Home Residents Aged over 80—A Cross-Sectional Analysis on Which Activity Traits Correlate to Positive Affect

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Abstract: Admission to a care facility is assumed to enhance depressive symptoms and dependent behavior in old age. In this context, the relevance of participation in activities that make everyday life in a care facility more pleasant has been pointed out. This study examines if there is a relationship between participation in different activities as well as the frequency of this participation and the positive affect of nursing home residents aged over 80. Data from the unique cross-sectional representative study 'Quality of life and subjective well-being of the very old in North Rhine-Westphalia' in Germany (n = 150, aged 90.15 years in average) were used. The data were collected between 08/2017 and 02/2018 using computer-assisted personal interviewing. The variability in and frequency of activity participation functioned as independent, and positive affect as dependent variable. Multiple regression analysis was performed. Residents' predicted positive affect significantly increased with a higher variability in activity participation. There was no independent effect of frequency in participation. Our findings indicate that there is a significant and positive relationship between participating in a high number of different activities and the overall positive affect of residents aged over 80 years. This does not hold true for the frequency of participation.

Keywords: affect; depressive symptoms; activity participation; nursing home; aged 80 and over

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1. Introduction

The growing number of the oldest population (here defined as 80 years and over) might lead to an increased demand for inpatient care in the future [1]. Evidence shows that individual well-being is particularly influenced by change of living environment such as nursing home admission, preservation of independence, and social integration [1–3]. Furthermore, admission to a care facility is assumed to enhance depressive symptoms and dependent behavior in old age [2–4]. Both the prognosticated increasing number of nursing home inhabitants and the shown influence on the psychological well-being when moving into a nursing home also hold true for Germany [5,6].

One way to ease the process of adapting to a new living environment and to make everyday life in old age more pleasant is to participate in activities [1,7,8]. This also holds true for residents as has been shown by McGuinn and Mosher-Ashley [9] as well as Chao and Chen [10]. In this context, the relevance of activities that reduce stress, promote interest [11] and thus also allow the experience of one's own competence and scope of action in institutions has been pointed out [5]. In this context, the frequency of participation in activities seems to play an important role [12]. At the same time, the variability in activities appears to be relevant [13].

In Germany and internationally, however, research on this topic is rare, especially regarding residents aged over 80 who are disproportionately overrepresented in nursing homes [5]. Hilleras et al. [14] investigated activity patterns of cognitively intact subjects aged 90 years and older. Silverstein and Parker [13] analyzed leisure activities and their impact on changes in quality of life in oldest-old Swedes. Chao and Chen [10] studied the role of activity profiles for very old adults in long-term care. Cho et al. [15] focused on positive and negative affect in oldest-old adults. No study could be identified that explicitly investigated residents' participation in activities at an age higher than 80 years and no study was found dealing simultaneously with positive affect. In order to bridge this gap, we have analyzed if there is a relationship between the positive affect of residents and the two components of frequency and variability of activity participation in nursing homes.

Conceptual Framework and State of Research

Following Lawton's activity model (1983) [14], the antecedents and consequences of older adults' participation in activities were distinguished in the current study. The antecedents comprise personal and competence variables (e.g., age, gender, education, activities of daily living (ADL)), preferences, and the environment (e.g., accessibility of the physical environment, activities offered). The consequences include personal meaning of activities, satisfaction, and psychological well-being [16,17]. In order to allow residents to continue their social participation and to maintain their quality of life, many nursing homes (NH) offer a variety of activities [1,5,18]. These activities should be freely selectable and 'fit into a support process in which the primary purpose is to improve the fulfillment of daily life with satisfaction and enjoyment' [1].

In the current analysis, activity is defined as 'everyday activity NH-residents do as individuals, with their families and within their NH-community to occupy time and bring meaning and purpose to their life' [19]. Measuring activities as well as categorizing them into different activity types represent challenges in research [20], but authors have confirmed that participation in different activities is more beneficial for quality of life than engagement in only one type of activity [10,13,21–23].

The extent to which offers of social [24], physical [25–28], and general activities [4,29–31] are related to depressive symptoms in long-term inpatients has been examined numerous times with diverging results. For instance, Roh et al. [32] have shown that a decrease in risk of depression in the elderly was associated with participation in physical, social, and religious activities, whereas Hsiao and Chen [2] could not observe any significant interaction between leisure activity participation and depression.

Chao [21] has pointed out that depressive symptoms consist of different components such as negative and positive affect, somatic symptoms, and interpersonal difficulties. Chao [21] is in favor of not analyzing summary depressive scores, but of performing domain specific analyses. Positive affect describes having an active, enthusiastic, as well as awake state of mind [33]. It refers to the experience of 'many pleasant emotions and moods' [34]. Lawton [15] has concluded in his model that depression in older people is related to both activity level and positive affect level. He has also pointed out that increasing participation in activities can help raise positive affect scores. Furthermore, Meeks et al. [35] have shown that activity engagement is associated with depression through its impact on positive affect. A number of other studies have also exhibited that there is a positive link between residents' participation in specific activities and their positive affect [4,14,36–38]. This has led us to conduct an analysis of only one dimension of depressive symptoms: the positive affect. The objective of this study is to discover a potential relationship between the participation in activities and the frequency of this participation, related to the positive affect of nursing home residents aged over 80. Based on the literature review, we hypothesized: residents participating in several different activities and residents participating more frequently in activities declare a higher score of positive affect.

2. Materials and Methods

2.1. Data and Study Sample

Data from the representative cross-sectional study set of 'Quality of Life and Well-Being of the Very Old in North Rhine Westphalia (Representative Study NRW80+)' [39]—carried out between 08/2017 and 02/2018 in the most populated federal state in Germany (North Rhine-Westphalia (NRW))—were analyzed in this study. The federal state of North Rhine-Westphalia can be regarded structurally as a kind of mini Federal Republic of Germany. Germany itself can be described as average in terms of social structure in an international comparison. Furthermore, it has currently one of the fastest aging societies. With the 3-year study NRW80+ representative statements on the living conditions, quality of life and subjective well-being of very old people are made possible for the first time in Germany. A representative survey is being conducted to determine the circumstances under which very old people live, the role they play in our society and how they would like to live to be satisfied, even with various health impairments. The NRW80+ study was planned for many years. The study protocol, the designed questionnaire and the addressing of the very old were prepared by a feasibility study [39,40]. The standardized questionnaire as well as the data have been transmitted to GESIS and are publicly available [41].

Participants in NRW80+ were recruited drawing a random sample from the civil register including nursing home population. 8040 persons were approached, 1863 interviews could finally be realized. Among them were 150 residents of nursing homes. The latter were examined in the present study. Nursing homes here are defined as a type of residential care offering continuous nursing care, a safe environment, as well as physical and cognitive support in daily living activities [1].

Computer assisted personal interviewing (CAPI) of approximately 90 minutes' length were conducted by the survey institute Kantar Public Germany at the respondents' places of residence. The fact that the questionnaires used were standardized ensured concordance in the survey. As the oldest old persons and especially residents are difficult to reach and interview, proxy informants (relatives or nursing staff) were included when the target persons were unable to answer the questions for health reasons (acute illness or severe dementia).

2.2. Model Specification

The analysis in consideration of the research objective required the operationalization of seven constructs. Following Chao [21], depressive symptoms were operationalized in terms of positive affect. In NRW80+, a short version of the scale 'Positive and Negative Affect Schedule (PANAS)' [42] with five items ($\alpha = 0.89$) was applied in the questionnaire to assess the positive feelings experienced within the past 12 months. Residents and proxies were asked: 'How many times have you (has he / she) felt enthusiastic/ alerted/ elated/ inspired/ determined within the last year?' All five items were answered on a five-step scale (1 = 'never' to 5 = 'very often').

In line with Lawton [15], personal (1) and competence-related indicators (2) were considered as independent variables in the current analysis. Personal factors (1) included age (1a), gender (1b), education (1c), residential attachment of participants (1d), and their participation in activities (1e). Education (1c) was operationalized in NRW80+ following the German aging Survey (DEAS) [43]. It was separated into the categories 1 = 'low' (no vocational training; secondary school leaving or lower), 2 = 'medium' (completed vocational training or university entrance qualification), and 3 = 'high' (completed studies). Concerning residential attachment (1d), residents were asked: 'How closely connected do you feel to your living environment?' Answers ranged from 1 ('not close at all') to 4 ('very close').

Based on the theoretical background mentioned above, participation in activities (1e) was measured on two scales. Residents were asked in a first step: 'Which of the following activities did you do within the last twelve months?' The selection of the 17 activities that were probed was based on the survey of the Berlin Age Study I [44]. Just like in the Berlin Age Study [44] we asked for sports activities, participation in coffee parties, café visits, travelling, cinema visits, theatre or museum visits, artistic activities, hobbies, volunteering, playing games, and participation in further education or political events. Five questions were added to the items of the Berlin Age Study covering low-threshold activities in old age: taking a walk, receiving visitors, doing mental exercises, reading, watching television. This first scale had a width from 0 ('No') to 1 ('Yes'). Thus, participants answered for every activity with 'yes' or 'no', depending on whether they participated or not. If the residents affirmed their participation in an activity, they were subsequently asked: 'How often did you do this activity?' The answers of this second scale ranged from 1 ('daily') to 5 ('once a year').

Afterwards, total scores (indexes) were calculated. The index for the participation in activities consisted of the mean value of the activities probed and shows a continuous width from 0 (participation in none of the activities probed) to 1 (participation in all of the 17 activities). Thus, higher values correspond to a higher heterogeneity and variety of exercised activities. The frequency index was composed of 16 items. Watching television was excluded due to the fact that it was recorded in hours. The width for frequency of participation was also continuous (from 1 = 'daily' to 5 = 'once a year') and can be interpreted with lower scale values indicating more frequent participation in activity.

Competence variables (2) comprised activities of daily living (ADL) measured according to Katz et al. [45]. ADL items focus, inter alia, on the ability to eat, dress, walk, or use the bathroom. The ADL scale values were calculated from the mean value of the respective seven items and interpreted on a continuous scale point width from 0 ('Only possible with help') to 2 ('No help'). Higher values mean better functional ability.

2.3. Statistical Analysis

We conducted the statistical analysis with Stata 16.0 (2019) [46]. The first step was the descriptive analysis of all variables. Continuous variables are expressed as means with standard deviations and categorial variables are shown as percentages. Secondly, Spearman's rho correlation was calculated. Finally, we conducted a multiple regression analysis to determine the effect of the number of activity participations as well as their frequency on the older individual's positive affect. For this purpose, we calculated three models by taking into account different control variables: age, gender, education, functional health (ADL), and residential attachment. R^2_{adjusted} was used as goodness of fit measure for the regression calculations.

Model I represents the full model and shows how the associations of the explanatory variables of frequency and variability appear under control of the others. Model II and III explore the interaction of the individual explanatory variables: Model II does not control for frequency of participation, model III excludes the variability.

Variables were tested for normality and homoscedasticity using the Shapiro-Wilk test and the Levene test. Multicollinearity was examined using the Variance Inflation Factor. Missing data were imputed for the regression analyses by multiple imputation. The dependent variable of positive affect showed 7 missings, while the frequency of participation showed 3 missings, and education showed 15 missings. The missing data does not seem to be intentional, related to outcome measurements or other variables in the study. Following the Markov chain Monte Carlo technique [47], 20 complete data sets using multivariate normal regression were generated. The results after multiple imputation and after complete case analysis allowed the same conclusions. This enabled us to use all possible information and to address the potential bias due to missing data [22,48]. Statistical significance was defined as $p < 0.05$. NRW80+ was approved by the Research Ethics Committee at the University of Cologne (Germany) (17-169) [39].

3. Results

150 people older than 80 years and living in a long-term care facility for 3.14 ± 0.291 years in mean were included. Table 1 descriptively shows participants' characteristics. The study sample consisted of 111 women (74.0%) and 39 men (26.0%). Residents were aged 90.15 ± 0.40 years on average. 74.0% (n = 111) of the residents were directly available for the study, 26.0% (n = 39) weren't able to participate. In these cases, a proxy was asked. Four proxies were spouses, 14 were residents' children, eight were (professional) caregivers, and 13 were other relatives.

Table 1. Descriptive characteristics of study participants.

Variables	%	Mean	SD	Min	Max
Age (in years)	100 (n = 150)	90.15	±0.40	80	101
Women	74 (n = 111)	90.51	± 0.48	80	101
Men	26 (n = 39)	89.13	± 0.67	81	98
Marital status	100 (n = 150)			1	4
married	10 (n = 10)				
widowed	76.67 (n = 115)				
divorced	6.00 (n = 9)				
unmarried	7.33 (n = 11)				
Education	100 (n = 150)	1.67	±0.67	1	3
low	43.70 (n = 59)				
medium	45.19 (n = 61)				
high	11.11 (n = 15)				
Residential connection	100 (n = 142)	2.57	±0.09	1	4
Activities of daily living (ADL)	100 (n = 150)	0.98	±0.65	0	2

55.6% (n = 65) of the nursing homes were non-profit, 42.6% (n = 49) were privately operated. The size of the nursing homes ranged from 10 beds to 206 beds. More than half (55.6%; n = 79) of the residents described their residential attachment as very close or rather close.

Regarding the positive affect (Table 2), it was found that for all items, less than a third of the respondents answered the questions with 'often' or 'very often'. About half of the respondents (52.9%, n = 74) never or rarely stated enthusiasm or were elated (48.0%, n = 68) within the past twelve months. Moreover, 47.0% (n = 64) never or rarely felt inspired, 47.4% (n = 62) never or rarely felt a determination, and more than a third (36.4%, n = 57) never or rarely felt alert.

Furthermore, 98.5% of the nursing home residents were regularly active in some form (46.7% (n = 69) participated in at least four different activities within the last twelve months, 34.0% (n = 49) in at least seven activities, 15.3% (n = 22) in at least ten activities). The average variability of activities was 0.30 ± 0.013 (range 0–1). This means residents engaged in five different activities on average. 40.7% (n = 61) have been physically active during the past twelve months and 19.3% (n = 29) of the residents go for a walk on a daily basis. Moreover, 32.0% (n = 48) were regularly mentally active, of which 35.4% (n = 17) did brain teasers on a daily, 45.8% (n = 22) on a weekly basis. 95.2% (n = 141) of the residents have received visits within the past year, of which 13.0% (n = 18) have received daily and 63.3% (n = 88) weekly visits. The average frequency of participation in activities was 2.31 ± 0.05 (range 1–5) with 84.4% (n = 123) of the residents taking part in the activities they mentioned at least once a week.

Table 2. Descriptive results concerning positive affect of the residents.

Expression	Mean	SD	Never	Rarely	Sometimes	Often	Very Often
enthusiastic ($n = 140$)	2.53	±1.20	23.57% ($n = 33$)	29.29% ($n = 41$)	23.57% ($n = 33$)	17.14% ($n = 24$)	6.43% ($n = 9$)
alert ($n = 129$)	2.95	±1.11	10.08 ($n = 13$)	26.36 ($n = 34$)	29.46 ($n = 38$)	26.36 ($n = 34$)	7.75 ($n = 10$)
elated ($n = 142$)	2.73	±1.12	12.68 ($n = 18$)	35.21 ($n = 50$)	24.65 ($n = 35$)	21.13 ($n = 30$)	6.34 ($n = 9$)
inspired ($n = 136$)	2.66	±1.12	15.44 ($n = 21$)	31.62 ($n = 43$)	29.41 ($n = 40$)	17.65 ($n = 24$)	5.88 ($n = 8$)
determined ($n = 135$)	2.64	±1.18	19.26 ($n = 26$)	28.15 ($n = 38$)	28.89 ($n = 39$)	16.30 ($n = 22$)	7.41 ($n = 10$)
Positive and negative affect schedule Sum Score ($n = 143$)	2.71	±0.08					

Table 3 shows the results for the Spearman correlations calculated in this study. Sample size for correlation analysis was $n = 118$ as we did not use multiple imputation at this step yet. The 32 missing values ($n = 150–118$) resulted from the different number of missings per variable included in the correlation analysis. The latter allowed the identification of initial trends as well as consistencies with the research literature. Using correlation analysis and the original sample an attempt was made to create a valuable basis for the following regression analysis.

A strong positive and statistically significant correlation was identified between the sum score of the PANAS scale and the variability in activities (r = 0.54; $p < 0.001$). A moderate correlation was found between PANAS and residential attachment (r = 0.32; $p < 0.001$). Furthermore, there was a moderate positive and statistically significant correlation between variability in activities and ADL (r = 0.28; $p < 0.01$) as well as residential attachment (r = 0.20; $p < 0.05$) and education (r = 0.25; $p < 0.01$). Age and education were moderately and positively correlated (r = 0.34, $p < 0.001$). The frequency of participation in activities showed no statistically significant correlations to any of the other variables.

Table 3. Correlation calculation.

Variables	1	2	3	4	5	6	7
1 Age							
2 Sex	0.115						
3 Education	−0.094	−0.336 ***					
4 Activities of daily living (ADL)	0.090	−0.132	0.203				
5 Residential connection	−0.068	−0.015	0.175	0.116			
6 Variability in activities	−0.010	0.092	0.250 **	0.283 **	0.204 *		
7 Frequency of activities	0.114	−0.039	0.064	0.121	−0.126	0.051	
8 Positive and negative affect schedule (PANAS) Sum Score	−0.022	0.120	0.201 *	0.176	0.320 ***	0.544 ***	−0.143

$n = 118$; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Multiple regression analysis (Table 4) was performed to predict positive affect based on the variability and frequency of activities. This calculation intended to verify our findings from the correlation calculation and to answer our central research question which activity trait is more likely to predict positive affect. Sample size for regression analysis was 150 as we decided to use multiple imputation for this step. The results indicated that all of the models are significant predictors of positive affect (model I: F(7, 138.4) = 9.19, $p < 0.001$; model II: F(5, 140.4) = 7.55; model III: F(6, 139.5) = 8.18). We observed no multicollinearity in terms of VIF.

Model I best explains the relationship between positive affect and participation in activities ($R^2_{\text{adjusted}} = 0.30 \pm 0.25$). It includes both of the independent variables and all control variables. All of the models show significant and robust positive effects of variability on positive affect (β = 2.35–2.42; $p < 0.001$) as well as of residential attachment on positive affect (β = 0.25–0.27; $p < 0.01$). As was already apparent in the correlation calculations, the frequency of participation in activities is not significant in any of the models calculated.

Table 4. Regression analysis.

Variables	**Model I**		**Model II**		**Model III**	
PANAS	**Coeff.**	**SD**	**Coeff.**	**SD**	**Coeff.**	**SD**
Age	0.007	0.015	0.003	0.015	−0.050	0.016
Sex (male)	−0.247	0.178	−0.262	0.179	−0.445	0.188
Education	0.091	0.117	0.077	0.118	0.196	0.126
Activities of daily living (ADL)	0.083	0.120	0.097	0.122	0.328 **	0.116
Residential attachment	0.253 **	0.069	0.262 ***	0.070	0.276 ***	0.074
Variability in activities	2.423 ***	0.520	2.349 ***	0.524		
Frequency of activities	−0.222	0.120			−0.183	0.128
$R^2_{\text{adjusted (based on Fisher's z transformation)}}$	0.302	0.251	0.286	0.245	0.193	0.166

PANAS: Positive and Negative Affect Schedule; $n = 150$; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

4. Discussion

The present study focuses on one component of depression symptoms, as we have found strong arguments in previous studies which suggest that it is worth analyzing positive affect as a specific domain of depressive symptomology. This should allow not to overlook relevant information hidden under different facets of depressive symptoms [22,49].

The findings of the present analysis are in line with those of Silverstein and Parker [13] showing that a wider variety of activities is more beneficial for quality of life than only participating in a single type of activity. Silverstein and Parker [13] were able to demonstrate a cumulative effect of participating in different activities because each activity type makes its own contribution to different aspects of depressive symptoms. The data basis of this study did not allow for an investigation of such an accumulation as it was not possible to analyze the extent to which a single additional activity contributes to an increase in positive affect of a resident.

One the one hand, the fact that frequency of participation is not significantly related to an increase in positive affect scores contradicts the results of Pushkar et al. [12] as well as Meeks et al. [35]. On the other hand, our findings agree with those of Diegelmann et al. [30] as well as Hsu and Wright [24] assuming that not frequency alone, but the enjoyability of participating in activities counts for a decrease in depressive symptoms. It might be possible that enjoyability or meaningfulness function as mediating factors between positive affect scores and both participation in a high number of activities and frequency of participation. Further analyses should thus be carried out in this respect.

The model of successful aging established by Rowe and Kahn [50] assumes that an active engagement helps promoting positive mental health. Nevertheless, we have also shown that not only participation in activities influences the prediction of positive affect. As the literature points out, functional ability, reduced physical function [51,52], as well as environmental factors [2,17,53] are linked to depression in general or to positive affect specifically. It would also be conceivable that the phenomenon of frailty of nursing home residents plays a role in this regard [54]. In this study, ADL and residential attachment to the nursing home showed a significant correlation with positive affect. Residential attachment also showed significance in the regressions calculated. This is in line with the findings of Altinas et al. [18]. The analysis of other factors, such as frailty or environmental aspects such as the maintenance of social contacts, and their influence on both participation in activities and positive affect should be investigated in more detail in further studies.

Since the everyday life of nursing home residents is focused around health-related events, they are at risk of rarely having positive experiences and of having their negative affect deteriorate. The high incidence of depression in nursing homes might be attributed to these interrelations. Van Haitsma et al. [38] claim that positive affect is closely related to factors of the environment, whereas negative affect is rather associated with internal factors like health and personality. Altinas et al. [18] have proven that the number of activities a person engages in contributes to a better adjustment to the nursing home. With these results, Altinas et al. [18] as well as this study reproduce the findings of McGuinn and Mosher-Ashley [9]. Chao [21] has shown in a longitudinal analysis that an increase in social activities not only contributes to higher scores in positive affect, but also to a decrease in negative affect and interpersonal difficulties. Even though we have argued in favor of only analyzing positive affect as a specific domain of depressive symptoms, the link between depressiveness in general and the participation in activities can only be established if all specific domains of depression are considered in the analysis. Positive affect can thus be seen in close relation to other dimensions of depression. Many older adults, however, show depressive symptomatology but do not meet the criteria for a depression diagnosis [21]. For this reason, it is important to focus on the individual components of depressive symptoms, such as positive affect in this case.

NRW80+ did not study one particular facility, but residents came from many different facilities, spread across the federal state of NRW. This means that it was not possible to study one specific activity program. The fact that we asked for superordinate activities makes the surveyed activities comparable since it can be assumed that residents should have access to these activities regardless of the nursing home in which they live. Noting that activity engagement in long-term care settings seems to play an important role, activities on offer are increasingly seen as an indicator of quality of care [23,38]. Knowing about the attributing value of offering different activities in nursing homes for positive affect may be action-guiding for the nursing staff in how to carry out and offer activities. The current analysis is not limited to activities explicitly offered by the nursing home. It can be assumed that having the possibility to engage in activities outside of the nursing home has an influence on the feeling of independence while transitioning to a long-term care setting. Supporting activities outside of the nursing home can therefore also be an important task.

It should generally be noted that analyzing activity does not reveal a person's lifestyle. However, counting participation in different types of activities, thereby showing the effect of variability, shows that nursing home staff should offer a series of different group and individual leisure activities. In this context, it is also important to identify a person's interests and preferences and thus encourage continuous participation in activities that residents have enjoyed before moving into a nursing home. This is especially relevant for residents with physical or mental disabilities [10]. As Tak et al. [23] have shown, activities are especially interesting to residents if they are related to their previous work or life; age and cohort specific-experiences may be a factor. At this point, the importance of biographical work in nursing homes can be emphasized, in the context of which preferences could easily be identified. This goes along with the demand for person-centered care and staff's engagement in offering activities to encourage participation. Meeks and Looney [31] have shown that staff behavior plays a central role for residents' depressive symptoms in general and positive affect in particular. In this regard, governments or nursing home management should focus on interventions and make efforts to train staff.

As oldest-old persons and especially residents are difficult to reach and interview, proxy informants (relatives or nursing staff) were included in NRW80+ when the target persons were unable to answer the questions for health reasons. Although self-reports should always remain the gold standard [55], many studies have shown no significant differences between reports done by participants and proxies [15,56]. Perspectives of proxies might even be useful to gain different viewpoints on oldest-old subjective well-being [15]. Asking proxies (e.g., family or staff members) thus seems preferable compared to the alternative option of excluding those residents altogether from the analysis. Nevertheless, relatives and staff certainly do not always have the same estimation as those affected. This plays a role especially in the course of dementia [57,58]. As Crespo et al. [59] showed, assessments of proxies can underestimate the state of mind of residents. Ratings from residents about their own quality of life may be higher than those of proxies. Therefore, it must not be ignored that there may be a distortion.

Strengths and Limitations

Our study offers two main strengths. Firstly, despite a small sample size, our analyses reveal significant results for a very specific group of individuals for which there is still little research. This emphasizes the importance of our results. By providing new insights our findings contribute to a better understanding of the activity engagement and positive affect of the oldest old population in Germany. Secondly, the data set represents a new and unique representative sample of nursing home residents with very good data quality. With this the results gain in significance beyond the German and European context.

The analysis has nevertheless some limitations. The sample size is relatively small considering the number of variables included. As some variables have shown missing values, we have decided to use multiple imputation to allow for a comprehensive analysis of the established hypotheses. Siddiqui [60] requires a minimum of 15 observations for each variable included. Exceeding the indicated minimal number of subjects per variable (seven in this study), this has been considered.

The cross-sectional design of our study prevents an analysis of cause-and-effect relations. As Janke et al. [61] have shown, it is also possible that residents with lower positive affect participate less in activities. Secondly, residential attachment may influence how activities in the nursing home are recognized. We therefore can't prove if the effect is due to activity or residential attachment. The time spent in a nursing home might also have an influence on both participation in activities as well as well-being (regardless of participation in activities). We could not confirm this possible confounder effect in analyses that are not shown here. As we have dealt with a retrospective study based on the assessment of the residents on the one hand and on the evaluation of proxies on the other, it is possible that the Likert-type scale that was used for positive affect as well as the scales used for variability in activities and frequency of participation limit the precision of the answers given and thus may include recall bias. This may be accompanied by a memory bias in terms of remembering participation. Since very old people as well as their proxies were interviewed, it is conceivable that there are some imprecisions regarding the frequency of participation as well as the differentiation of the individual activities from each other.

The aim of the current analysis is to focus only on the associations between participation in activity and positive affect. Given the named limitations, our results are explorative and not fully conclusive, but bear in them the potential for future research. We stress that longitudinal analyses are indispensable to explore causal relationship between living environment, participation in activities, and positive affect outcome. In addition, multi-level models seem optimal in order to separate context features of facilities from effects of residential attachment and participation in activity. Furthermore, this would allow for approximate effects of nursing staff or nursing home management.

Whether or not nursing home residents can participate in activities depends on the availability of continuous and trained personnel to enable activation. It can be hypothesized and it should be investigated in further analyses if the human resource management has an impact on the degree of activation of nursing home residents. In line with this, it should be analyzed if the organization (the nursing home) as a whole has an influence on the human resource management and thus also on the emotional outcome of the residents.

5. Conclusions

Our findings support the hypothesis that participating in a high number of different activities is positively associated with the overall positive affect of residents aged over 80 years. In our study sample this effect was significant even after controlling for demographic characteristics, functional ability, and residential attachment. Frequency of participation was not significant. Our second hypothesis therefore must be rejected.

The present explorative study provides new data both on the German nursing home population as well as on the specific group of very old people. Although we did not use population-based analytical methods, the analysis provides new evidence on the potential associations between positive affect of nursing home residents aged over 80 years and both the engagement in different activities as well as the frequency of participating in activities. Our findings certainly warrant further investigation. Nevertheless, it can be assumed that our results are relevant for health policy as a whole and specifically for actors involved in long-term care, providing incentives for various policy or structural initiatives. Questions and analyses concerning aspects of depression in nursing homes—such as positive affect—indirectly represent an opportunity to involve nursing home residents in the development of quality indicators. Furthermore, surveys of activity preferences could lead to more individualized care and thus to greater satisfaction or well-being among residents.

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SettleIN: Using a Manualised Intervention to Facilitate the Adjustment of Older Adults with Dementia Following Placement into Residential Care

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Abstract: The authors examined the feasibility of delivering an adapted version of SettleIN, a manualised staff-led programme designed to facilitate adjustment to care for new residents with dementia. The effects of SettleIN on resident adjustment, mood and quality of life were also investigated. A pilot randomised controlled trial was conducted. Nineteen new residents with dementia and 21 staff participants were recruited. Residents were randomly assigned to receive the SettleIN programme or residential care as usual. Resident quality of life, mood and overall adjustment were measured at baseline and post-intervention, in week seven. Interviews were conducted with staff in week seven to explore intervention feasibility. Despite medium to large effect sizes, there was no significant difference in mean change scores between the two conditions, with regards to quality of life, psychological wellbeing or overall adjustment outcomes. Qualitative feedback indicated that SettleIN was not feasible across all areas, with problems around recruitment and practicality. However, SettleIN was deemed feasible in terms of retention and acceptability among staff. The majority of staff felt that SettleIN was beneficial for residents but that organisational and programme factors impacted upon intervention feasibility. Further exploration of organisational barriers is needed in order to reduce the impact of such factors on care home research.

Keywords: dementia; adjustment; residential care; psychological wellbeing; staff training; quality of life

1. Introduction

Sixty-nine percent of people with dementia live in a residential care setting [1]. The circumstances around relocating into care can mean that the transition is rushed. Many residents consequently feel powerless in the decision to move and experience negative outcomes, including increased emotional responses and difficulties adjusting [2].

Relocating into residential care has been linked to increased cognitive decline, behavioural and psychological symptoms of dementia (BPSD) [3]. One study found that 34.3 percent of residents who relocated from their own home into residential care met criteria for depression symptomology [4]. Residents have also reported having a poorer quality of life following relocation [5]. This finding, however, has not been consistently supported, suggesting that successful adjustment is possible [6].

To successfully adjust, people with dementia need to accomplish three processes: settle in, fit in and find meaning within this process [7]. To achieve this, they must adjust to the schedule of the home, form new meaningful relationships and modify their identity as they adapt. A review of the research also focused on the specific factors affecting relocation adjustment [3]. Sury and colleagues [3] highlighted the role of resident autonomy, the physical environment, relationships, sociocultural needs and stimulating activity. A primary recommendation of the review was that an intervention, which considered these factors, needed to be developed to aid resident adjustment. Various strategies were recommended as part of the proposed intervention, including creating a home-like environment and having a buddy system in place.

Care home staff are considered to have a vital role in the transition process [8]. Their position allows them to promote new relationships among people with dementia. Staff training can therefore be a means of reflecting with staff on the emotional impact of relocation and ensuring that suggested strategies are incorporated into everyday care [8].

In response to this unmet need for resident adaptation support and related staff training during relocation, Hayward, Nunez, Ballard and Spector [9] created the SettleIN programme. SettleIN is a person-centred tool for people with dementia that is designed to facilitate healthy adjustment. Hayward et al.'s feasibility, pre- and post-intervention pilot study was conducted (N = 13) in order to evaluate the acceptability of SettleIN and the effectiveness of the programme in improving residents' mood and quality of life. In its existing form, SettleIN was not found to be feasible to deliver in care homes across the UK and, due to high attrition rates of 62 percent, the study lacked sufficient data to draw conclusions on programme effectiveness. The SettleIN programme was found to be highly acceptable among stakeholders and staff who implemented the programme [9]; this is key for an effective intervention [10].

Since Hayward's initial pilot study, there appears to be no further published interventions to facilitate resident adjustment [11] but recent research continues to conclude that an intervention of this nature is needed [12]. The main aim of this study was therefore to create a more feasible, enhanced version of SettleIN. Recommendations for improvement by Hayward and colleagues were adopted in a second feasibility study. Recommendations included reducing and simplifying SettleIN, as well as removing dependence on family members for programme completion. For more information about these recommendations, see Hayward et al. [9]. This study also expanded on the research carried out by Hayward by including a control group, enabling comparison to natural adjustment.

In the form of a pilot randomised controlled trial, the study examined the feasibility and effectiveness of the enhanced version of SettleIN. It was hypothesised that (a) those receiving SettleIN would experience an improvement in their mood and increase in their quality of life compared to those in the control group, and (b) SettleIN would be feasible for staff.

2. Method

2.1. Phase One: Developing the Intervention

The framework of designing, delivering and evaluating interventions is often not linear [10]. Drawing upon feedback from the previous study, this study returned to the development phase to modify the programme. Modifications made included reducing the intensity of SettleIN, formalising staff supervision, removing dependency on family members and adding an additional module for residents who struggled to engage.

Consultation

Seven care homes involved in Hayward's trial were invited to discuss the changes made to the programme. Due to high levels of staff turnover, only two staff members from one home were available to participate. Both staff members were care assistants who had delivered the programme in the previous trial.

The principal researchers met with the care assistants individually for approximately forty-five minutes. They were shown the enhanced SettleIN programme, following which the principal researchers conducted a semi-structured interview. See Table 1 for a summary of responses. Following this consultation, further changes to the new SettleIN workbook were finalised and made ready for use in the feasibility study.

Table 1. Summary of consultation qualitative feedback.

Theme	Feedback	Further Changes Made
Programme intensity	• Reducing content made the programme more accessible • Programme looked easier to do alongside job role • There was too much to do in the previous version	Some activity repetitions were reduced further
Additions to the programme	• New activity added would work well • New activity met resident's needs • New module would be helpful for some but not all residents • Supervision would be helpful	Kept new module but made it optional Agreed that supervision would be offered weekly
Individual resident factors as barriers	• Resident personality and dementia severity, would influence programme feasibility and usefulness • Programme dependent on resident's verbal ability	Inclusion criteria to not include individuals with severe dementia as measured by the Functional Assessment Staging Test To meet this criteria, resident participants had to be able to speak more than 5–7 words a day

2.2. Phase Two: Feasibility Study of the Enhanced SettleIN Intervention

2.2.1. Design

The study used a between-subjects randomised experimental design to evaluate the feasibility of implementing an enhanced version of SettleIN. The study also focused on the effects of the SettleIN programme on new residents' quality of life, psychological wellbeing and overall adjustment. A sequential explanatory mixed-methods design was employed with quantitative results collected and qualitative data then used to build on the quantitative findings.

2.2.2. Ethical approval

Ethical approval, covering both phases, was obtained from both University College London Joint Research Office and the Camden and Kings Cross Research Ethics Committee (Ref: 15/LO/0611).

2.2.3. Recruitment

Setting

Between April 2017 and January 2018, 156 care homes were contacted to take part in the research. Care homes were identified using the Care Quality Commission (2013) care directory and the Enabling Research in Care Homes (ENRICH) database. Opportunity sampling was also employed.

Of the 156 care homes initially contacted, 10 care homes responded expressing an interest in participation. The care homes that did not respond were contacted again by the principal researchers. From this an additional 17 care home managers expressed an interest in partaking in the research.

The principal researchers met with the care home managers from the 27 homes to clarify eligibility (see Table 2) and provide information about SettleIN. From this, formal written consent was obtained from 17 care homes. All care homes were offered a certificate for partaking in the research.

Table 2. Inclusion criteria.

Criteria	Setting	Residents	Staff
Inclusion	• Care Quality Commission (CQC) rating of 'requires improvement' (that does not include safety as an improvement factor), 'good' or 'outstanding' • Staffing levels to allow individual staff members leave to attend training • Managerial support to participating staff	• Dementia diagnosis • Dementia classified as mild to moderately severe (stages 2–6) on the Functional Assessment Staging Test (FAST) • Able to converse in English • Relocated to the care home within the past month	• Employed to support residents within the care home (may include nurses, health care assistants, care workers, team leaders, activity coordinators, etc.)

Participants

Using G*Power 3 [13], it was calculated that a minimum of 24 resident participants would be required to achieve sufficient power (0.8) at a 0.05 level of statistical significance and to detect a conservative effect size of 0.3, which is typical for a pilot study and chosen due to the lack of methodologically equivalent research. To account for possible attrition, the study aimed for a sample size of 30. However, as this was a pilot study, the chief aim was to assess feasibility for a full trial, retention rates and effect sizes.

In line with recent evidence about the importance of managerial support [14], a partnership approach was emphasised with recruited care homes. Participating managers agreed to take a key role in the running of SettleIN. They were encouraged to talk to new residents and carers about SettleIN as part of their routine process when discussing relocation. The researchers then assessed resident suitability and sought formal consent.

The intervention was a staff-led programme which required one or two staff participants for every resident participant. Care home managers provided staff members with information leaflets about SettleIN. The principal researchers then gained formal consent. All staff participants were given a £10 high street gift voucher and a certificate for partaking in the research.

2.2.4. Procedure

Once written consent was obtained from the staff participant, and the resident (or their family), the baseline assessment was conducted.

Randomisation

Following baseline assessment, each resident was randomised to one of two conditions: the intervention group, which received the SettleIN programme, or the control group, which received residential care as usual. Care as usual consisted of the existing standard practice and adjustment support given by the homes. This was monitored as part of the demographic measures taken. An independent researcher randomised participants using a computer-generated sequencing programme. Block Randomisation was employed using a fixed block size of four to ensure an equal proportion of residents in each condition. The researcher responsible for data collection remained blind to the condition, ensuring that the study was single blinded.

Intervention Training

Staff participants, working with residents assigned to the intervention condition, attended a one to one training session on the SettleIN programme, conducted by a principal researcher at the care home and lasting one hour and 15 min.

The training involved an introduction to the factors that influence successful adjustment. The training systematically went through each module of the programme and covered how to deliver the tasks within modules. Staff in the control condition did not receive training.

The SettleIN Programme

The SettleIN programme is a staff-led manualised intervention that consists of four mandatory modules: orientation, lifestyle, friends and family and identity, along with one optional module: for residents who struggle to engage. The modules consist of various activities that are designed to promote healthy adjustment in new residents (see Table 3 for example module questions).

Table 3. Examples of an activity from each of the five SettleIN modules.

Module	Activity	Frequency	Minutes
Orientation	Introduce a buddy or buddies (at least one staff member and possibly another resident who knows their way around) to the new resident	1 time in week 1	15
Lifestyle	Gently ask the resident about how they spent their typical day, week and month prior to moving into the care home. Plan with the resident about how to keep up as many of the routines as possible (examples given)	1 time in week 2 and week 3	20
Family and Friends	Complete a simple family tree (see resources in the management manual for an example)	2 times in week 1	20
Identity	Create a 'This is Your Life Book' with the resident (refer to SettleIN Management Manual for guidance)	2 times in week 3 and week 4	20
Struggling to Engage (optional module)	Get to know the resident by talking to them about topics unrelated to their move. Example questions given e.g., what was your favourite holiday?	2 times in week 1	15

Note. Frequency refers to different days unless stated. Minutes refers to per attempt.

All of the activities were carried out with the residents by staff participants, normally a resident's key worker. Following activity completion, the staff participant was required to document the relevant information in the workbook. The programme was designed to take a full time staff member four weeks to complete, taking up to six weeks for part time staff.

Staff were offered weekly telephone supervision, which lasted an average of 10 min. This focused on the challenges experienced and gave staff the opportunity to share positive experiences. Supervision involved problem solving difficulties, including liaising with management to review their support.

2.2.5. Measures

Measures were collected from all residents and staff participants at two stages: baseline (week zero) and post-intervention (week seven). The functional stage of dementia and demographic information were collected at baseline only. In week seven, 30 min interviews were conducted with the staff participants who had received training and the SettleIN workbooks were collected to provide information on implementation.

Demographics

Information regarding resident demographics and relevant medical information was obtained from residents' care plans. Staff demographics, usual care home adjustment support (such as an orientation programme and any procedures to keep families informed), and resident adjustment support (including prior visits to the home) were also asked about.

Functional Stage of Dementia

The tool, completed with staff, consists of seven main stages from normal functioning (stage one) to severe dementia (stage seven), with five substages at stage six and six substages at stage seven [15]. The FAST has been found to be both a reliable and valid assessment tool across all stages of dementia severity [16].

Quality of Life

Quality of life was measured using the Quality of Life in Alzheimer's disease (QOL-AD) [17]. This 13 item measure is rated on a 4-point scale, with answers ranging from poor (1) to excellent (4). A total score is calculated, ranging from 13 to 52, with a higher total score suggesting a higher quality of life. The measure consists of the following dimensions: finances, physical health, mental health and social activities. The QOL-AD was completed by both the resident, where possible, and their keyworker. The measure has high levels of internal consistency for people with dementia (Cronbach's alpha = 0.84) and by proxies (Cronbach's alpha = 0.86) [18].

Psychological Wellbeing

The Cornell Scale for Depression in Dementia (CSDD) [19] was used to measure improvement in mood. It consists of 19 items, which can be scored as absent (0), mild/intermittent (1) or severe (2). The total score ranges from 0 to 38, with a higher total score indicating a greater level of depression. The measure has good internal consistency among residents with mild and moderate to severe dementia (Cronbach's Alpha= 0.81, 0.82, respectively) [20]; this is maintained when completed by proxy (Cronbach's Alpha= 0.86) [21].

Overall Adjustment

Adjustment was measured using the Index of Relocation Adjustment Scale (IRA) [22]. This consists of six items, which are measured on a 4-point Likert scale with answers ranging from completely disagree (0) to completely agree (3). The total score ranges from 0 to 18, with a higher total score denoting a greater level of adjustment. The use of the measure in this study was explorative; Hayward et al. [9] adapted the IRA to include pictures of faces ranging from very unhappy to very happy and found it to be a useful measure for residents with dementia. This brief measure was completed with residents only.

Feasibility of SettleIN for staff

The interviews focused on staff participants' views on delivering the SettleIN programme. Questions included: 'what challenges have you experienced?' and 'how easy or difficult has it been to finish the programme in the 4–6 weeks?' To reduce response bias, interviews were not conducted by researchers responsible for training.

Feasibility Measures

To fully examine the feasibility of the enhanced version of SettleIN, the following dimensions of feasibility were measured, as recommended by Bowen and colleagues [23]: acceptability, demand, implementation, practicality and limited efficacy testing; recruitment and retention were also considered (see Table 4).

Table 4. Key dimensions of feasibility examined and outcomes measuring this.

Area of Feasibility	Related Research Question	How Assessed
Acceptability	Is an enhanced version of SettleIN acceptable, attractive and satisfying to stake holders?	(1) Consultation following modifications to SettleIN (2) Staff participant interview (3) Descriptive statistics of recruitment feasibility
Demand	To what extent was enhanced SettleIN used?	(1) Staff interviews
Implementation	To what extent was enhanced SettleIN successfully delivered?	(1) Analysis of SettleIN documents (2) Staff participant interview
Practicality	To what extent was enhanced SettleIN carried out with intended participants without outside intervention?	(1) Staff participant interview
Limited efficacy	Is an enhanced version of SettleIN effective in facilitating the adjustment of people with dementia who have recently been placed into residential care?	(1) QOL-AD (2) CSDD (3) IRA
Recruitment	How easy was it to recruit?	(1) Number of contacts made (2) Time taken to recruit (3) Numbers recruited
Retention	How many participants stayed in the trial?	(1) Attrition rates

Note. QOL-AD = Quality of Life in Alzheimer's Disease; CSDD = Cornell Scale for Depression in Dementia; IRA = Index of Relocation Adjustment.

2.2.6. Analysis

Missing Data

By proxy reports were used in the event that residents were unable to complete QOL-AD and CSDD measures. The IRA measure could not be collected by proxy. Missing data due to attrition was analysed using the last observation carried forward approach.

Qualitative Data

Data obtained from staff interviews was analysed using thematic analysis. Analysis was carried out using the six phases recommended by Braun and Clarke [24]. Both principal researchers coded the data individually as to ensure that the codes generated were consistent with the data set.

3. Results

Over nine months, care home managers informed the researchers of 42 new residents who had relocated into the recruited care homes (see Figure 1). From this, 19 residents from 12 care homes were eligible and took part in the study. As two of the residents had an additional staff member involved, 21 staff participants were involved in the study.

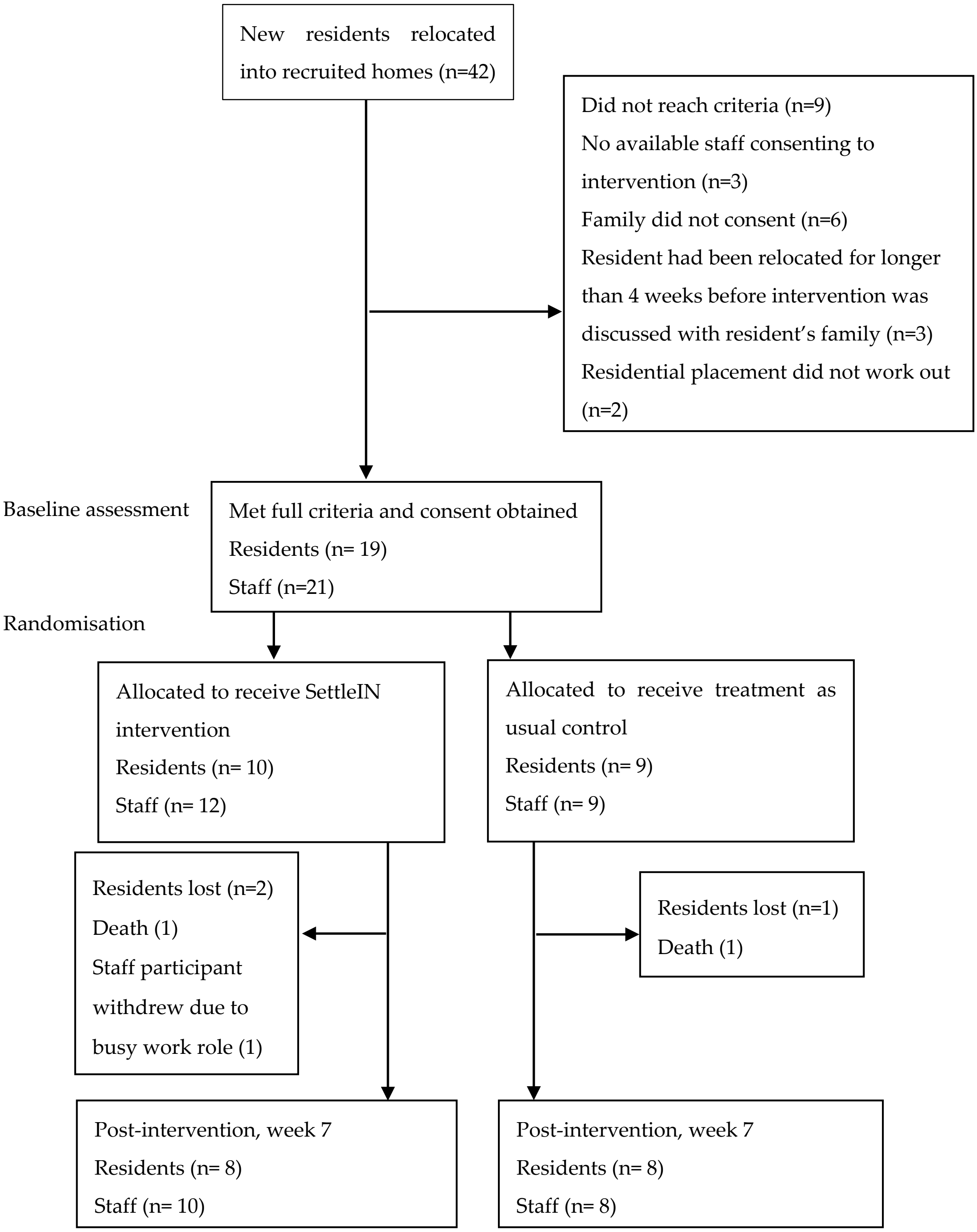

Figure 1. Resident participant flow chart.

3.1. Resident Characteristics

The age of resident participants ranged from 73 to 96 years (see Table 5 for a summary). The majority were white British and spoke English as a first language. In total, 74 percent of residents had an Alzheimer's disease diagnosis, as opposed to vascular or other forms of dementia. There were no significant between-group differences at baseline with regards to residents' demographic characteristics.

Table 5. Baseline resident demographic characteristics.

Characteristics	**Control Condition (N = 9)**	**Intervention Condition (N = 10)**
Age, mean (SD)	87.90 (7.20)	86.33 (6.58)
Number of days since relocation, mean (SD)	17.00 (9.30)	17.11 (7.83)
Gender, N (%)		
Female	9 (90)	7 (78)
Male	1 (10)	2 (22)
Ethnicity, N (%)		
White (British)	10 (100)	7 (78)
White (Other)	0 (0)	2 (22)
Religion, N (%)		
Church of England	3 (30)	5 (56)
Catholic	1 (10)	2 (22)
Jewish	3 (30)	0 (0)
No religion	3 (30)	2 (22)
First language, N (%)		
English	10 (100)	7 (78)
Other	0 (0)	2 (22)
Marital Status, N (%)		
Single	0 (0)	2 (22)
Married	0 (0)	1 (11)
Widowed	9 (90)	6 (67)
Divorced	1 (10)	0 (0)
Dementia diagnosis, N (%)		
Alzheimer's disease	7 (70)	7 (78)
Vascular	3 (30)	1 (11)
Other	0 (0)	1 (11)
FAST score, N (%)		
Mild dementia	1 (10)	1 (11)
Moderate dementia	1 (10)	1 (11)
Moderately severe dementia	8 (80)	7 (78)
Number of long term health conditions, mean (SD)	4.20(1.99)	3.00 (1.58)
Number of prescribed medications taking, mean (SD)	7.70(3.68)	8.00 (5.07)

3.2. Staff Participant Characteristics

The majority of staff were female and employed as care assistants, with the total number of years working in dementia care ranging from 9 months to 32 years (see Table 6). Their age ranged from 21 to 61 years. No significant between-group differences were found at baseline with regards to staff participants' demographic characteristics.

Table 6. Staff characteristics.

Characteristics	**Intervention Condition (N = 12)**	**Control Condition (N = 9)**
Age (years), mean (SD)	43.17 (13.72)	38.78 (12.85)
Gender, N (%)		
Female	11 (92)	7 (78)
Male	1 (8)	2 (22)
Job title, N (%)		
Care assistant/support worker	8 (67)	5 (56)
Senior care assistant	1 (8)	2 (22)
Team leader	1 (8)	2 (22)
Activities co-ordinator	1 (8)	0 (0)
Care manger	1 (8)	0 (0)
Years working in dementia, mean (SD)	9.88 (9.59)	7.97 (6.77)

3.3. Current Adjustment Support

All 12 care homes completed a checklist about the standard adjustment support they provided. None of the homes had a formal buddy system. Six homes showed new residents around on their first day but not as part of a continued orientation programme. Relocation assessments were used as an opportunity to learn new information about residents. Seven homes used the opportunity to ask about residents' preferences and four used this time to ask about residents' background information. None of the homes had special arrangements to contact family members around the adjustment period, unless there were urgent medical concerns. Five care homes also used additional methods to support adjustment including, introducing the resident to their keyworker and informing new residents of activities taking place within the home. One home also created memory boxes with new residents.

All of the residents recruited had attended a relocation assessment prior to moving into the care home. Two had a life book made, six were asked about their background information and 10 were asked about their preferences before joining the study. Notably during post-intervention interviews, staff commented that these methods were not as in depth as the SettleIN tasks.

3.4. Missing Data

Dementia-related impairments, physical illness or personal preference meant that ten residents (six, intervention; four, control) did not complete the Quality of Life in Alzeimer's Disease (QOL-AD) and Cornell Scale for Depression in Dementia (CSDD) measures at baseline. All residents were approached at follow up, and nine (five, intervention; four, control) were unable to complete the measures. Nine participants (five, intervention; four, control) did not complete the IRA measure; this measure could not be collected by proxy.

Attrition-related missing data involved three resident participants (two, intervention; one, control) lost to follow up due to death and one staff withdrawal (see Figure 1 for details).

3.5. Exploratory Analysis of the Efficacy of the SettleIN Intervention

3.5.1. Resident Psychological Wellbeing

On average, the control group experienced more depressive symptoms, as measured by the CSDD, at baseline compared to the intervention group (see Table 7). This difference was not found to be significant, $t(17) = 1.14$, $p = 0.27$.

Table 7. Mean pre- and post-intervention scores, mean change scores and statistical significance.

Characteristic	N	Baseline Mean (SD)	Post-Intervention Mean (SD)	Mean Change from Baseline (SD)	P	Effect Size
			CSDD			
Intervention	10	10.60 (5.18)	8.20 (5.07)	+2.40 (5.52)	0.17	0.70
Control	9	13.17 (4.57)	14.83 (4.30)	−1.67 (6.69)		
			QOL-AD			
Intervention	10	31.50 (5.21)	33.60 (6.17)	+2.10 (3.78)	0.43	0.47
Control	9	30.83 (4.37)	30.78 (5.65)	−0.06 (7.13)		
			IRA			
Intervention	5	6.40 (2.88)	11.80 (4.67)	+5.40 (6.23)	0.24	0.91
Control	5	8.00 (3.67)	8.00 (5.05)	0.00 (7.07)		

Note. (+) = improvement; (−) = deterioration. CSDD = Cornell Scale for Depression in Dementia; QOL-AD = Quality of Life in Alzheimer's Disease; IRA = Index of Relocation Adjustment.

The mean change score in the CSDD scores was compared between groups. Although a large effect size was found in favour of the intervention group (d = 0.70), independent sample t-tests indicated that this difference in mean change between groups was not statistically significant ($t(17) = 1.45$, $p = 0.41$).

3.5.2. Resident Quality of Life

The change in QOL-AD scores was compared between groups. A medium effect size was found in favour of the intervention group ($d = 0.47$). However, independent sample t-tests revealed that the mean change in QOL-AD scores was not significantly different between the two groups ($t(11.88) = 0.81$, $p = 0.43$).

3.5.3. Resident Overall Adjustment

At baseline, the intervention condition (n = 5) had a lower mean rating of adjustment, compared to the control condition; this difference was not significant ($t(8) = -0.77$, $p = 0.47$).

The change in IRA scores between assessment points was compared between the two groups. A large effect size was found in favour of the intervention group ($d = 0.\ 91$). However, independent sample t-tests indicated that the difference was not statistically significant between groups ($t(8) = 1.28$, $p = 0.24$).

3.6. Feasibility

3.6.1. Recruitment and Retention

There was a low uptake among care homes, with one in nine of the care homes contacted consenting to partake in the intervention. Within the recruited care homes, however, there was a reasonable resident uptake; approximately 50 percent of the newly relocated residents were recruited into the trial. The study had an acceptable level of attrition; three of the 19 residents were lost to follow up.

3.6.2. Implementation

All 12 staff participants in the intervention condition received one individual training session; the length of training was on average 75 min, but ranged between 60 and 90 min. The training and supervision sessions were conducted by the same principal researcher.

SettleIN workbooks were intended to provide information on programme implementation. Staff participants, however, were unable to fully complete SettleIN documentation due to their work loads and time constraints. Implementation could therefore not be assessed in this study.

3.6.3. Qualitative Analysis of Staff Interview Data

Analysis of the 12 interview transcripts revealed five themes and 13 subthemes (see Table 8).

Table 8. Themes and subthemes from staff interview data.

Themes	Subthemes
Organisational barriers	Existing heavy workload Existing task-focused approach Difficult to find the time Absence of managerial facilitation
Programme factors acting as barriers	Documentation was challenging Inflexibility of programme structure affects programme completion
Individual resident factors	Dementia severity affected implementation Resident preference affected engagement
Acceptability of SettleIN	SettleIN is difficult for staff SettleIN content is acceptable to staff SettleIN is positive for residents
Overcoming challenges	External support is needed Adopting problem solving

Organisational Barriers

Ten participants spoke about the impact of organisational barriers on programme implementation.

Existing heavy workload. Some described their job as *"stressful"* without the additional demands of the intervention. It seemed that implementing any programme on top of this felt like a significant addition.

> "care staff are inundated and under, sort of, are under it with their work pressures and their day to day routine". (P3)

Existing task-focused approach. Participants spoke about the multiple tasks that they needed to complete as part of their job role. There was a sense that they were unable to dedicate time to a single resident as multiple residents needed their attention.

> "I can't sit in one place and only do one thing because it's the work place". (P9)

It was especially difficult to implement the programme during a morning shift, as participants were preoccupied with care tasks during this time.

> "if there is still someone not up, you can't just go to do the programme, you have to keep going around". (P19)

Difficult to find the time. Many participants described their job role as '*busy*'. The lack of time available to do the programme meant that several participants had to work on the programme outside of work hours by coming in early, working during their breaks or working at home.

> "I had to work overtime, to catch up with work I couldn't do". (P17)

Absence of managerial facilitation. Four participants described how managerial factors prevented them from implementing the programme. They reported that their shift was frequently located on a different care floor to the resident or that they were not allocated to work with the resident participant.

> "I am nearly always in the last stage of dementia, when (resident) is in the first stage … so it was a lot harder to do any of the work". (P19)

Staffing provisions also seemed to be a problem, as low staffing levels meant that participants had more responsibilities.

Programme Factors Acting as Barriers

Another theme was that elements of the programme made it less feasible to deliver.

Documentation was challenging. Half of participants commented on the SettleIN documentation, describing it as "*confusing*" and "*difficult*".

> "the problem is only the writing. It's very stressful.". (P2A)

The documentation was perceived to be time consuming and more challenging than delivering the programme. Recommendations were made to reduce the volume of documentation or to move it on to an electronic format, a method of recording that was more familiar.

Inflexibility of programme structure affects programme completion. The weekly structure of the programme was seen as a barrier to programme completion. Outside factors such as annual leave, resident or staff illness meant that the programme was delayed and not completed within the four to six weeks.

> "it took me two weeks to finish week one itself." (P11)

One participant recommended that the programme should be more flexible as to accommodate these outside influences.

Individual Resident Factors

All of the staff who delivered SettleIN noticed the impact of resident factors on ease of delivery.

Dementia severity affected implementation. The programme seemed more difficult to carry out in the context of more severe dementia. Dementia severity was perceived to affect residents' ability to remember personal information, understand the questions asked and communicate their answer.

> "I cannot assume that she does not understand, but she is not responding back, just a smile". (P8A)

Some felt that the programme would be easier to deliver with residents whose dementia was less severe.

> "I think this is focused on the early stages of dementia". (P11)

In contrast to this, one participant felt that it was not the severity of the dementia that mattered, but rather the skill set of the staff.

Resident preference affected engagement. Five participants expressed difficulties carrying out SettleIN activities due to individual resident factors including mood, personality and physical wellbeing. On occasions, residents did not want to engage in conversation.

> "It was challenging for me trying to engage with her ... cos she was very 'no no no, I don't want to talk'". (P14)

Acceptability of SettleIN

All participants also spoke about the different feelings they had about the programme.

SettleIN is difficult for staff. Four participants discussed the elements of the SettleIN experience that felt testing. Two talked about having initial difficulties with the programme, struggling to understand it or feeling overwhelmed by it, which delayed implementation.

> "I found it quite daunting to get it up and running." (P3)

There was also a perception that others would find the programme difficult in the context of their busy work role, and one participant felt that, consequently, the programme was too lengthy for a care home setting. Two participants also spoke about finding some of the conversations with residents '*uncomfortable*', and one commented that the programme would be difficult for staff who were '*not as chatty*'.

> "I didn't feel that comfortable to ask her those kinds of things ... the more personal questions." (P11)

SettleIN content is acceptable to staff. In contrast, some described the intervention as "*manageable*" and "*easy*". Indeed, the majority spoke about their positive experiences of delivering SettleIN despite the challenges present. The programme was felt to be both "*helpful*" and "*enjoyable*". Specifically, participants spoke about enjoying the opportunity for more in depth conversations with residents and working more closely with family members.

> "It is nothing to not enjoy, because its, all the tasks, we are finding they are pleasant to do ... And it is just for the benefit of knowing the person more". (P8A)

Participants also spoke about how much they developed during the experience. SettleIN provided them with an opportunity to be exposed to new experiences and to learn more, suggesting that there was a demand for the intervention.

> "this sort of training will help people acknowledge more about dementia". (P6)

SettleIN is positive for residents. All staff participants felt that the programme had been of some benefit to the residents. The intervention helped them get to know residents more quickly and facilitated friendships with residents. Participants gave specific examples of changes they noticed in the resident as a result of the programme.

> "Independence. Definitely. She'll still come and say something, you know 'where's my room' and I'll go ' . . . You show me'. And off she goes . . . You just stand up here with a silly grin on your face! Yeah! She's doing this!" (P13)

Overcoming Challenges

Eight participants spoke about ways in which they had attempted to overcome the feasibility issues they faced.

External support is needed. Half employed colleagues to support programme implementation and some relied on others to complete care tasks whilst they delivered the programme. Those who conducted the programme in pairs found this to be particularly valuable.

> "If you have partner, your colleague who you can ask . . . they give you good ideas". (P8B)

Participants expressed that more support was required from the researchers for SettleIN to be fully implemented.

Adopting problem solving. When challenges were present, participants came up with various ways to try and solve these. Solutions included planning ahead, relying on family members, being flexible with the programme structure and using alternative means to document SettleIN conversations.

> "I have no time to write it down on the paper. But I have a list . . . for myself". (P2B)

4. Discussions

The study explored whether an enhanced version of SettleIN improved new residents' psychological wellbeing, quality of life and overall adjustment. In addition, it aimed to evaluate the feasibility and acceptability of SettleIN.

4.1. Summary of Results

4.1.1. Efficacy of SettleIN

Contrary to the initial hypothesis, and despite medium to large effect sizes, the change in scores between assessment points did not differ significantly between the two conditions for any of the three outcome measures employed.

4.1.2. Feasibility

SettleIN was found to be feasible with regards to staff acceptability and retention but not in terms of recruitment, wider organisational acceptability, and practicality. Most staff participants, who took part in the intervention, spoke about their satisfaction with the programme and the positive effects on residents. Organisational barriers, however, indicated that the intervention did not fit in with the wider care home culture. Organisational and individual programme factors meant that implementation could not be assessed as intended.

In the qualitative interviews, staff spoke about not having enough time to do the programme. They reported that staff shortages and difficulties getting breaks made the programme feel '*stressful*' to deliver on top of other care duties. The difference in organisational support between homes perhaps contributed to the highly contrasting staff feedback, with other staff participants finding the programme both enjoyable and manageable. This highlights the significant variation between care homes and the impact that organisational factors, such as managerial support [14], can have on intervention feasibility within care settings.

4.1.3. Comparison to the First SettleIN Study

The qualitative data from the first trial indicated that people found SettleIN to be too intensive in the context of organisational barriers. There were also difficulties engaging particular residents in SettleIN tasks and the reliance on family members delayed the programme. In response to the first trial, the current study reduced the length of SettleIN, included a focus on residents struggling to engage and removed dependency on family members.

Despite these changes, organisational factors remained a barrier to implementation and the impact of resident factors on programme implementation was noted. In contrast to Hayward and colleagues' [9] findings, only one participant commented negatively on the length of the programme. This study also found evidence that SettleIN was feasible with regards to retention, disconfirming Hayward, who found high rates of attrition.

4.2. Limitations

This study did not manage to recruit 30 participants as desired. The small sample size likely meant that it was underpowered to detect effects. The effect size measure Cohen's d was used to calculate the magnitude of difference between mean change scores of the two groups. Cohen's d is a widely used and standardised effect size estimate. However, it is recognised that Cohen's d is positively biased when sample sizes are small [25]. The mixed-methods design and qualitative results enabled bias to be mitigated. Despite the small sample size, credible and important information about programme feasibility, a chief aim of the study, was obtained.

Due to the methodology of the study, contamination effects may have occurred between the conditions. Each resident was recruited individually upon relocation; individual rather than cluster randomisation was therefore utilised for ethical reasons. To minimize contamination, staff in the intervention condition were instructed during training to not discuss the programme with colleagues or to use the programme with other residents.

To deal with missing data due to attrition, the last observation carried forward method was used. Although this is a widely used approach, it can introduce bias into the results [26]. The effect of the intervention may therefore have been either exaggerated or minimised for these participants.

The QOL-AD and CSDD have been shown to be valid measures for individuals with severe dementia [20,27]. However, the high proportion of residents unable to complete both measures in this study suggested that they are challenging for such individuals to complete. Staff by proxy reports were therefore relied upon. The measures selected had high levels of internal consistency for by proxies, in order to account for this. Training, however, can alter how staff perceive residents' behaviour [28]. Staff who received training learnt about the difficulties experienced by residents and so were perhaps more likely to notice these.

Furthermore, no formal measure of adherence was included in this study, which makes it difficult to determine whether staff in the intervention condition followed the programme as intended. The study was also unable to measure implementation as planned due to challenges with SettleIN documentation. It is therefore unclear whether the full benefits of the programme were achieved. Staff qualitative feedback, however, did provide us with information about the ways in which staff completed the programme.

Phase one of the current study involved conducting a consultation with staff participants from the initial trial. Understanding the context of an intervention is key to ensuring that an intervention is deemed accessible by those delivering it [10]. Staff turnover though meant that the researchers were unable to consult with numerous participants from the previous trial. Qualitative feedback from the first trial was used alongside the consultation to account for this. However, it is likely that valuable information was lost that could have been used to improve the programme, perhaps impacting on the feasibility findings of this study.

It is possible that common systemic challenges including staffing levels and competing care priorities mean that homes do not have the resources available to support the implementation of psychosocial interventions. Attempting to evaluate SettleIN in this study was therefore problematic, and ultimately unsuccessful, within this climate.

4.3. Implications for Future Research

There has been little focus in dementia literature on interventions that facilitate adjustment to residential care. Sury and colleagues [3] did, however, propose various strategies that could be employed to aid the adjustment process. The findings reported do not support their suggestions that such strategies result in significant change compared to residential care as usual.

This poses a dilemma, as the qualitative feedback obtained indicated that a programme of this nature is needed whilst also suggesting that the number of barriers to programme implementation was severe. A further feasibility trial could attempt to address this. However, it would require re-thinking and re-structuring the current programme, in line with staff qualitative feedback, without losing the integrity of the evidence base that informed the design [3]. Researchers would need to return to the development phase of the Medical Research Council framework [10] to make changes to SettleIN. Despite attempts to address these barriers during the design and development stage of this study, including involving managers and reducing programme intensity, the organisational and programme-specific barriers present remained formidable. It is recognised though that trailing complex interventions can be an extensive process and several pilot studies may sometimes be needed before a full-scale trial can be conducted [10].

In order to address the programme-specific barriers found, SettleIN documentation would need to be simplified and condensed. This is in line with recent research that has found that training programmes of reduced intensity are more satisfactory to staff [13]. The structure would need to be more flexible. A possible solution would be to extend the four-week framework. This could reduce the likelihood of disruptions, which often occur in this setting, negatively affecting programme completion.

Participants spoke about the need for additional support to facilitate programme delivery. To address this, staff could be trained in pairs to help with increasing programme flexibility. A greater focus on recruitment would also be needed in order to increase the sample size and power of the study. It would also be beneficial to consider alternative ways of measuring implementation and adherence, aside from staff self-report measures.

The impact of resident factors on programme completion came up here and in the Hayward study [9]. Hence, an optional module for residents who struggle to engage was developed in response. Unfortunately, this did not fully resolve the difficulties present. The views of the resident participants were not collected during either phase of this study. Interviews with residents might have provided information about their experience of relocation and the support they would have liked to receive. Moving forward, where possible, residents should be involved during programme development stages. This is in line with Medical Research Council recommendations which highlight the importance of service user involvement during intervention development [10].

There is a need for further research to focus on the validity and accessibility of outcome measures for people with dementia. Many residents struggled to complete the measures used in this study. Creating measures that are more accessible would allow us to gain more insight about the usefulness of interventions from the perspective of the individuals that they are designed for.

4.4. Clinical Implications

This study highlighted the negative impact that relocation can have on residents' psychological wellbeing, as over half of residents met criteria for depression at baseline. There is a need for adjustment support to be imbedded into care practice. Adjustment support currently offered by care homes appears minimal and often targets family members, rather than residents.

When delivering the psychosocial intervention, the majority of staff felt that they developed a stronger relationship with new residents and that the programme provided support and comfort to residents. These results point to the usefulness of staff-led psychosocial interventions for new residents and refer to factors that were perhaps missed when using quantitative outcomes. The organisational barriers present, however, showed the negative impact that heavy workloads and consequent time constraints have on care staffs' ability to deliver psychosocial care on top of routine care tasks. These organisational issues, alongside individual programme factors, meant that SettleIN was not feasible to deliver as part of standard care, reflecting the findings of Hayward. It was hoped that making changes to SettleIN, in line with the literature, would reduce the impact of such barriers. Instead, there continues to be a challenge in fitting these strategies into everyday care.

5. Conclusions

Overall, the changes in resident's quality of life, wellbeing and overall adjustment following SettleIN did not differ significantly to residential care as usual. The programme was not found to be feasible in its current format. However, qualitative data suggested that the intervention was acceptable to most staff and beneficial in some way for residents. Interviews with staff highlighted barriers to programme implementation stemming from organisational, resident and programme factors. An increased focus on reducing organisational barriers in care home research is required, so that such factors do not prevent programme implementation and change to care practice from taking place.

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Article

The Impact of Implementing a Namaste Care Intervention in UK Care Homes for People Living with Advanced Dementia, Staff and Families

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Abstract: Care homes can struggle to provide optimal care for residents with advanced dementia. Namaste Care provides a structured daily programme of physical, sensory and emotional care delivered by regular care workers. A three-year, mixed method process study of implementation and impact created a manualised Namaste Care Intervention for UK care homes (NCI-UK). This article reports on the impact of NCI-UK delivered consistently in five care homes for 12–24 weeks. Impact for residents was assessed using, pre-post data, showing significant positive effects for QUALID ($t = 2.92$, $p = 0.01$, $n = 31$) and CMAI ($t = 3.31$, $p = 0.002$, $n = 32$), alongside many qualitative examples of positive impacts on wellbeing, responsiveness and communication. Pre-post staff questionnaire data ($n = 20$) were not significant. Qualitative data indicated that NCI-UK is a positive staff experience, providing sense of purpose, improved wellbeing and relationships. The care homes reported benefiting from implementing NCI-UK in terms of reputation and quality improvement. Family interviews were also positive, relating to seeing the difference, improving relationships and being involved. NCI-UK can therefore be recommended as an impactful intervention for residents, staff and families.

Keywords: care homes; long term care; advanced dementia; namaste care; implementation; change; psychosocial intervention

1. Introduction

The European Association for Palliative Care suggests that optimal palliative dementia care should provide relief to the emotional, psychological, relational and physical challenges that people with advanced dementia face [1,2]. Care currently provided in care homes does not meet the needs of the majority of the most dependent residents, regardless of end of life status [3]. For example, untreated or undertreated pain is commonplace [4] leading to distress, disturbed behaviour, depression, decreased functioning and increased dependency [5]. In addition, people living with advanced dementia often become isolated, which leads to depression, withdrawal, and negative health outcomes. A new way of providing care as part of everyday practice is urgently needed [6].

The Namaste Care programme was developed in the USA by Simard [7], to fill a perceived gap in provision for the social and psychological support needs of people with more advanced dementia; recognizing that, whilst physical and medical care was adequate, consideration of these additional needs was absent. Namaste Care is a multi-component intervention, using aromas, lighting, sensory items and music to create the ambience of the Namaste Care space. Sounds, touch, objects from a variety of sources (including nature), and food and drink generate a feeling of connection and wellbeing. A review of the quality of scientific evidence underpinning the various activity intervention components of Namaste Care was undertaken [8]. This demonstrated a good evidence base for including these activities within Namaste Care for people living with advanced dementia.

A small but compelling amount of recent research indicates that bringing these components together in a structured way in Namaste Care may offer an effective means of supporting people living with advanced dementia. There is evidence from small-scale UK, US and Australian care home studies that Namaste Care alleviates symptoms such as agitation, distress, depression, disengagement and pain for people in advanced stages of dementia [9–12], and a consequent reduction in sedating medication has been suggested [13]. Family members have reported positive appraisals and improved quality of visits [11,13,14]. Studies have also reported improvements in staff-resident interactions [12].

Overall, the evidence of effectiveness is promising, but not yet conclusive. Nonetheless, the approach has high face validity across a number of countries with families, staff and people living with dementia. It also fits well with expert opinion [15] on what needs to be delivered to meet the end of life needs of people with advanced dementia. A feasibility study in two Canadian care homes demonstrated reduced pain and improved quality of life, as well as high acceptability of the intervention for staff and families, although noting that participants only received 72% of the intended 2-h twice-daily sessions [16]. The most recent feasibility randomised controlled trial (RCT) in the UK demonstrated that Namaste Care was potentially impactful for residents and acceptable for care homes, but 'dose' (implementation) varied substantially by care home staffing and physical environment [17].

Understanding how such interventions work in practice and how to implement them at scale is a challenge. A recent realist review of Namaste Care and other multi-sensory interventions [18] explored how such interventions could improve the quality of life for those living with advanced dementia. They concluded that interventions such as Namaste Care provide people living with advanced dementia a means of connecting with others and the world around them. This occurs through providing structured access to social and physical stimulation, by equipping staff to respond to residents' complex needs, and providing a framework for the delivery of person-centred care.

Implementing an innovative complex intervention such as Namaste Care within care homes is not a straightforward undertaking. The realist review [18] and the emerging evidence on the effectiveness of Namaste Care, however, indicated that a study to investigate the process and impact of implementing Namaste Care in UK homes was necessary and timely. We completed a three-year mixed methods process evaluation to identify an appropriate Namaste Care Intervention for UK care homes [19]. The central aim of our study was to determine the most appropriate intervention and optimal implementation based on the Namaste Care principles. The focus of this study was to highlight how care homes could successfully implement Namaste Care. The main outcome of the research was to provide robust guidance for care homes wishing to implement Namaste Care as part of everyday practice for people living with advanced dementia [20–22]. A further article is being prepared on the implementation process. As part of this larger study, one of our research questions was to assess the impact that Namaste Care had on residents, family members and staff in care homes overall within the care home case studies that successfully implemented Namaste Care. Implementation and effectiveness are intertwined in practice. We gathered qualitative and quantitative data on the impact on residents, staff teams and families. This adds to the evidence base for Namaste Care in the UK context and is reported here.

2. Materials and Methods

2.1. Study Design

The research aimed to elucidate the implementation processes of Namaste Care within six UK care homes that had made a positive decision to introduce the intervention as part of regular practice. As part of this, data on residents, staff and families were collected before Namaste Care was implemented and at regular intervals throughout the implementation process. The decision to include six care homes was taken as a reasonable number of case studies, given the design of the process evaluation and the scope of funding. It was not powered as an effect study. The numbers of residents, families and staff that provided data here are from an opportunistic sample from the participating care homes. The research questions addressed here are:

- What was the experience of Namaste Care for care home residents with advanced dementia?
- Did Namaste Care have an impact on resident quality of life and agitation for those that attended sessions on a regular basis?
- Did Namaste Care have an impact on sedating, anti-psychotic and analgesic medication levels for those that attended sessions on a regular basis?
- Were there any other benefits or negative impacts of Namaste Care noticed for those residents that attended sessions on a regular basis?
- What was the impact of the experience for care home staff delivering Namaste Care?
- Did Namaste Care have an impact on staff stress or job satisfaction?
- What was the impact for family members of their relatives with advanced dementia taking part in Namaste Care on a regular basis?
- What were the benefits or negative impacts of implementing Namaste Care to the care home as a whole?

2.2. The Intervention

Namaste Care is a complex intervention consisting of many component parts that can be applied flexibly to support residents with different individual needs and preferences. As an implementation study, we aimed to articulate the intervention in a way that would be grounded in the experience of UK care home providers. In the first phase of the research, we articulated the "Namaste Care Intervention UK" (NCI-UK) that practitioners could rely upon as an evidence-based intervention. It is based upon a literature review [8] of the evidence for Namaste Care components identified in the original source [7], alongside a UK Namaste Care practitioner survey and interviews [19] of successful implementation. Details of the specific components of how we described the NCI-UK to participating care homes are shown in Table 1. This was used as the basis for the implementation of Namaste Care in the context of the current study. The TIDieR [23] guideline description of the intervention is available as Supplementary Information 3 (S3).

Each participating care home received 2 days' training. This was open to all staff and visitors and delivered in the home by a member of the research team fulfilling the role of Dementia Practice Coach. Staff also received a guidance manual produced for the study [20]. Following the preparation phase, standardised instructions were given to each care home to guide their NCI-UK implementation:

- NCI-UK sessions should be provided at least once a day, every day of the week.
- Sessions should be approximately 2 h in length.
- Sessions should bring participants together in a group, rather than one-to-one sessions in people's rooms.
- Sessions should target people living with advanced dementia.
- Attendance/facilitation should be based on the usual staff-resident ratio in the home or unit. (e.g., 7 residents to 1 staff member).
- Staff delivering the NCI-UK session should be drawn from the care team (rather than activity staff or volunteers).

Three of the six care homes in the study were instructed to aim for two sessions a day, with others delivering only one. This was done to enable an exploration of the challenges and impacts afforded by the twice daily application. This was stipulated in the source text [7] as the optimal "dosage" of Namaste Care. However, twice a day frequency had been identified as a deterrent to implementation by practitioners [19]. In addition, care homes' training acknowledged the practice-ambiguity regarding the definition of 'advanced dementia', providing broad guidance (included as Supplementary Materials S1) rather than a diagnostic tool. This was because, as a process implementation study, the real-world decision-making and application of the intervention was of significance, and diagnostic tools for advanced dementia are not commonly used in UK care homes. To use a specific diagnostic tool for the purposes of exclusion as part of the study would therefore have introduced an element of abnormality from the usual process and thus prevented practically useful knowledge arising from the study.

Table 1. Key Components of the Namaste Care Intervention (NCI-UK).

	Component	Detail
The Namaste Care Space	A beginning and an end	Participants are welcomed individually into a relaxed, calm space at the start of a session. Towards the end of a session participants are activated through change to music, aroma and lighting.
	The overall ambience	The space is prepared in advance and attention paid to creating a calm, warm, welcoming and safe atmosphere.
	Natural light and the ability to alter light levels	Strong light levels are avoided, and it should be possible to adjust light levels. Additional atmospheric lighting may be used.
	Specific and calming aroma	Natural aromas are used rather than artificial ones.
	Background sounds or music	Gentle and relaxing sounds or music are used to create an atmosphere rather than providing entertainment.
	Background visual stimuli on a screen	Gentle and relaxing images are used to create an atmosphere rather than providing entertainment.
Basic activities	Physical comfort	Comfortable seating is provided. Pain assessments are undertaken with individual participants prior to sessions. Levels of comfort are monitored throughout.
	Expressive touch	Closeness is communicated using touch, through activities such as hand massage, foot massage, hand and face washing, foot washing, and hair brushing.
	Food treats	Opportunities are created so participants can experience favourite tastes, sensations and textures.
	Drink/hydration	Opportunities are created so participants can experience favourite drinks and ice lollies.
	Tactile stimulation	Opportunities to experience different touch sensations are offered, including soft blankets and fabrics.
	Nature	Opportunities are created so participants can engage with and experience nature such as plants.
Individualised activities	Involvement of the family	Families and visitors are actively welcomed to join the Namaste Care Intervention UK sessions.
	Personalised music	Playlists that are significant to individual participants are incorporated into sessions where appropriate.
	Significant items	Connection and interaction is enhanced by using objects that are significant to individual participants.
	Use of dolls	If participants enjoy interacting with or holding dolls then this is incorporated.
	Use of animals	If participants enjoy interacting with or holding animals (live or toys) then this is incorporated. If in-house or visiting animals are available, these can be included in Namaste Care Intervention UK sessions. Robotic simulations can be used if already available.
	Snoezelen/multi-sensory equipment	If sensory equipment/Snoezelen environments are already available, they can be used in Namaste Care Intervention UK sessions.

Outside of these boundaries, care homes were free to make decisions as appropriate (for example, to choose when a session would happen or how many residents would attend). This enabled the prescription of a 'standardised' intervention, but also an exploration of real-world decision-making required by care homes in their practical implementation, and thus the likely challenges of implementation beyond a research study.

2.3. Recruitment

Between February and April 2017, 11 care homes answered an expression of interest call for homes wishing to implement Namaste Care, following a series of Namaste Care workshops. From this group, 6 care homes (plus 2 reserves) were purposively selected based on: contrasting characteristics of registration and size. Stable management of 6 months was stipulated to aid implementation and feasibility of researcher travel to location was also considered.

The recruitment of individual residents into Namaste Care was managed at the care home level. We provided the home with general guidance for including residents in Namaste Care, which were;

- Living with advanced dementia (as determined by the care home) and experiencing one or more of the following: sensory or communication impairment, frequent falls, limited mobility, challenging behaviour.
- Not experiencing acute physical or mental health challenges at the time of recruitment.

2.4. Measures and Enquiry

In addition to demographic data for each care home and resident, the following qualitative and quantitative data were collected to examine the impacts of NCI-UK.

2.4.1. Residents

Data regarding dementia stage (using Global Deterioration Scale [24] GDS) were recorded at baseline. Analgesia, sedative and anti-psychotics medication use was monitored throughout. In addition, quality of life (quality of life in late dementia [25] QUALID) and agitation (Cohen–Mansfield agitation index [26]; CMAI short form) were proxy-rated by the same staff member at baseline and 12 weeks (and 18/24 weeks for those homes implementing longer). Staff also rated each resident's emotional wellbeing, physical wellbeing and awareness, before and after every NCI-UK session the resident attended, using the Namaste Short Questionnaire (NSQ) (included as Supplementary Materials S2). This was designed specifically for the project and is not a pre-validated measure. Qualitative observations of selected residents in each home occurred at 2 and 12 weeks (and 24 weeks for longest implementing homes). Observations used the PIECE-dem Observational Framework [27] within an NCI-UK session and a comparable time-period of regular care at each observation visit.

2.4.2. Staff

Questionnaire data were collected at baseline and 12 weeks (and 18/24 weeks for homes implementing longer) regarding job-related stress (Stress in General [28]), job satisfaction (Job in General [29]) and burnout (Copenhagen Burnout Inventory [30]). In addition, qualitative data were collected using monthly reflective diaries and semi-structured interviews at the end of the implementation period, reflecting on the experience and impact of implementing NCI-UK.

2.4.3. Family Members

Semi-structured interviews were conducted towards the end of implementation of NCI-UK, focussing on both their experience and observed impact on their relatives.

2.4.4. Care Home Overall

In addition to basic comparative demographic data, the care home gathered data on all NCI-UK sessions run in the home via the NSQ. They included: date, time and length of session, attendees, and the components used. The NSQ is provided as Supplementary Materials S2.

2.5. Data Analysis

Quantitative data were initially analysed using descriptive statistics to capture basic information about the level of participation by the care homes and residents, and characteristics of the sessions such as average duration and group size. For the data captured using the standard measures, baseline and post-intervention comparisons of scores were carried out using descriptive statistics, including mean and standard deviation, with additional significance testing through the use of paired and one-sample t-tests as appropriate. The type of data captured meant that a more detailed analysis was not required for the study.

Qualitative data (interviews, diaries and observations) were initially thematically analysed independently by two researchers (one involved in data collection, one uninvolved in the study). The two resulting and overlapping descriptive coding lists were then cohered into a single coding framework (list of codes and sub-codes) and applied to the data set using NVivo 12 computer software by a third researcher (involved in data collection). This enabled an in-depth descriptive and analytic exploration of data; sorting data to identify significant ideas (themes), their characteristics and contingencies from across the data set [31,32].

2.6. Ethical Permissions

Ethics approval, including an appropriate process for involving people living with dementia who were not able to provide informed consent, was sought from and granted by the Health Research Authority on the 05/09/2017 (South Central-Oxford C Research Ethics Committee; Reference: 17/SC/0430). The process for involving people living with dementia was two-step. Each possible participant's capacity to provide informed consent about the research was assessed, and their personal consultee (a close relative or someone who knows the person well, unconnected to the care or research team) advised whether the participant may wish to be involved in the research. Where a participant lacked the capacity to provide informed consent (as was the case with all participants), consultee advice and the individual's own wishes (as assent/rejection of research activity) expressed through words and behaviour were used to decide upon the individual's participation in research activity on the basis of the person's best interests in line with the Mental Capacity Act, 2005 [33]. This was undertaken throughout the duration of the study, in line with the principles of process consent as good practice when involving people living with dementia in research [34].

3. Findings

3.1. Participating Care Homes

Following recruitment, 6 care homes moved forward to the training phase of NCI-UK implementation. One home withdrew at this point due to inability to facilitate staff training; a reserve home was brought in as a replacement. The characteristics of the 6 care homes included in the implementation are provided in Table 2.

One care home participated through the training stage, but then withdrew. Five care homes completed as planned. Two homes implemented NCI-UK for 24 weeks, two for 18 weeks and one for 12 weeks.

Forty-eight residents were recruited into the study, adhering to the approved consent and consultee process. Table 3 provides an overview of the number of participants and the level of data collected in each home. In this findings section, both quantitative and qualitative data will be presented with regards to impacts of NCI-UK participation for different stakeholder groups. However, first, a brief overview of the implementation findings will be presented to enable contextualization of the impacts shown.

Table 2. Characteristics of participating care homes.

Care Home Name	Total Number of Residents	% Residents Funded by Local Authority	% Residents Living with Dementia	Care Home Registration	Size of Owner	Type of Owning Organisation
Azalea Court	69	64%	46%	With nursing	Large	For profit
Bluebell Drive (withdrew during implementation)	60	1%	43%	With nursing	Large	For profit
Clover House	80	1%	69%	With nursing	Large	For profit
Foxglove Place	24	21%	100%	Care only	Medium	Charity
Elm Gardens	80	81%	75%	With nursing	Small	For profit
Gardenia Lodge	59	53%	56%	With nursing	Small	Charity

Table 3. Number of participants and data type by care home.

Care Home	Azalea Court	Clover House	Foxglove Place	Elm Gardens	Gardenia Lodge	Totals
Length of implementation	24 weeks	12 weeks	18 weeks	24 weeks	18 weeks	
Data source and type						
Number of NCI-UK sessions run (NSQs received)	121	60	165	144	31 (i)	521
Resident participants (quantitative data)	7	7	14	13	7	48
Residents participants (observation data)	4	4	5	6	4	23
Staff-questionnaires	5	None (ii)	5	3	2	15
Staff-reflective diaries	7	1	4	11	6	29
Staff-interviews	4	2	4	5	4	19
Family/visitor-interviews	2	1	3	2	1	9

(i) Manager confirmed that, for a substantial period of time, sessions ran but no NSQ was completed; (ii) In this home, problems with the confidentiality of this data led to it being withdrawn from analysis.

3.2. How Successful Was the Implementation of NCI-UK in This Study?

The patterns, explanations, facilitators and barriers for implementation will be discussed in a separate paper (Latham et al. manuscript in preparation), which provides important insight into the realities of implementing an intervention such as this. However, a summary of the practical features of implementation is provided here, in order to contextualise the impact findings that follow.

All five homes continuing beyond the training phase implemented NCI-UK successfully over the specified time period, on a daily basis. In total, 528 individual sessions were recorded, as shown in Table 3. The frequency of returned NSQ (as a proxy for sessions run) by care home is shown in Figure 1. This illustrates that, broadly speaking, NCI-UK sessions became a regular part of care at each participating care home, although real world implementation involved missed days and blocks of time when it did not occur (or NSQ forms were not submitted). Only one care home (Foxglove Place) succeeded in running two NCI-UK sessions a day, although for different groups of residents. Those other homes requested to attempt two sessions a day (Azalea Court and Elm Gardens) cited insufficient staffing as the primary barrier to running a second daily session.

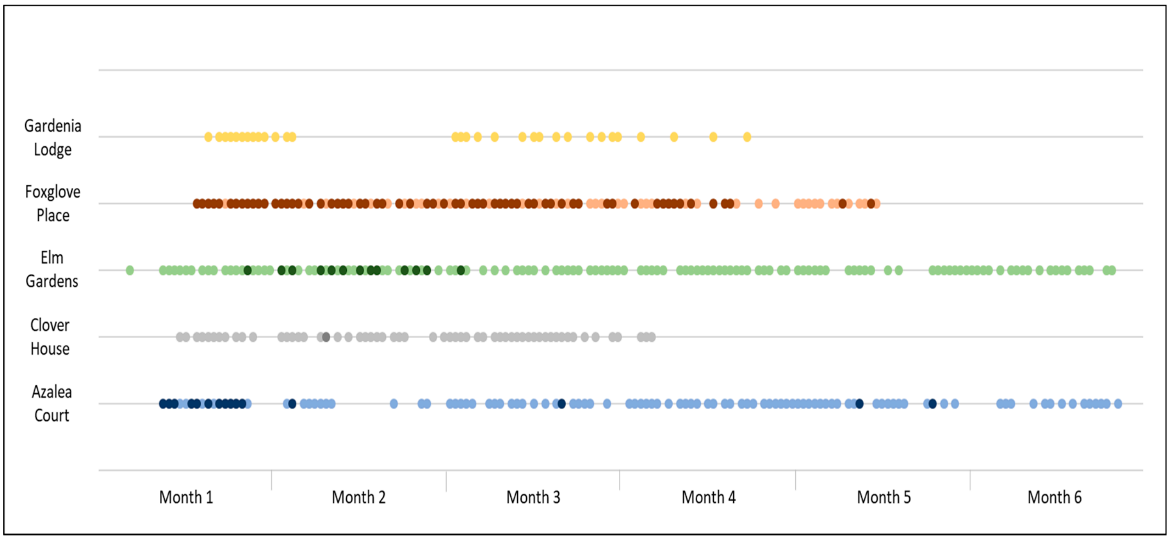

Figure 1. Frequency of NCI-UK sessions by care homes across implementation period (bold indicates 2 sessions in a day).

Table 4 shows the mean duration of sessions, timing, participant numbers, and staffing of the sessions in the homes. Sessions included residents with a GDS score ranging from 4–7, with the majority at stage 6 and 7 (most advanced dementia). Three homes (Elm Gardens, Foxglove Place and Gardenia Lodge) used a dedicated permanent Namaste Care space, with Azalea Court and Clover House choosing to convert a space each day.

Table 4. NCI-UK sessions as enacted by participating care homes.

Session Data Care Home	% of Sessions AM	% of Sessions PM	Mean Length of Sessions	Mean No. of Participants p/Session	Modal Number of Facilitators per Session (Inc. Volunteers)
Azalea Court	78.51	20.66	1 h 7 min	8.03	2
Clover House	96.67	3.33	1 h 29 min	9.15	1
Elm Gardens	88.89	10.42	1 h 32 min	6.36	2
Foxglove Place	58.79	39.39	1 h 49 min	4.75	1
Gardenia Lodge	0.00	100.00	1 h 59 min	3.97	1

Overall, implementation of NCI-UK in the five care homes was achieved in line with the standardised practice requested, but the flexibility enabling individual care home choice was cited by all care homes as a significant facilitator of successful and ongoing implementation, particularly with regards to timing, duration, staffing and participants to sessions. Implementation was considered to have been successfully achieved for the purposes of this study, as the norm of care for the duration of the study was to deliver a Namaste Care at least once a day to a particular group of residents in the home.

3.3. What Impact Did NCI-UK Have on Residents Living with Dementia?

48 residents were recruited into the NCI-UK intervention. The range of session attendance was 1–103 total sessions for the whole group. When examining the impact of NCI-UK 'low attenders' (those residents attending less than 10 sessions) were excluded from analyses, as it was considered that they had not adequately received NCI-UK. This left a sub-group of 36 on whom the following results are based, unless otherwise stated. The flow of residents through the study is shown in Table 5 below.

Table 5. Resident participant flow through the study.

Care Home		Azalea Court	Clover House	Foxglove Place	Elm Gardens	Gardenia Lodge	Total
Participant number at each stage of data collection	Recruited	7	7	14	13	7	48
	Excluded as 'low attenders'	1	1	4	3	3	12
	Included in final data set	6	6	10	10	4	36
	Full data returned QUALID	6	5	9	9	2	31
	Full data returned CMAI	6	6	9	10	2	33
	Full data returned NSQ	6	6	10	10	4	36

3.3.1. Quality of Life

Residents' QUALID data, based on complete data sets ($n = 31$), are shown in Table 6. It shows an average actual change score of −4.29 points and an average proportional change score of −0.12, indicating a statistically significant improved quality of life across the group of 31 residents. The paired samples t-test on actual change showed $t = 2.92$, $p = 0.01$ (df = 30). The one-sample t-test, on changes in proportional scores, showed $t = -2.48$, $p = 0.02$ (df = 30). On an individual level, 22 out of the 31 residents showed an improvement in quality of life, whilst 9 showed a decline on the measure.

Table 6. QUALID change from baseline to 12 weeks intervention for 31 residents.

Score (Lower Score Indicates Better Quality of Life. Minus Figure Indicates Improvement in Quality of Life)			
Baseline Range (Mean, Standard Deviation)	**12 Weeks Range (Mean, Standard Deviation)**	**Average Actual Change**	**Average Proportional Change**
12–39 (26.29, 7.69)	11–35 (22.00, 6.85)	−4.29	−0.12

Further data analysis showed that, for those residents in homes participating for more than 12 weeks, there was no further statistically significant improvement of participating in NCI-UK sessions over a longer period. That is to say, the positive impact of attending NCI-UK on quality of life is achieved within 12 weeks, and after that, any improvement is maintained rather than advanced.

3.3.2. Agitation

The CMAI scores for 32 participating residents showed a statistically significant reduction overall, and on all subscales from baseline to 12 weeks (Table 7). This shows an average actual change score of −4.81 points and an average proportional change score of −0.13, indicating a statistically significant improvement in quality of life at group level. The paired samples t-test on actual change showed $t = 3.31$, $p = 0.002$ (df = 31) The one-sample t-test, on changes in proportional scores, showed $t = -3.00$, $p = 0.01$ (df = 31). On an individual basis 23 out of the 32 residents saw less agitation over time; 7 saw an increase in agitation and 2 remained stable.

Further data analyses were undertaken for those residents who participated in the study longer than 12 weeks. Table 8 reports the statistical significance of the proportional change to scores at these additional intervals. This shows that there continues to be a smaller improvement on the overall score after the first 12 weeks of the intervention, with the majority of this appearing to be within the verbal agitation sub-score.

Table 7. CMAI scores from baseline to 12 weeks intervention for 32 residents.

CMAI over All Scores			
Baseline Range (Mean, Standard Deviation)	**12 Weeks Range (Mean, Standard Deviation)**	**Mean Actual Change**	**Mean Proportional Change**
14–54 (25.81, 10.03)	14–42 (21.00, 6.99)	−4.81	−0.13

3.3.3. NCI-UK Impact on Individuals during Sessions

Across a total of 528 individual NCI-UK sessions, staff recorded their perception of residents' physical wellbeing, emotional wellbeing and alertness before and after participation in each session. Using total scores from all recorded sessions the effect of sessions on these dimensions for 36 participating residents are shown in Table 9. Staff perception was that there was a positive impact on residents in all dimensions, with staff either recording stability or improvement. This is a positive outcome, although caution is required as staff are more likely to report their actions as having a positive impact than not.

Table 8. Statistical significance of proportional change to CMAI scores over time.

	Baseline to 18 Weeks		**Baseline to 24 Weeks**		**12 to 18 Weeks**		**12 to 24 Weeks**		**18 to 24 Weeks**	
CMAI Score	**N**	**Significant Change?**	**N**	**Significant Change?**	**N**	**Significant Change?**	**N**	**Significant Change?**	**N**	**Significant Change?**
Aggressive	29	Yes ($p = 0.02$)	15	No ($p = 0.66$)	28	No ($p = 0.35$)	16	No ($p = 0.23$)	16	No ($p = 0.85$)
Physically nonaggressive	29	Yes ($p = 0.02$)	15	No ($p = 0.39$)	28	No ($p = 0.41$)	16	No ($p = 0.08$)	16	No ($p = 0.14$)
Verbally agitated	28	Yes ($p < 0.01$)	14	No ($p = 0.70$)	28	Yes ($p = 0.04$)	15	Yes ($p = 0.04$)	15	Yes ($p < 0.01$)
Total	28	Yes ($p < 0.01$)	14	No ($p = 0.40$)	28	No ($p = 0.85$)	15	Yes ($p = 0.02$)	15	Yes ($p = 0.04$)

Table 9. Staff perceptions of resident wellbeing across all domains of NSQ data.

	Physical Wellbeing			**Emotional Wellbeing**			**Alertness/Awareness**			**Total**		
	Improve	Stable	Decline	Improve	Stable	Decline	Improve	Stable	Decline	Improve	Stable	Decline
Number of residents ($n = 36$) who scored more than 50% of total sessions in this domain	6	30	0	16	20	0	14	22	0	22	14	0

3.3.4. Medication

Sedative, anti-psychotic and analgesia medications were tracked for participating residents across the implementation period, enabling the calculation of changes in dose administered between baseline and 12 weeks. Low levels of these medications at baseline and few changes during intervention meant that no impact of the intervention could be seen within the sample.

3.3.5. Qualitative Data

The qualitative data confirm the quantitative impacts identified. Every care home reported positive impacts for residents that related to physical wellbeing, mental wellbeing and responsiveness and communication. No negative impacts were reported, although some less than optimal situations were observed and discussed, with some residents identified as not 'taking to' NCI-UK. Of particular note, these impacts were seen across all the homes, regardless of their varied experiences and choice within implementation. This suggests that impacts are seen even with the flexibility allowed within our intervention design; whether a home ran one or two sessions per day; when, where and whom they chose to deliver it. In addition, these positive impacts were seen in both care-only and nursing home settings, suggesting that NCI-UK is a useful approach in both settings.

A summary of the impacts as themes identified across all affected groups is provided in Table 10 for ease of reference, and then a detailed explanation of each theme follows.

(i) Physical wellbeing

All homes reported both individual examples and generalised trends of residents eating better, showing weight gain and drinking more. In particular, the environment and slowed pace of NCI-UK sessions resulted in a quieter and far more relaxed atmosphere throughout, and this was said to circumvent behaviour from some residents that obstructed their ability to eat and drink in more routine mealtime situations, such as increased stress and distraction, as this example showed

> We've found that a lot of the residents who have come (to Namaste Care) have been taken off food and fluid (monitoring) because of the drinks that we have, the biscuits, chocolates and whatever we have... So (Resident) his intake, he has 400 mL of milkshake, he'll have a banana, an orange, a couple of biscuits and that every day has made such an impact on him . . . Another (who used to be known to hide food rather than eating it) she has a banana every day, she doesn't hide it she eats it all, a little fudge bar, a whole milky way. I've never seen her eat a whole biscuit and she actually had a whole one yesterday!
>
> Namaste/Activity Co-ordinator—Clover House

The constant presence of snacks and drinks throughout the sessions and the staff member's ability to stay focussed on those individuals in the room, returning time and again to a single person, ensured that more opportunities for eating and drinking were presented to residents in a session than might normally be offered and taken up within regular care.

Namaste Care also impacted positively on residents' physical wellbeing because of the relaxation it encouraged. This was of particular benefit for those residents who spend long periods of time walking in the home;

> And she's getting a lot of rest to her feet because you know with her . . . she's walking 100,000 steps a day, really. So she is (resting in Namaste Care) and her feet are slightly better as a result. But even slightly better has got to be good!
>
> Namaste Care Worker—Elm Gardens

In each of the care homes, residents who were known to be hard to 'settle' and who would often remove themselves from group activities, mealtimes or communal areas were reported to be willing and able to spend longer periods of time within Namaste Care sessions than initially expected. For some individuals, this was not an entire session, but still long enough to allow some relaxation, connection with staff and a snack or drink. In addition, over time, some residents transformed from 'intermittent' attendees who brought themselves in and out of sessions, to attendees who stayed for most or all of a session, suggesting that increased familiarity contributed to this effect. This is particularly significant because these residents were generally those on the 'cusp' of advanced dementia (GDS of 5)—with lower physical levels of disability—who may have been excluded had inclusion criteria been enforced by the research team rather than pragmatic care home level decision-making being encouraged.

Table 10. Summary of qualitative impacts of NCI-UK implementation for all affected groups.

Qualitative Impacts of NCI-UK Implementation	
Themes	**Sub-Themes**
RESIDENTS	
Improvements in physical wellbeing	- eating better - weight gain - relaxation - increased mobility where restricted
Improvements in mental wellbeing	- reduced displays of anxiety - reduced frustration - increased positive emotional expressions
Improvements in responsiveness/connection	- increased verbal communication - use of words - increase in eye contact - increase in spontaneous verbal expressions
STAFF	
Increased sense of purpose	- pride in Namaste Care - reflection on other areas of care
Improved staff wellbeing	- opportunity for relaxation - provide meaning to work - 'magic moments' with residents
Developing positive relationships	- between staff and residents in session - between staff and residents outside session - between family and staff
FAMILY	
Seeing a positive difference in their family members	n/a
Improving relationships	- with their resident - with staff members
Being involved and utilised	- resource donations - invitations to training - volunteering in sessions - sharing information - sitting in on sessions
CARE HOME	
Improved reputation	- to demonstrate to visitors - opinions of external professionals
Contribute to a journey of improvement	n/a

Attendance at NCI-UK also positively affected some residents' movement and circulation, particularly those with high levels of physical disability, a factor that was attributed to the regular use of massage within the sessions;

> (Resident) with very poor mobility in her hands ... to the point where she wasn't even stretching them out ... So she was getting hand massages almost daily and it was helping her. She was not as bad as she was, she was using cutlery again.
>
> Activity Co-ordinator—Azalea Court

Hand massage was by far the most common form of massage used in sessions, followed by foot and leg massage. In homes where staff members had experience of other forms of massage then shoulder, head and seated back massages were also observed to benefit attendees. Massage occurred for most residents in every session, forming the central 'activity' of the event. However, in each home, there were one or two individuals who staff identified as not liking massage (usually interpreted through verbal or physical rejection of attempts).

(ii) Mental wellbeing

This was the most frequently reported impact, perhaps in part because it is an impact that can be seen and heard immediately. The most significant effect appeared to be in reducing levels of anxiety for residents and the behaviours that may stem from that, such as anxious phrasing, calling out, crying, frantic searching and wanting to leave the space;

> A resident who constantly repeats the phrase 'please help me, Lord' is able to relax and fall asleep in Namaste. She entirely stops the repetition of the phrase ... she seems so much less agitated in the sessions ... Another resident who pulls her hair out and is constantly agitated during the day ... completely relaxes during the session and does not pull her hair out at all.
>
> Staff Reflective Diary—Elm Gardens

In a number of cases, these effects were quite profound and served as early learning points for staff in understanding the benefits of NCI-UK, and reflecting on care practice overall. Importantly, it appeared to be a combination of both the calm atmosphere and the attentiveness of staff within NCI-UK sessions that led to this impact, as anxiety or behavioural symptoms did not disappear, but would re-emerge during a session (particularly if a noise/event—such as a door slamming—disturbed an individual). However, within NCI-UK, compared with regular care, this was identified and attended to (usually with a comforting word or touch) much more quickly by the Namaste Care worker, thus preventing an escalation of the behaviour and impact on others.

Further to this, a longer-term impact of reducing physically challenging behaviours outside of NCI-UK was also noted for particular residents in three of the homes. This was commonly attributed to an overall reduction in anxiety and distress, and improved relationships with care staff via NCI-UK sessions. In one home with a permanent Namaste Care room, the room was also used at other times for a particular resident who showed physically challenging behaviours, in recognition that its calming effect and association appeared to enable the person to relax.

In addition to reducing negative emotional states, sessions also saw an increase in positive emotional expression from residents, in the form of smiles, touch, positive words, noises and laughs;

> One lady who hardly speaks or shows any emotion normally, with hand massage and one-on-one time she is clearly very happy in a chilled environment and to see her smile is a joy!
>
> Namaste Care Worker—Foxglove Place

Again, this is an impact that was reported to continue beyond the sessions themselves, with staff sharing examples of residents, who were more likely to show signs of recognition at other times, or offer spontaneous smiles, speech or hugs. Whilst it is not possible to tell whether this effect is due solely to NCI-UK on residents (it is also possible that staff subsequently interacted differently with residents), it is notable nonetheless.

(iii) Responsiveness and Connection

Following on from the positive impacts on mental wellbeing, Namaste Care appears to improve residents' responsiveness and ability to connect. For some residents, this manifested as verbal communication, either from a non-verbal state, to using words or increased clarity and purpose in language. In all homes, staff were able to recount stories of individuals who verbalised in unexpected and positive ways within the first few weeks of attending Namaste Care, and these functioned as important success stories across the home. In particular, these verbal revelations often provided significant opportunities for staff to reflect on the approaches and expectations within regular care that did not afford such connections. In addition, non-verbal connection and responsiveness also increased. This included increasing eye contact, smiles and spontaneous expressions, as shown in this example;

> She stroked the student's hand and tapped. She continued to hum, tapping both her feet and her eyes opened widely whilst smiling … She (beckoned) the student to give her the other hand and she danced, holding them both whilst sat down. She sang the words to the song and continued to tap her feet
>
> Observation, Resident Y—Azalea Court

Non-verbal connection was unsurprisingly noted most vividly in those residents who had little verbal communication remaining. For these individuals, the recognition of purposeful eye contact or smiling became an important route for communication between staff and resident.

Furthermore, NCI-UK improved connectedness by encouraging interactions between residents, as well as with staff. On the simplest level, in each home there were individuals who were willing and able to stay in NCI-UK sessions when usual communal social activities resulted in withdrawal and isolation. Within individual sessions, NCI-UK also prompted some increase in residents' interactions with each other, through smiles, greetings, waves and occasional verbal exchanges. However, it should be noted that there were occasions observed where lack of thought about placement of residents within NCI-UK sessions meant that antagonism could arise, especially if one resident was more verbose or physically active than their neighbour. These issues continue to be as important a consideration in NCI-UK sessions as in any other communal situation.

3.4. What Impact Does NCI-UK Have on Staff Working in Care Homes?

The 20 staff who provided data in the study were drawn from staff teams affected by the implementation. A small sub-group of these staff participants ($n = 6$) were directly involved in regularly delivering NCI-UK sessions in their home. Questionnaire data on work-related stress, job satisfaction and burnout showed no significant changes from baseline to 12 weeks. Overall, based on the measures used in this study, implementing NCI-UK does not appear to result in either positive or detrimental effects on staff within the implementing care homes.

The qualitative data, however, did show that delivering NCI-UK was an overwhelmingly positive experience for staff. This impact was related to three areas of practice: a sense of purpose in resident care; improvements in staff wellbeing; and developing positive relationships.

3.4.1. A Sense of Purpose in Resident Care

The process of implementing and delivering NCI-UK in their homes appeared to engender in staff a sense of purpose in resident care. This purpose manifested in two ways. Firstly, it was noted in several homes that there was a real sense of pride from staff to be doing something innovative and impactful for residents, as this interviewee commented;

> It was wonderful and the staff I think have really bought into it in a big way, not just (manager)... They all just seem to be so enthusiastic!
>
> Relative—Gardenia Lodge

Management also noted that staff directly involved with the planning and implementation of Namaste Care in particular showed signs of increased confidence in themselves and belief in the approach, becoming advocates for residents through that process.

Secondly, this pride and enthusiasm extended beyond NCI-UK itself to other areas of care, identifying improvements that could be made and increased expectations as to what could be achieved for residents. This was particularly so at Elm Gardens, a home whose management had explicitly spoken about the desire to improve care overall at the home;

> My staff are definitely starting to 'walk taller'. There is a new buzz about the place … Staff are beginning to take more pride and ownership in the quality of care they are delivering.
>
> Director—Elm Gardens

However, it was here that the potential for negative impact on staff could occur, because the training for and focus of Namaste Care encouraged reflection on existing standards of care for people living with advanced dementia, leading to the acknowledgement of less than optimal practice. This occurred in all the homes but was managed to good effect by allowing staff the time within training and planning to express these reflections and refocus on future practice.

3.4.2. Improvements in Staff Wellbeing

The most direct and frequent effect, occurring in all the care homes, was relaxation for staff when spending time in the slow-paced, calm environment of the NCI-UK session, as this staff member explained;

> Caring is a very stressful job … it sometimes gets you down and you're tired, you're exhausted … but I think being able to do the Namaste sessions … it gives you a bit of a break, gives you that one to one time and in those sessions you do calm down as well. You feel a bit of stress relief and I think that's amazing.
>
> Namaste Care Worker—Elm Gardens

It is important to note that NCI-UK sessions were described by facilitating staff as hard work and emotionally draining, and as such, this was a different type of stress to that presented by the more usual hectic pace of care work. It was the change in the nature of resident contact and surrounding environment that provided the sense of relaxation, rather than NCI-UK sessions being objectively 'easier' work. This is a significant distinction, given the initial contrasting perceptions in all homes between those running sessions and those continuing with regular duties 'on the floor'; perceptions that coalesced once more staff had run sessions themselves.

The next impact on staff wellbeing was indirect: being part of providing Namaste Care gave some staff a very special meaning to their work.

> It's a wonderful, wonderful thing … It's the ability to engage with another person on a much deeper level than every day … to reach them in ways that you can't normally reach them. I think it's a privilege to do it. … It's for the betterment of everyone, because we're reaching them and we're making a difference but they're also making a difference to us.
>
> Namaste Care Worker—Elm Gardens

From the outset, NCI-UK clearly suited those staff who sought this type of connection as part of their roles, and this influenced those who put themselves forward to attend training and lead implementation. However, in all homes, there were staff who emerged after this initial phrase, as particularly adept at, and rewarded by, this type of work.

Building on the sense of meaning that NCI-UK gave some care workers, an impact for staff was also seen through the 'magic moments' they shared with residents, as described here;

> It's had a big impact on me. Because to see them enjoying it, that to me, to see somebody . . . I've got tears in my eyes now haven't I? It makes me feel as if I'm doing a good job and at the end of the day that's what we try to do every day isn't it?
>
> Namaste/Activity Co-ordinator—Clover House

In addition to contributing to staff's sense of worth about their jobs, these magic moments were a significant part of the ways staff communicated with each other and with families about the impact of NCI-UK, and as such helped to build momentum and interest in continuing to implement NCI-UK in the care home. It is important to note that finding these meanings and moments with people could be highly emotional for staff, and as such, support was needed to ensure this does not become a negative burden for them. As one Namaste Care worker said;

> It's very emotional, because you're with that person and they're going through . . . they're dealing with dementia, they're at the end of their life. It's hard to describe, but I mean, there are a couple of times where I've sat in (Namaste room) and can't help but cry. You know, it's a, I don't know . . . it's a happy emotion. Because you're doing good and you're helping them get through.
>
> Namaste Care Worker—Elm Gardens

3.4.3. Developing Positive Relationships

Building on the positive impacts on staff's own wellbeing was a contribution that it made to enhancing positive relationships throughout the home; something likely to have a long-term effect on both staff and resident wellbeing. This started with improvements in relationships between staff and residents;

> I'm finding that, as I'm doing (Namaste Care) the bond has grown much stronger. For example (resident) he sees me in the corridor, he'll come up and give me a hug, which he didn't used to before . . . the other day he got really upset. He was crying in the lounge and he came over to me and just threw his arms around me. He just wanted that closeness, a hug. That's all come from Namaste.
>
> Namaste/Activity Co-ordinator—Clover House

The positive relationships also extended to the whole staff team in the home, as many housekeeping and kitchen staff became involved with ensuring NCI-UK sessions were delivered. In addition, many relatives also commented on improved relationships with staff, through communication and involvement in NCI-UK.

3.5. What Impact Does NCI-UK Have on Families Visiting Care Homes?

The impact of a care home implementing NCI-UK on the families and visitors of residents, will of course be tied to the impact it has on residents directly. However, it is important to consider these independently, as family members can be a key mediator between the care home and resident, involved in and affecting the process of implementation for an intervention. In particular, as NCI-UK is aimed at those people living with advanced dementia, the sensitivities and impacts on family members become particularly significant, as they may be the primary contact between the person and the outside world. Within this study, the impact of NCI-UK implementation on families was primarily positive and related to the following aspects: seeing the difference; improving relationships; and being involved and utilised.

3.5.1. Seeing the Difference

The first and foremost impact for relatives was seeing a difference in their family member who was attending NCI-UK. This gave them a positive feeling at a stage of dementia that can be very challenging for families to adjust and live with;

> For me, I have noticed some things with my mother because before Namaste I used to massage her hands etc ... and she was usually quite placid then, but now, she kind of tries to respond ... and just now I went to see her and she was kind of, you know, exploring my finger. You know those are very small little things, but those things didn't happen before Namaste.
>
> Relative—Clover House

Seeing the difference also extended to an awareness of a renewed focus on their relative from the care home and staff through NCI-UK, including increased communication about daily events, sharing stories about 'magic moments', and a general sense of increased knowledge and concern for the relative. This occurred in all of the homes.

3.5.2. Improving Relationships

Extending on from seeing the difference for their relative, Namaste Care also had an impact by improving the relationship between the relative and their loved one. Several identified changes that had occurred in the way they engaged with their relative as a result of attending training or seeing Namaste Care in action;

> I will be honest, doing the whole training myself has encouraged me to do more things with him in that way. So when it snowed, I took snow into him., in a bowl and put his hands in it ... I planted a window box for him and we put lavender in so I can rub the lavender and give him that smell ... It was a real eye opener for me, because as a relative of somebody with dementia you get nothing ... It's given him more quality of life through what the home have done but also making me think differently. It was a real light bulb moment for me.
>
> Relative—Elm Gardens

Not every home had relatives take part in training, but where they did, positive stories emerged, both in terms of relatives learning new skills and care homes and staff gaining new insights into relatives. This suggests an extended effect of improving the relationships between the family member and the care home overall. Indeed, those care homes who did experience family members attending training recommended it to others as a positive course of action. In particular, both families and care home staff highlighted that identifying the small things that could make a difference to a person at the later stages of dementia was enlightening, and enabled common ground to be established between staff and family members, at a time when 'good care' could be hard to articulate.

3.5.3. Being Involved and Utilised

Contributing to improved relationships was the extent to which NCI-UK provided a practical way for the care homes to ensure that relatives and visitors could become directly involved with this aspect of home life. Across the five homes, visitors were utilised through a wide range of methods, including: asking for resource donations: inviting them to training; volunteering in sessions; sharing information at visits; or sitting in on sessions.

> Those relatives who do come for sessions and are very much involved in Namaste, they want to stay with their relative while they're in the room and they want them to have Namaste and they say how important it is that they have Namaste.
>
> Activities Co-ordinator—Foxglove Place

This involvement was reflected on by all homes as a positive aspect of NCI-UK, regardless of how in-depth involvement was. Even those homes where involvement was primarily through resource donation only, care homes regularly expressed surprise and gratitude for the commitment relatives demonstrated. Only one home elected not to use family members in this way, and this was because of a previous donation request that had finished recently.

Moreover, family involvement could also become a reinforcing element for NCI-UK and care improvement in the home with family members and visitors, once on board, becoming strong advocates for Namaste Care and the home. The director of Elm Gardens reflected on their journey with family members and the impact of the NCI-UK implementation:

> People who were quite negative maybe 20 months ago, when (organisation took over the home) there was a negative attitude. But those very ones were the ones that were very, very positive at the last meeting and actually said 'we don't need negative people in the room'. A lot of that is down to the Namaste programme and what they've seen ... in terms of engagement ... It's a palpable, tangible difference.
>
> Director—Elm Gardens

3.6. What Impact Does NCI-UK Have on the Care Homes as a Whole?

Just as it is important to understand the impacts of an intervention on staff and residents, so it is important to understand the effect an intervention has on the care home as a whole. This is because it helps to enlighten the motivations behind adopting an intervention and any possible pitfalls and advantages to putting work into implementation of an intervention, such as Namaste Care. There was no significant impact on the number of incidents (falls, accidents or other incidents); unplanned hospital admissions; number of resident deaths; number of vacant beds; and staff turnover over the implementation period. However, the qualitative data again indicated a positive impact on how the care home as a whole benefitted from NCI-UK relating to the home's reputation and the home's journey of improvement.

3.6.1. The Home's Reputation

The managers and deputies of all but one care home identified positive, reputational impacts of implementing NCI-UK. Clover House was the only care home that did not, and this could be because only the activity co-ordinators engaged with the researchers to a significant extent, and their perspective will necessarily be more inward facing than more senior staff. The reputational impact was noted to occur in two ways. Firstly, as something that could be demonstrated when visitors came to be 'shown around' the home;

> What's also been lovely is when we've had open days and done show arounds, people have been very impressed because they've walked past a session ... peering through and saying what's going on in there? It's been a bit of a selling point for our home ... we've (even) had community psychiatric nurses come up and go in a session.
>
> Manager—Azalea Court

Four out of the five homes reflected that they routinely showed NCI-UK sessions/rooms in this way, explaining that it was seen as a selling point, something to prompt conversation and a point of pride for the home.

Secondly, this impact was also felt in terms of how external parties perceived the home, whether the regulator, local authorities or visiting professionals;

> Good feedback from CQC–says that the home feels 'well-loved'. Honestly, I feel like (Namaste Care) is one of the most effective things that I've done in the last 20 years ... I have relatives come up to me and say 'what do you think about that?'
>
> Director—Elm Gardens

Several care homes shared stories of individual visitors who had shown curiosity regarding the sessions, providing the home with an opportunity to share the rationale and research participation. In addition, visitors sometimes commented on the uniqueness of the sessions, enabling homes to feel that they stood out amongst their competitors. Two homes took the opportunity to engage local authorities and communities in their NCI-UK preparation and launch (such as inviting key people to information sessions), again identifying an opportunity for using NCI-UK as a tool for influencing external perceptions of the home.

3.6.2. The Home's Journey of Improvement

A second area of impact for care homes was the extent to which NCI-UK could support wider changes to care practice and become part of an improvement journey. Whilst identified by all homes in a general sense, this was an aspect overtly relevant to Elm Gardens, as from the outset, they were explicit about their overall desire to improve and using Namaste Care as a vehicle for that. The Dementia Practice Coach recognised this;

> (Elm Gardens) I think is a really lovely example … because of the place that they've come from and where they've gone to. They have a lot of residents with advanced dementia who were, I think, probably a kind of classic example of receiving good personal care but not necessarily the emotional and psychological care. And that's the bit they've done brilliantly, and they're really proud of themselves. (Namaste Care)'s become part of their identity.
>
> Dementia Practice Coach–Interview

This is significant because it illustrates how a specific intervention can be incorporated into that wider agenda; something of relevance to many care homes and provider organisations. Whilst the nursing home registration of Elm Gardens may have helped this wider impact (because it was applicable to a wider resident group than some other participating homes), it is important to note that Elm Gardens also worked hard to explicitly translate elements of NCI-UK from their dementia unit and specific residents to other non-dementia areas of the home (such as residents with physical disabilities), suggesting that some focussed effort may be required to 'activate' NCI-UK as part of a whole-home improvement journey.

4. Discussion

Overall, this process implementation evaluation study demonstrated that Namaste Care has a positive impact on residents, families, staff and the care home environment, when it is implemented on a daily basis in UK residential and nursing homes. All five care homes continue to implement Namaste Care on a regular basis, suggesting a utility and practicability beyond this study. This was a relatively small study, and impact has yet to be evaluated through a fully powered controlled trial within the UK. Nonetheless, the quantitative and qualitative data presented here from residents in care homes of different types suggest that the intervention has much to offer. The following specific areas are noteworthy for care home practitioners and future research.

4.1. The Intervention

There is always an inherent tension in complex intervention research between standardising the intervention for research purposes but providing flexibility, so that the intervention can meet diverse needs that exist in practice. Those living with advanced dementia in care homes present with diverse, complex and changing needs. Care homes themselves present diverse contexts for care delivery, in terms of resources, knowledge and skills. Research into Namaste Care will lead to more definition of the intervention and potentially a greater divergence within the detail of those interventions. The NCI-UK intervention described here and in the implementation manuals [20] operationalised Namaste Care in greater detail than set out in the source text [7]. The NCI-UK intervention manual was developed from a rapid evidence review of the efficacy of sensory interventions for those living with advanced dementia [8], alongside a survey and focus groups of practitioners attempting to use Namaste Care in UK care homes [19]. A contemporaneous UK RCT Feasibility Study [17] utilised a realist review [18] and refinement through workshops and consultation, to develop their Namaste Care intervention manuals. Both these research studies have led to remarkably similar detailed interventions, despite their different focus of enquiry. They both provide care home practitioners with a similar toolkit of approaches to be utilised, with small groups of residents with complex needs within a Namaste space on a daily basis. The NCI-UK provides more flexibility in who provides the intervention and more choice for care home staff in determining who should be included in Namaste Care groups than the one utilised by the feasibility study [17]. For the purposes of this paper, we decided to maintain the label 'NCI-UK' for clarity, in distinguishing it from other specific research interventions. Nonetheless, NCI-UK is clearly recognisable as a Namaste Care complex intervention in its delivery.

There are some subtle differences of NCI-UK compared to a Namaste Care intervention that would be utilised within a controlled trial. One of the aims of the NCI-UK intervention was to empower care home decision-making. An example of this was with regards to the inclusion criteria for participating residents. This resulted in 'advanced dementia' being determined by the care home themselves, rather than the more focussed inclusion and exclusion criteria required for RCT studies. The profiles of residents that received NCI-UK, however, were confirmed by the GDS data as having advanced dementia. The current study focussed on an exploration of the likely challenges and acceptable boundaries of decision-making necessitated by the care home environment. It gave care homes decision making power over who would deliver Namaste Care, and how this could best be undertaken to meet the specific needs of the home.

4.2. The Care Home

This study showed that all participating care homes that had consistent leadership through to the implementation phase were able to implement Namaste Care sufficiently and consistently enough to achieve positive effects. In particular, positive impacts were achieved within the flexible boundaries of NCI-UK, occurring despite no home delivering two sessions a day to the same residents, and variation in the duration and timing of sessions. This is promising for wider implementation, suggesting that flexibility can be used to aid implementation in each unique care home environment, without compromising the intent and outcomes of the programme. Moreover, qualitative data also identified that NCI-UK had positive impacts on the homes' reputation and journey of improvement, and so would be worthy of consideration by care providers searching for implementable interventions for quality improvement. Furthermore, successful implementation and evident impact in both care-only and nursing-care registered services suggest that NCI-UK is suitable for and flexible enough to adapt to these different settings. This is an important factor considering the range of resident needs that can exist in a care home, regardless of registration, the variation in service organisation that currently exists in the sector, and the complex co-morbidities of many people living with dementia.

4.3. Residents

The statistically significant improvement on resident quality of life and agitation shown by standardised measures is important to note. However, this was a small pre-post study, and group statistical significance does not always equate to clinical improvements at an individual level. In this respect, the qualitative data showing positive impacts on physical wellbeing, mental wellbeing, responsiveness and connection are perhaps more pertinent for practice. It is important to point out, however, that both qualitative and quantitative outcomes may have been accounted for by increased staff attention that the study facilitated, rather than NCI-UK sessions specifically. The small number of residents involved in this study makes definitive assertions regarding efficacy challenging, and indicates the need for a larger-scale trial. However, given that these findings, and others from the study (Latham et al. manuscript in preparation) have shown that NCI-UK is a relatively low cost, high reward and achievable intervention to implement, it is arguable whether delaying widespread implementation is justified, until definitive trial data is available. Although relatively small-scale, positive impact was demonstrated across a diverse range of residents, including those in need of nursing care. This feature appeared to help the implementation process, as the care homes were able to implement NCI-UK across different parts of the care home registered for different needs. Care homes in the UK cater to a wide range of residents, often on sites with multiple units, but in which people's dementia needs do not separate easily into discrete groupings. Therefore, an intervention that can flexibly meet diverse needs (such as those of a very mobile resident and someone with high levels of physical disability) may well have a particularly high value and likelihood of success.

The positive impacts identified by family members for both the resident and their own involvement are of particular note, given that facilitating positive relationships between care homes and families is a long-stated need [35,36], and that disruptions of connection that accompany advancing dementia are contributors to the anticipatory grief experienced by family members [37]. This study would suggest that NCI-UK is an intervention with which family members can engage and that inviting, and utilising, such engagement not only facilitates implementation but also enhances impact.

The lack of apparent impact of NCI-UK on analgesia medication is worthy of further consideration. It was hypothesised that NCI-UK sessions could result in a group effect in favour of increased recognition and response to pain, because NCI-UK facilitated closer attention to the subtle signs and symptoms of pain in participating residents. However, attending NCI-UK sessions did not result in changes in analgesia medication, and no qualitative indicators of this were noted either. There are several possible explanations for this result. It could be that the participating care homes were already appropriately identifying and treating pain, and therefore there was no added effect of NCI-UK. However, given the well-documented concerns regarding pain diagnosis and treatment in people living with advanced dementia [4], it may be that the pain assessment aspect of NCI-UK was not prioritised by the homes. Future implementation should therefore foreground this aspect of the intervention and evaluate the outcomes.

4.4. Staff

Involvement in NCI-UK did not show statistically significant improvements on standardised measures of stress, job satisfaction or burnout. Qualitative staff data showed positive effects for staff directly involved in NCI-UK sessions, whereas the standardised questionnaires were completed by staff fulfilling a range of roles in the care home. This, combined with the small group size, may have made it difficult to see improvements. However, it may simply highlight the numerous contributors to staff's experience of their work and work environment, and it is perhaps too optimistic to believe a single intervention could change this. Nonetheless, qualitative data do strongly indicate positive impacts for staff when directly involved in delivering NCI-UK: sense of purpose, improvements in wellbeing, creating positive relationships between staff, residents and family. Overall, this suggests that NCI-UK can be successfully implemented, with likely positive impacts for staff once past the initial stages of implementation. This bodes well for its initial uptake and continued use in care homes, as acceptability by staff is imperative for success, particularly on a long-term basis without the impetus of a research study.

5. Conclusions

Identifying interventions to improve the lives of people living with advanced dementia in care homes is a challenging process. This is because, in addition to the intricacies of building and testing an intervention to meet the complex and subtle needs of this group, it must also address the needs of the multiple actors necessary for successful and long-term implementation. The findings of this study suggest that NCI-UK is an intervention that manages to achieve both of these; evidencing positive impacts for residents, staff, family and the care home overall, alongside a comprehension and acceptability of its requirements from all that contributes to a successful implementation process. Notably, there were no negative impacts, and negative implementation process experiences were minimal.

Taken together with other findings from this study published elsewhere, NCI-UK appears to be sufficiently achievable, acceptable, cost-effective and impactful, to merit an immediate recommendation for implementation by any care provider or commissioner wishing to improve outcomes for this vulnerable group in a nursing or care home setting. Whilst further investigation within a larger resident and care home cohort would certainly strengthen the evidence base by compensating for limitations within this study, the urgency of need, likelihood of positive impact and acceptability of this intervention suggest that this should not unduly delay widespread implementation.

Supplementary Materials: The following are available online at http://www.mdpi.com/1660-4601/17/16/6004/s1; Table S1: Guidance, Table S2: NSQ, Table S3: TIDieR Guidance.

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Article

The Perceptions of People with Dementia and Key Stakeholders Regarding the Use and Impact of the Social Robot MARIO

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Abstract: People with dementia often experience loneliness and social isolation. This can result in increased cognitive decline which, in turn, has a negative impact on quality of life. This paper explores the use of the social robot, MARIO, with older people living with dementia as a way of addressing these issues. A descriptive qualitative study was conducted to explore the perceptions and experiences of the use and impact of MARIO. The research took place in the UK, Italy and Ireland. Semi-structured interviews were held in each location with people with dementia ($n = 38$), relatives/carers ($n = 28$), formal carers ($n = 28$) and managers ($n = 13$). The data was analyzed using qualitative content analysis. The findings revealed that despite challenges in relation to voice recognition and the practicalities of conducting research involving robots in real-life settings, most participants were positive about MARIO. Through the robot's user-led design and personalized applications, MARIO provided a point of interest, social activities, and cognitive engagement increased. However, some formal carers and managers voiced concern that robots might replace care staff.

Keywords: dementia; Alzheimer's; older adults; social robots; companion robots; MARIO; qualitative research; quality of care; long-term care

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1. Introduction

Dementia is a progressive neurocognitive disorder that has a profound effect on a person's personality, memory, social skills, ability to communicate and make decisions as well as on mood and emotional reactions [1–3]. Currently there are 50 million people worldwide with this condition, however as the estimated number of people over 60 increases to over two billion people by 2050 [4], and because the incidence of dementia is correlated with increased longevity, it is projected that the number of people with dementia will increase to 82 million by 2030 and 152 million by 2050 [5]. In Europe, it is estimated that the figure will reach 14.3 million by 2050 [6]. Therefore, it is not surprising that dementia is one of the greatest societal and economic challenges associated with ageing in the 21st century [7–10]. It is imperative, therefore, that strategies are identified to support people with dementia and their families to live well with dementia.

Living well with dementia requires the implementation of interventions that can impact positively on the person's quality of life. Many people with dementia may live meaningful lives and retain abilities if a supportive psychosocial environment exists. Spector and Orrell [11] suggest that there are protective/destructive psychosocial factors at play and that social engagement and sustained connectedness are crucial to improving the outcomes for people with dementia. Increasingly the potential of social robots to enhance engagement for people with dementia is recognised as a means of combating loneliness, social isolation and boredom [12–14]. This paper presents the perceptions and experiences of people with dementia and key stakeholders as regards the use of the social robot, MARIO, deployed with people with dementia in three different countries and clinical contexts.

Social participation is a critical contributing factor to successful and healthy aging. Indeed, high levels of social participation have been found to be associated with less cognitive impairment and depression, irrespective of physical frailty [15] However, dementia can lead to reduced social engagement, isolation, and loneliness [13,16,17]. Loneliness and social isolation are recognised as major public health issues associated with higher all-cause mortality rates [18,19]. The risk to health due to social isolation has been equated with the risk associated with cigarette smoking, hypertension and obesity [20]. In the UK, over a third of people with dementia reported feeling lonely and had difficulties maintaining social relationships [21]. In the context of long-term care many studies found that residents spend most of their time socially unconnected and not engaged in any meaningful activity [13,22–29]. Such persistent and continued lack of stimulation and social interaction exacerbates further the lethargy, boredom, depression, and loneliness that are often manifest in the progression of dementia [30,31]. Engaging activities and identifying ways of occupying time meaningfully is an essential part of quality of care. Social engagement can enhance the well-being of people with dementia by maintaining their self-esteem and social connectedness as well as providing a purpose for day-to-day living [32–35]. Social robots are increasingly seen as having the potential to provide such meaningful activities [14] and therefore have a part to play in the overall quality of care.

Social, or companion robots, are defined as robots that have the capability of interacting with people in a socially acceptable way [36]. While these terms are used interchangeably in the literature the term social robots will be used throughout this paper. The development of social robots for the psychosocial wellbeing of people with dementia is a young discipline and a recent area of research. It started with the development of animal shaped zoomorphic robots that built on the success of animal therapy in dementia care. Zoomorphic robots can positively impact the emotions and communication of people with dementia. PARO, which is designed to appear as a baby harp seal has been most widely implemented into care practice [37]. To date there have been at least twenty three EU funded projects that have conducted research into a wide variety of robots. These include the MARIO project (www.mario-project.eu). Currently robots have limited capacity to read human emotions and current development aims to increase their ability to communicate in a more humanlike way [38]. Several studies describe the important role that social robots can play in dementia care by providing companionship and opportunities for people with dementia to engage in meaningful activities [13,39–42] resulting in improved social engagement [43–46]. Research has also found that people with dementia are generally positive toward and accepting of social robots [47–50].

Social robots have been found to have positive effects by reducing negative emotions and behavioural symptoms, improving social engagement, and promoting positive mood and quality of care experience [51]. Additionally, patients who use social robots in a patient-centred manner are perceived as having higher emotional intelligence themselves and can affect caregivers to form more positive impressions of the person that the robot cares for [52]. These findings demonstrate that social robots also have the potential to enhance human-human relationships in the healthcare context.

Factors that influence the acceptability of social robots include having humanlike facial features, being an embodied presence and having social capabilities [17,53,54] being able to deliver specific personalised activities that meet the needs of the individual end user [17,54] and having reliable technology [55]. The perceptions of significant others, such as relatives or carers are also important in determining the acceptability of social robots [54]. Having positive perceptions toward the use of social robots as a means of communication and providing social engagement for the person with dementia is identified as important [56,57]. However, most studies that examined the use of social robots with people with dementia have been conducted over relatively short testing periods [48,49,57,58] and were conducted in the participant's home or simulated home set-up in a laboratory rather than in the real world of practice [47,48,59,60].

2. Materials and Methods

2.1. The MARIO Robot

A multidisciplinary trans-European consortium of researchers, clinical practitioners from community, hospital and residential care settings, ICT specialists and industrial partners with expertise in robotics were assembled with the aim of developing a social robot. In total, the MARIO consortium brought together the skills and expertise of 10 partners from six countries. MARIO is a social robot whose functions aim to support the psychosocial wellbeing of people with dementia, through supplementing the care provided by human carers. MARIO has no functional capacity to address a person's physical needs. A user-led design process involving people with dementia and other relevant stakeholders was used utilised. This resulted in a 1.5-metre-tall white robot with large animated eyes that moved on wheels and could be activated by voice or touchscreen (Figure 1). An iterative design process was used whereby the applications were developed, and refined based on user preferences, testing and feedback [40,61]. This led to the development of several bespoke applications (Table 1) tailored to the specific needs of each person with dementia. MARIO was deployed in three pilot sites, in different health care contexts a purpose-built long-term care setting (Ireland), a geriatric unit in a hospital (Italy), and a community setting (UK). A MARIO robot arrived in each pilot site equipped with the ability to map out a given location and then subsequently autonomously navigate around the dementia care setting. However, because the clinical practice environment constantly changed, necessitating remapping each time, autonomous navigation was not possible. MARIO therefore was not fully autonomous during this research and interaction sessions were supervised requiring the presence of a researcher to guide navigation and provide assistance as required. However during the final evaluation stage of the research the researcher supervised at a distance to give MARIO as much autonomy as possible.

Table 1. Participants numbers. Interactions with MARIO.

	Hospital (Italy)	**Long-Term Care (Ireland)**	**Community (UK)**	**Across Sites Total**
Participant Categories				
People with dementia	20	10	8	38
Relatives/Carers	18	6	4	28
Formal Carers	20	8	0	28
Managers	2	5	6	13
Total Participants across categories	60	29	18	107
Number of Interactions with MARIO	Hospital	Long-Term Care	Community	Across Sites
Number of interactions with MARIO.	75	96[1]	24	195
Duration per interaction	Hospital	Long-Term Care	Community	Across sites
Average with MARIO per session.	43.7	35	60	41.3
TOTAL INTERACTIONS				Values
Total duration of interactions with MARIO (minutes)— Mean ± SD Range				198.62 ± 101.09 15—524
Number of Interactions between people with dementia and MARIO— Mean ± SD Range				5.13 ± 3.44 1—12

[1] In the residential care setting 3 participants completed one, seven, and four MARIO engagements respectively, whereas all the other 7 residents completed twelve engagements.

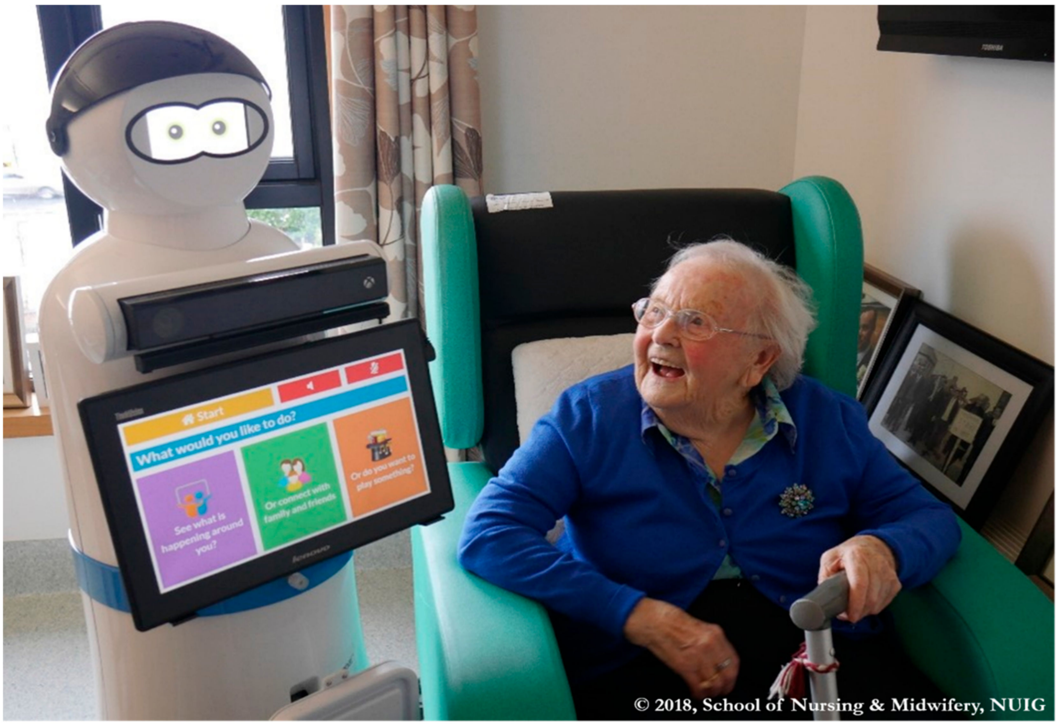

Figure 1. A resident of the nursing home in Ireland interacting with the MARIO social robot as part of her daily routine. (The first author has copyright of this figure).

2.2. Ethics

All participants, including people with dementia gave their informed consent for inclusion before they participated in the study and confidentiality was maintained. Suitably qualified health professionals or psychologists, at each pilot site, ensured that participants had capacity to consent following procedures that conformed to national laws, regulations, and best practice in dementia research. Process consent was utilised, in that, consent was sought, not just for involvement in the overall research but, consent was checked again for each interaction with MARIO. The study was guided by experts in ethics who developed and implemented an ethical framework, and the study was conducted in accordance with the Declaration of Helsinki, and the study was approved by Research Ethics Committees in Ireland (REC, NUI, Galway) UK, (REC, Stockport Metropolitan Council) and Italy (REC:Casa Sollievo della Sofferenza) In addition, it was recognised that there was a need for careful management of the disengagement process between MARIO and the person with dementia, particularly for those who had spent longer times with MARIO. Issues connected with the disengagement process were identified as potential ethical challenges and a disengagement plan was utilised.

2.3. Research Phases

There were three phases in the research. Phase one and two focused on the acceptability of MARIO and the development of MARIO applications. A description of the five applications (app.) is given in order to contextualise findings. (1) The My Memories app. was designed to facilitate reminiscence, and drew on the preserved memories of the PWD. The researcher gathered, often with the help of family, carers and friends, pictures of relevance to the interests and life of each individual PWD and then uploaded these to the MARIO platform. Mario utilised these pictures to stimulate conversation with the PWD using the pictures as prompts. (2) The MY Music app. enabled the PWD to select what music they listened to, when they listened to it, and switch music if they wished. The researcher created a file containing personalized music preferences and these were uploaded to the MARIO platform. The application built knowledge of selections over time and choices were refined based on usage. (3) The My News app. was linked to news feeds from the web. It allowed the PWD to access news headlines or follow personalised interests, like sports, politics, community events. MARIO could read news items of interest to the PWD or display it in written form on the monitor for the PWD to read. The purpose of the application was to keep the PWD briefed and connected. (4) The My Calendar app. reminded the PWD of events like birthdays, anniversaries, visits from others, appointments, community activities, the app. was personalised to each PWD, and facilitated active participation in community and family events. The My Games app. included a range of games which were personalised to the PWD. Games like chess, drawing, solitaire, puzzles, bingo, tennis, painting could be selected as preferences. The aim of this app. was to stimulate cognitive activity and sustain engagement.

During phase 1 focus groups and questionnaires with carers, managers, relatives and people with dementia explored the acceptability of MARIO to people with dementia. Phase 2 gathered perceptions through focus groups with carers, managers, people with dementia and relatives of what they believed MARIO should be able to do in order to help people with dementia. In addition, researchers, with consent, also accessed the life history and personal interests of each person with dementia to inform the development of the MARIO applications. In phase three, the focus of this paper, an evaluation of MARIO was conducted. People with dementia were invited to engage with MARIO over a period of two months in each respective site and qualitative data were collected from people with dementia, carers, managers and relatives to ascertain their perceptions of the use and impact of MARIO. In addition in order to determine the respective costs and savings derived from using a social robot like MARIO, value maps for each of the different settings, namely hospitals, nursing homes, and communities were developed. However, these economic aspects are beyond the scope of this paper. This paper reports on the findings from the qualitative data collected in phase three, with the following aim.

2.4. Aim

To explore the perception and experiences of people with dementia and key stakeholders as regards the use and impact of the social robot, MARIO.

2.5. Methods

A qualitative interpretive descriptive design based on the work of Thorne [62] was used to explore the perceptions and experiences of people with dementia and key stakeholders as regards the use and impact of MARIO. Interpretive description is designed to give participants a voice about their own experiences. It is particularly appropriate when seeking to understand complex "phenomena", such as those investigated in this study. Semi-structured one-to-one interviews using interview guides developed from the literature and directed by the research aims were used to collect the data. These guides were initially created in English and then subsequently translated by members of the Italian research team for use in Italy. Ethical approval was obtained in each of the three pilot sites (UK, Ireland, and Italy).

2.6. Sample

A purposive sample of 107 stakeholders (people with dementia, carers, relatives, managers) who were directly involved with MARIO across the three pilot sites participated. An overview of the number of participants involved at each site during phase 3; the MMSE range in each site, the number and duration of interactions with MARIO are presented in Table 2 below. A total of 195 engagements with MARIO were completed with people at different stages of dementia.

Table 2. Pilot site stakeholder codes.

Stakeholders	Ireland: Residential Care Setting	UK: Community Setting	Italy: Hospital Setting
Person with Dementia	GD	SD	ID
Relative	GR	SRC *	IR
Carer	GC		IC
Manager	GM	SM	IM

* Indicates that some relatives fulfilled the role of carer in the community setting.

In the UK eight people living with dementia in their own homes (five females and three males), were involved. All had mild dementia (MMSE range 20–23) and six were 60+ years of age. Five relative/informal carers took part (three male and one female), and three were 60+ years of age. There were six managers (four female and two male), and most were in the 50+ age group. Two managers were responsible for managing dementia support groups, one was responsible for commissioning services for older people, and three were managers within the adult social care department.

In Italy, 20 people with dementia who were in-patients in a hospital (12 females and 8 males) participated most of whom were over 76 years of age and all had mild dementia (MMSE range 19–23). Eighteen relatives participated (13 female and five male), with the majority in the 70+ age group (*n* = 10). A total of 20 formal carers (13 females and 7 males) participated of these over 60% were geriatricians. Two managers were interviewed both of whom were male with an average age of 49 years.

Ten people with dementia living in long-term care participated in Ireland. Six had moderate dementia (MMSE range 14–19) two mild dementia (MMSE range 20–30) and two severe (MMSE range 3–13). Nine were over 70 years of age and one over fifty. Six female relatives aged between 40–59 years and eight formal carers, (6 females and 2 males), participated. Of the latter six were registered nurses and two were health care assistants. Five managers participated, (three female and two male) three were aged between 50–59 years and two. Numbers of participants in each pilot site, and number and duration of interactions are outlined in Table 1.

2.7. Data Analysis

All interviews were transcribed verbatim and directed qualitative content analysis based on the work of Hsieh and Shannon [63] was used to analyse the data. A coding framework for each stakeholder group data set was developed based on literature analysis and findings of prior research undertaken with people with dementia [64,65]. Four researchers (KM, TK, SW, EB) from the Irish pilot site were involved in the initial development of the data analysis coding frameworks. To ensure coding consistency, a sample of interview transcripts from each stakeholder group, (people with dementia, carers, managers and relatives) was then independently coded by researchers. Researchers worked independently but in pairs to analyse three transcripts from each respective stakeholder group. Then, inter-rater reliability testing was conducted on the set of codes they produced, using a Cohen's 'Kappa' [66] that scientifically measures the degree of agreement between coders. The inter-rater reliability scores for each pair of researchers ranged from 0.67 to 0.76. Following this, a meeting was held to agree coding, examine any differences, resolve discrepancies, and agree the final coding frameworks. Then, the coding frameworks were discussed and shared with pilot partners in Italy and the UK who subsequently tested and confirmed the applicability of the frameworks to their respective data sets. The frameworks were then used to analyse the data across all pilot sites, G was the code for Ireland, S for the UK and I for Italy. The following codes were used: D is a person with dementia, R is a relative of the person with dementia, C is a carer of a person with dementia and M is a manager in the practice site. These participants are collectively referred to as stakeholders. The country and stakeholder codes used to report the findings are presented in Table 2.

3. Findings

Data analysis revealed five key themes: perceptions of MARIO, impact of MARIO, utilisation of MARIO applications and interfaces, challenges in the use of social robots in the real-world context of dementia care and improving MARIO.

3.1. Perceptions of MARIO

The findings revealed that most participants across all sites had positive perceptions of, and attitudes towards, MARIO and they were generally accepting of a social robot referring to the robot as 'he' or 'she', conceptualising him as an embodied presence or a 'friend'.

> *I can talk to her and she's lovely and she's tolerant. (GD1)*

> *MARIO is like a friend. I really enjoyed this experience. (ID4)*

Some people with dementia in the community were initially wary about MARIO. However, as prolonged engagement occurred, the development of a mutual care relationship became evident in the way that the participants greeted and interacted with the robot. Sometimes asking questions about its well-being and telling it "Don't worry pet" when they perceived there was something wrong with it or looking for the robot when it had left their company.

> *MARIO and I have made a very close relationship over the last few months. (SD3)*

> *Where did the man {MARIO} with the music go? (researcher tells her that MARIO had gone to the dayroom. She replies 'Oh I would have gone with him if I had known (GD12).*

Participants with dementia reported that they liked that MARIO was non-critical and commented that it helped them forget they had dementia which in turn made them feel more confident, supported and they enjoyed the experience.

> *She makes me feel normal. (GD13)*

> *It has made me feel surer {confident} (ID10 Trial 2).*

> *I look forward to using MARIO and I feel I am learning … (SD3).*

In addition, people with dementia across all sites expressed a desire to have a MARIO robot in their own home, intimating at the positive impact this might have on their lives.

> *I enjoyed it, first time I went home I wanted one. (SD4)*

> *Can you imagine if I could have one of these at home (ID3).*

Relatives across all the pilot sites were also mostly positive towards MARIO, seeing the robot as a source of interaction and entertainment as well as a companion and personal assistant that could help their relative with the challenges of living with dementia. Some commented that it took some time for people with dementia to get used to interacting with MARIO but that after spending time with the robot they became more confident users. Carers who were able to observe MARIO in action with their relative were able to give examples of MARIO's impact and they understood what MARIO could do and were generally positive.

> *Advantages would be companionship, reminders and having someone to talk to. You could have a conversation {with MARIO}. (SRC2)*

> *I mean I don't know but I think she's getting companionship of a sort, she's getting entertainment, diversion, fun with the conversations that the people with dementia directs or leads or you know, persuades out of her that are you know, the point, the touch point or the stuff on the screen. So it's brilliant, it's really good, love it, yeah its great (GR13).*

> *Using MARIO in hospital, my father showed an improvement of his mood, anyway not only for this aspect MARIO can be useful in Hospital. It can improve the hospitalization of participants with dementia and reduce the risk of cognitive decline (IR4).*

Carers in residential care and carers/relatives in the community commented on both their own acceptance of MARIO and the acceptance by people with dementia. Some carers/relatives reported being initially sceptical about the value of MARIO. Overtime they changed their views after seeing MARIO in action and the impact the robot had on people with dementia. In particular, personalising the robot according to the needs of people with dementia went a long way towards changing carers views and them having a more positive disposition towards MARIO.

> *They (participants) realised how much more useful it (MARIO) has become since it has been personalised (SRC3)*

> … *think it is brilliant. It could really be helpful; mainly because you can personalise it (MARIO) (SRC4).*

> *Since my mother forgets her medicines, MARIO helps her to remind her about daily medication. MARIO also notifies her about the hospital appointments* … *It is tailored to her needs. (IR9).*

However, within the hospital setting carers were overly optimistic about what MARIO would be able to do, some expected a fully independent robot and therefore were less positive at the end of the evaluation than they were at the start.

> *My opinion about MARIO changed. Initially I believed that MARIO was able to do more things. Now I think that technology is not ready to give to participants a fully independent and operational companion robot. (IC3)*

In the context of residential care, the experience of working with MARIO did not really change the perceptions of people with dementia, carers, managers and relatives. For the most part, those who were positive from the outset remained so and those who were sceptical and believed that social robots had a very limited role in the context of people with dementia continued to do so.

3.2. Impact of MARIO

Across all three settings, all participants suggested that the main impact of MARIO for people with dementia was; increased cognitive engagement, autonomy, reduced loneliness, and isolation, all of which led to some improvement in their quality of life.

For most participants with dementia, moments of positivity were experienced and witnessed whilst they engaged with MARIO. Some carers and relatives described their surprise when participants in residential care, with quite advanced dementia, were able to concentrate and sustain engagement with MARIO, while using the applications, despite having a history of problems with attention span. Participants reported that MARIO had helped to focus the attention of the person with dementia engagement increased and they felt the person with dementia benefited from this engagement.

> *. . . he could do it (use the painting app. on MARIO} . . . he spent 40 min one evening doing it which was great, 40 min like, even the nurses were surprised to see him doing it for 40 min (GR5).*

> *I have seen the person with dementia attentive and engaged during their interactions with MARIO. They told me that interacting with MARIO was fun and pleasant, and I have seen their great enthusiasm . . . (IC9).*

> *This is brilliant. Could get a lot out of it {MARIO}. (SD1)*

People with dementia were able to select from a menu of applications that were individualised to them. In the context of residential care, giving the person with dementia the opportunity to select what they wished to do, gave them choices that enhanced their autonomy. This was important to these participants as they reported that they sometimes felt bad about asking people for help.

> *Asking them {care staff} things, like show me this and are you able to do that and I feel bad. (GD14)*

In the context of the community setting, most participants with dementia had milder levels of dementia and were living well with their condition. MARIO therefore had little impact on their autonomy or choice selection as they were generally able to already make autonomous choices.

In all three sites, people with dementia, carers and relative participants described the lives of people with dementia as routine, dominated with long periods of inactivity and little interaction with others. Participants with dementia reported that MARIO made them feel less lonely as the robot provided distraction, allowed for engagement with a wide variety of activities and facilitated interaction with family members. Across all settings, MARIO also provided a topic of conversation with family and carers as well as providing a conduit by which participants with dementia could connect with others. In addition, carers/relatives and managers commented on the multifaceted social activities which MARIO offered which they felt had the potential to reduce loneliness and enhance social engagement and interaction for people with dementia.

> *MARIO could reduce and prevent the isolation and loneliness of the participants. (IM2)*

> *Real potential to connect people with the community, more with family and friends. (SM2)*

> *. . . she'd {person with dementia} have the different options of different things instead of just having the same thing—the television, playing bingo, the same...Just a couple of things that way because there would be more of an option with MARIO (GC18).*

Some participants with dementia reported that MARIO had improved their mood thereby improving their quality of life.

> *He'd {MARIO} make you good... I always thought that he'd make you feel good (GD14).*

> *It {MARIO} just cheers you up and makes me dead happy. (SD4)*

In addition, relatives in the residential care setting commented that it was the provision of extra activities for their relative that made a difference to daily living.

For most relatives in the residential and hospital setting, MARIO provided a diversion, something different, an embodied presence that provided companionship, connectivity and improved the overall mood of the person with dementia. Carers in residential care and carers/relatives in the community saw the personalisation of activities to the person with dementia as key to its positive impact.

> *Once the data and everything else was collected, I was really impressed that it was individualised … to the actual client. That there was actual research done of their likes and dislikes and family background and everything else and yeah, good. (GC16)*

> *It could really be helpful and always have done. Mainly because you can personalise this (SRC4).*

However, carers in all settings felt that the positive impact of MARIO was short lived and did not extend beyond the time of the interactions with MARIO. Therefore, they tended to describe the impact of MARIO as "in the moment only", suggesting that more time and consistent use of MARIO was needed to assess the long-term significance of this type of intervention.

3.3. Utilisation of MARIO Applications and Interfaces

Voice recognition failed across all sites in circumstances where the background noise in the environment was too loud. The noisy environments in these real-world settings meant that MARIO frequently had difficulty processing what the person with dementia said. In addition, some participants with advanced stage of dementia had unclear speech, and patterns of speech that were atypical. This meant that participants in the residential care setting often needed to operate MARIO via the touchscreen either by hand or a stylus.

Across all sites, the two most popular applications were the *My Music* and *My Memories.* The *My Music* app tended to be the first option selected when engaging with MARIO. Most people with dementia were able to use the application independently and were observed to engage fully with it. They described it as enjoyable and commented on the positive impact it had on their mood.

> *How did it make you feel when you listened to the music?*
>
> *I felt good … (GD1).*
>
> *I liked the music best, good music today...(SD2).*

Carers/relatives across all sites also commented positively on the impact of this app. In the residential setting people with dementia were observed dancing tapping their fingers or the floor with their foot to the music, singing along, and reminiscing about the content. In the hospital setting, carers commented on the benefits of the music app, as it prompted physical activity.

> *She was dancing and singing … She was so excited when using MARIO (IC3)*

The second most popular app. across all sites was the *My Memory* reminiscence app. For people with dementia this app. facilitated their recall of happy memories. Likewise, relatives/carers and managers commented on this app's importance in drawing on long-term preserved memories which stimulated the participant with dementia and created enjoyment for them.

> *To look at the photos has made me remember the beautiful moments of my life (ID6).*

> *So, I think looking at pictures and talking about them is—it's good. (GR13)*

> *The photos are really useful. (SRC1)*

3.4. Challenges to the Use of Social Robots in the Real-World Context of Dementia Care

Two main challenges emerged from the data: (i) negative attitudes/concerns towards the use of robots in care giving; (ii) the stage of dementia.

While most carers/relatives and managers were positive about MARIO, some expressed concerns regarding the future deployment of robots in dementia care. These concerns related to the fact that robots should not be a replacement for human interaction or carers.

> *Mario must be perceived as an aid, not as a human being that will substitute the staff or the family. (IM2)*

> *Note of caution that it doesn't become a replacement for human interaction … (SM2)*

> *… we used to have another fulltime occupational therapy assistant, once they retired, they weren't replaced. So, I can't see in any way that Mario would compensate in any way for the loss of that … (GC13).*

Instead some carers believed that social interactions needed to be with another human or even an animal in order to be beneficial. In addition, some did not believe that robots had the capacity to provide the care that they did, respond to cues or individualise their responses sufficiently to work effectively with people with dementia.

Carers, managers and relatives across all Sites also commented on the fact that the stage of dementia was an important consideration when deploying robots to work with people with dementia. They suggested robots were most useful at the mild to moderate stage of dementia because those with severe dementia may find it hard to understand the technology, use the touch screen or generally engage and interact without a lot of guidance and technical support.

3.5. Improving User Experience of MARIO

The key improvements suggested by most carers/relatives and managers across the pilot sites revolved around improving the speech recognition and adding monitoring and assessment devices for people with dementia to keep them healthy and safe.

> *maybe a safety thing … If you could use Mario that way? … Like if it was in somebody's home if they fell could they say 'Mario, ring the ambulance' or whatever? (GR16).*

> *Could do more, support people to do more physical activity, tools to encourage more movement, how do you do this? Check someone is doing it? It would be really good. It would be brilliant, more mobile, build in exercises, help with medication, these are key elements (SM2).*

With regard to speech recognition, it was suggested by all participants that MARIO's conversational ability needed to be developed further so that the robot could understand what people were saying, respond appropriately, and have more meaningful conversations. In addition, having a more humanoid type robot, with facial recognition, and with more autonomy were considered key to making MARIO more useful as a social robot for people with dementia. As regards the future of companion robots in dementia across all pilot sites, carer/relatives, managers and some people with dementia, believed that a MARIO type robot would be a useful addition and support. In particular, it was felt by some that MARIO would be suitable for people in the earlier stages of dementia and for those living in their own homes in the community. However, many of the participants with dementia in the community believed MARIO would probably be most useful for people more worse off than they were at that time.

Overall findings from this qualitative study demonstrate that the companion robot MARIO was an accepted part of social care for people with dementia and had an important role to play in combatting loneliness and increasing levels of engagement. The key strength of this project was that MARIO entered the real world of clinical practice for testing, development and evaluation in three different settings and countries. The applications were developed with regular feedback and testing by the potential end users, within the context in which they would eventually be deployed.

4. Discussion

The discussion focuses on four areas, acceptability, human-robot relations, social activities and social isolation and enhancing autonomy. These discussion themes are summarized below in Table 3.

Table 3. Summary of Discussion.

Discussion Themes	Literature	MARIO
Acceptability	There are divided views within the literature as to the acceptability of social robots in the care of people with dementia, with some researchers reporting that they are not acceptable and others that they are.	Robots were found to be acceptable to people with dementia. In addition the embodied presence of the robot and personalisation of the applications to the user was correlated with increased engagement.
Human-Robot Relationships	The nature and desirability of human-robot relationships is an area of divided opinion.	MARIO found evidence that the robot human relationship strengthened over time, many people with dementia referred to MARIO as 'he' or 'she' or as 'my friend'.
Social Activities and Social Isolation	Many studies conducted in long-term care and hospital care settings have found that participants' lives were dominated by routine with long periods of inactivity, an absence of social participation, low levels of communication and high levels of loneliness.	MARIO provided a conduit for connection to family and friends and provided information on personal interests, giving the person with dementia the potential to engage more in conversations.
Enhancing Autonomy	Many researchers have identified autonomy as a core attribute of the quality of care of older people	The MARIO findings support this claim as it was the autonomy given to people with dementia to make autonomous choices about what activities they wanted to do that was particularly valued.

4.1. Acceptability

There are divided views within the literature as to the acceptability of social robots in the care of people with dementia, with some researchers reporting that they are not acceptable and others that they are. Researchers who found that social robots are not acceptable report that this is because robots lack the capacity to perceive emotional cues or react appropriately [67–70] and that staff are concerned about sharing their working space with a robot [71,72]. Studies from the area of disability [68] and aged care [69] have reported similar issues. Ambivalent attitudes of staff towards robots, and in particular, the fear that robots would replace care staff, were uncovered in the MARIO study too. While MARIO was perceived as an important addition to older people's daily routine, a minority of carers were not keen on having robots in practice areas and believed that robots did not have sufficient capacity to interpret and respond to the needs of people with dementia. Some carers and managers believed that any resources should be channelled towards increasing numbers of staff not buying robots and that robots should not be used to replace human carers.

Researchers who found that social robots are acceptable in the care of people with dementia report that robots can provide companionship, cognitive stimulation and reduce loneliness [9,47–50,56,73–76]. While these studies display promising results many were conducted over relatively short testing periods; two days [22,49,50,59,60], 2 weeks [77], 3 weeks [47] or 6 weeks [58], conducted in the participant's home [47,48,50] or a simulated set up in a laboratory [59,60]. It is not known therefore if these findings would be replicated in the real world of practice and sustained over time. The MARIO findings that robots are acceptable to people with dementia are therefore important because they were conducted in the real world of practice, included the views of people with dementia and took place over 12 months and therefore strengthen the claims that social robots are acceptable in dementia care.

Researchers have also identified a number of factors that influence the acceptability of social robots including; perceived usefulness, trust, enjoyment, the opinions of the end user's significant others and a robot platform that provides meaningful applications and places low technical demands [54,57,59,72,78–80]. The findings of MARIO suggest that the embodied presence of the robot is also important and that the personalisation of the applications to the user is correlated with increased engagement.

4.2. Human-Robot Relationships

The nature and desirability of human-robot relationships is also an area of divided opinion [81]. Some researchers argue that human-robot relationships are positive because robots can provide companionship [13,39–42] and time spent with a robot, because it is stimulating, can enhance communication between the person with dementia and other people [40,56,74–76]. Other researchers disagree arguing that developing a relationship with a robot is undesirable because it is dehumanising and unethical [67].

Researchers who report positive human-robot relationships have found that people with dementia often referred to the study robot as a friend [48,82,83]. This was a finding also in the current study as many people with dementia referred to MARIO as 'he' or 'she' or as 'my friend'. In addition positive emotional responses have also been reported in studies involving the humanoid robot NAO [84] and PARO [73,84]. The benefits of small positive moments experienced throughout the day for people with dementia, such as those experienced during interactions with MARIO, should not be undervalued as it is believed that these significantly benefit the happiness, positive self-perception and overall quality of life of people with dementia [85]. Some researchers caution however that the robot-human relationship may not be sustained overtime as people with dementia lose interest in the robot [86,87]. However in contrast to these findings MARIO found evidence that the robot human relationship strengthened over time, although further studies of longer than three months are required to confirm this.

4.3. Social Activities and Social Isolation

Many studies conducted in long-term care and hospital care settings have found that participants' lives were dominated by routine with long periods of inactivity, an absence of social participation, low levels of communication and high levels of loneliness [13,23–26,28,29,86,88]. Cook [89] suggests that "social death" can occur in residential care arising from a lack meaningful activity. This is especially so for people with dementia who have often experienced an on-going lack of stimulation and social interaction leading to lethargy, boredom, depression, social isolation, loneliness and poor quality care [30,31,89,90]. Some researchers argue that in this context, social robots should be considered as a way of increasing social activity, facilitating communication, reducing loneliness and providing opportunities for people with dementia to engage in meaningful activities [38,91]. Many researchers have found that interaction with a social robot can lead to more engagement with people, not only because the robot provides a topic of conversation, but also because engaging with the robot is cognitively stimulating [13,14,40,48,73,92–94]. Liang et al. [73] found that the social robot PARO had a positive impact on the communication between people with dementia and day centre care staff. This finding is supported by a number of other researchers [13,39–42] who also found that communication with staff and relatives improved following work with a social robot. Robinson et al. [57] found that work with robots that offered stimulation and entertainment led to increased levels of social engagement and increased the person with dementias ability to interact with other people. Chu et al. [17] found social robots provided sensory enrichment, social engagement and entertainment. They concluded that social robots can improve quality of life for people with dementia. Across all sites MARIO was found to facilitate conversations and social engagement providing participants with dementia the opportunity to converse with staff and relatives about their own life and that MARIO was effectively able to provide activities for people with dementia. While engaging with MARIO, participants with dementia spent less time alone and more time socially engaged and MARIO facilitated people with dementia to focus on their preferred activities for lengthy periods of time, even if they usually found it difficult to focus. MARIO provided a conduit for connection to family and friends and provided information on personal interests, giving the person with dementia the potential to engage more in conversations. Moyle et al. [58] explored whether social robots could promote social connectedness via video calls between relatives and participants with dementia who lived in long-term care. They also found that the robot increased opportunities to reduce social isolation and encouraged engagement.

4.4. Enhancing Autonomy

Many researchers have identified autonomy as a core attribute of the quality of care of older people [95–97] However, previous research has found that many older people living in long-term care have reduced levels of autonomy [95,96]. Researchers claim that giving older people the choice of what they want to do and allowing them to select personalised activities when working with a robot can enhance autonomy [17,57,87]. The MARIO findings support this claim as it was the autonomy given to people with dementia to make autonomous choices about what activities they wanted to do that was particularly valued.

5. Conclusions

Findings from this qualitative study demonstrate that the social robot MARIO was an accepted part of social care for people with dementia. The embodied presence of MARIO, the user-led design process and development of personalised activities led to a broad acceptance of the MARIO robot in dementia care amongst people with dementia, relatives, carers and managers. The findings confirm that social robots may have an important role to play in combatting loneliness, enhancing autonomy and increasing levels of engagement. With the current challenge of the global COVID-19 pandemic there are compelling reasons for long-term care facilities to utilise more social robots. Many long-term care facilities across the world have had to limit visitors, because of the pandemic, thereby reducing social contacts. Caleab-Solly [98] argues that telepresence robots could be used to help alleviate this social isolation. In addition, a call to action from the robotics community on the role of social robots in managing public health and infectious diseases appeared recently [99] with a specific call for increased adoption of social robots as the widespread quarantine of patients, is resulting in prolonged isolation of individuals from social interaction. Social robots such as the MARIO robot could be deployed to provide continued social activities, connection with friends and family and adherence to treatment regimens without fear of spreading disease. However concerns remain around the emotional capacity of robots. Future research should ensure that robot designs for use in dementia care possess more human-like features and enhanced capacity to communicate and understand the speech of people with dementia. In addition, the introduction of social robots needs to ensure that health care expectations are realistic and focus on promoting positive attitudes when preparing staff to work with the technology. Finally, future evaluation of the impact of social robots in dementia care needs to include longer testing and evaluation periods with larger sample sizes. Despite the limitations, promising trends as to the positive impact of MARIO on improving social and cognitive health and the ability to reduce loneliness is evident in the context of using a companion robot such as MARIO for older people with dementia.

6. Limitations

Given the absence of a fully autonomous robot and the constant presence of the researcher it is difficult to come to categorical conclusions regarding the impact of MARIO. Further studies with larger sample sizes than the one used in MARIO and longer duration are required.

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Article

Pilot Study to Develop and Test Palliative Care Quality Indicators for Nursing Homes

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Abstract: An increasingly frail population in nursing homes accentuates the need for high quality care at the end of life and better access to palliative care in this context. Implementation of palliative care and its outcomes can be monitored by using quality indicators. Therefore, we developed a quality indicator set for palliative care in nursing homes and a tailored measurement procedure while using a mixed-methods design. We developed the instrument in three phases: (1) literature search, (2) interviews with experts, and (3) indicator and measurement selection by expert consensus (RAND/UCLA). Second, we pilot tested and evaluated the instrument in nine nursing homes in Flanders, Belgium. After identifying 26 indicators in the literature and expert interviews, 19 of them were selected through expert consensus. Setting-specific themes were advance care planning, autonomy, and communication with family. The quantitative and qualitative analyses showed that the indicators were measurable, had good preliminary face validity and discriminative power, and were considered to be useful in terms of quality monitoring according to the caregivers. The quality indicators can be used in a large implementation study and process evaluation in order to achieve continuous monitoring of the access to palliative care for all of the residents in nursing homes.

Keywords: nursing homes; quality indicators; quality measurement; palliative care; quality of care; end of life care

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1. Background

In the past decade, in many Western countries, an increasing number of elderly persons were admitted to nursing homes. Projection studies concerning numbers of deaths and place of death suggest that, by the year 2040, the majority of deaths will occur in nursing homes [1,2]. Moreover, prediction studies also indicate that the need for high quality care at the end of life will most likely double in the nursing home setting, because of an increasing prevalence of frailty and multimorbidity in the resident population [2,3], being linked to a strongly reduced average length of stay of residents in recent years [4]. The quality of care at the end of life in long-term care facilities is currently high on the agenda: WHO and other health care organizations have advocated for good palliative care for older people already for years [5,6]. Additionally, in research, emphasis in the past decade has been placed on the quality of advance care planning, autonomy of residents, and the implementation of palliative care in nursing homes [7,8]. Until now, palliative care has been insufficiently developed in nursing homes and international studies show the late initiation of palliative care and even mostly for residents with a cancer diagnosis. An urgent need arises for better access for all elderly persons to high quality palliative care provision in the nursing home context.

When implementing palliative care in a nursing home context, it is important to evaluate its success and measure its outcomes for residents. One way to do so is the use of quality indicators within a continuous cycle of implementing, monitoring, and improvement [9]. By continuously monitoring quality of care and its outcomes and conducting implementation trajectories that are based on the results of these measurements, care teams are able to optimize the quality of care based on information, patient experiences, and best practice examples [10–13]. Quality indicators can be used within this monitoring cycle to provide data on subjective and objective aspects of quality of care over time. They are defined as measurable aspects of care, calculated as a percentage with a predefined numerator and denominator [14,15]. These indicators give caregivers information on their performance in terms of care processes and outcomes and which elements of care may need improvement [16]. Several national health care monitoring programs have been started in Western Countries, including Belgium, based on quality indicators. However, they mainly focus on the hospital or home setting or circumstances surrounding death such as symptoms and place of death [17–25]. Although initiatives have been taken for improving palliative care in nursing homes [24,26,27], researchers were not yet able to validate and implement solid quality indicators for palliative care in this specific setting.

A previous program to develop and implement palliative care quality indicators, the Belgian Q-PAC study, used a rigorous development method combining literature review, expert consultation, and pilot testing, resulting in a core set of 31 quality indicators covering a broad range of aspects of palliative care. The set was meant to be used for all palliative care services and settings, including nursing homes [24,28,29]. However, because the nursing home setting appeared to be too different from the specialized palliative care services in terms of organization and structure of care (e.g., no dedicated palliative care teams), and in characteristics of the population cared for (e.g., specific population with frailty, dementia, cognitive decline), the quality indicator set was implemented into all specialized palliative care services, but not in the nursing homes from 2014 onwards [30]. Therefore, a need persisted to investigate which indicators can be used for monitoring the quality of palliative care in the nursing home context.

Because of the increasing need for development of palliative care and its monitoring in nursing homes, we started a project to develop a set of quality indicators for the quality of palliative care in nursing homes. Previous research already highlighted the importance of person centered care through autonomy and involvement of family, but also communication and advance care planning in nursing homes [31–34]; hence, we decided to develop quality indicators specifically targeting advance care planning, palliative care, and end of life care. The main aim for nursing home teams is to obtain insights in their care processes and outcomes, and further develop missing elements in the care for their residents. In this study, we develop and test a quality indicator set and measurement procedure for palliative care in nursing home context.

2. Methods

2.1. Design

We used a two-step approach with a mixed-method design based on a standardized indicator testing protocol for generic quality indicators in order to develop the quality indicator set and measurement procedure [29,35]. First, we developed the set of quality indicators using the Rand/UCLA appropriateness method in three phases: (1) literature review to develop a preliminary set of quality indicators, (2) interviews with experts to test face validity of the preliminary set of quality indicators, and (3) indicator selection by expert evaluation [36]. Second, we evaluated the face validity, feasibility, discriminative power, and usefulness of the quality indicators in a quantitative cross-sectional application of the quality indicators in combination with qualitative interviews. Figure 1 shows an overview of the development process and pilot testing.

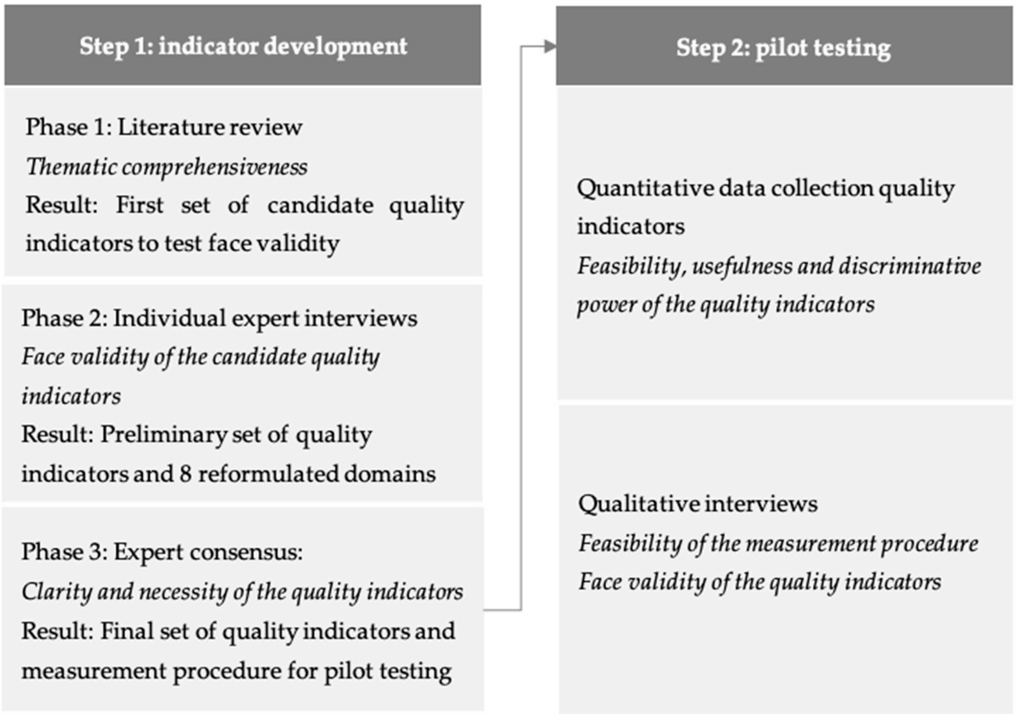

Figure 1. Overview of study phases and accompanying results.

2.2. *Step 1: Indicator and Questionnaire Development*

2.2.1. Phase 1 and 2: Literature Study and Expert Interviews

In phase 1, we identified a comprehensive set of candidate quality indicators for palliative care in nursing homes. Therefore, we adapted the existing Belgium quality indicators for specialized palliative care listed in the Q-PAC (Quality indicators for Palliative Care) study [24] to the nursing home context. To do so, we searched literature in PubMed while using a snowball method starting with the reviews of Pasman et al. and De Roo et al. [37,38]. We searched for existing quality indicators, domains of quality of care for elderly and questionnaires or instruments for quality of palliative care, advance care planning, and end-of-life care in the nursing home context. Candidate quality indicators could be processed or outcome indicators and emphasis were placed particularly on subjective quality indicators in order to reflect the user perspective on quality of care. In phase 2, we performed interviews with relevant stakeholders (i.e., healthcare professionals, community-based organizations, and policy makers) that are involved in Flemish nursing home care, to test face the validity of the candidate quality indicators and gather additional indicators and domains for this specific context not found in literature. This way, an iterative process of literature search and interviews lead to the selection of a preliminary set of quality indicators representing all of the identified domains. Furthermore, to be able to calculate the quality indicators, we operationalized each of them into questions for residents, bereaved family and nursing home staff, accompanied with measurement instructions. This was done based on input that was provided by the experts and questionnaires identified in the literature.

2.2.2. Phase 3: Expert Consensus

The preliminary set of candidate quality indicators was sent to 15 experts (see results infra). They were asked to score the quality indicators with “1” as “not appropriate” to “9” as “very appropriate” in order to measure the quality of palliative care in nursing homes. Experts were provided with the candidate indicator’s description, rationale, numerator and denominator, question (per response type: residents, bereaved family, or nursing home staff) and literature source. They were also able to suggest missing domains or themes.

The median scores on appropriateness were calculated per candidate indicator. The quality indicators were then categorized based on the RAND/UCLA consensus method: accepted, to be decided, or rejected. Indicators were immediately accepted if they had a median score of 7 or more and if no more than two experts scored the indicator with a 1, 2, or 3 (strict positive consensus). Indicators with a median score of 3 or lower and for which no more than two experts scored the indicator 7, 8, or 9 were immediately rejected (strict negative consensus) [36]. All other to-be-decided indicators were discussed during the one-day plenary discussion until consensus was found regarding rejection or acceptance among the experts. During the discussion, additional selection criteria were to be considered as defined by the researchers: (1) a maximum of eight quality indicators per questionnaire (i.e., response type) was suggested to ensure feasibility of the quality monitoring in nursing homes, without overburdening nursing home staff, and (2) experts were encouraged to consider a good balance between process and outcome indicators, as well as objective and subjective quality indicators. As such, experts were asked to select the eight most important indicators for each response type.

2.2.3. Questionnaires to Measure the Quality Indicators

After defining the quality indicators together with the experts, we developed four questionnaires to be able to calculate the performance score per quality indicator. These questionnaires were based on questions of validated scales as much as possible, or if no good question gathering the right information for a specific indicator existed in the literature, it was developed by the researchers, together with the experts. An overview of all indicators, accompanying questions and evidence can be found in the Supplementary Table S1.

Two questionnaires were developed to measure indicators of quality of care for residents who currently lived in the facility: one for the resident [1] and one for the most involved professional caregiver [2]. To be able to question every resident, we decided, in consultation with the experts, to create an adapted version of the questionnaire for residents who needed help to fill out a questionnaire because of physical or mental health issues. The questions in this version are the same as the questions in the standard resident questionnaire, but are reformulated from second to third person. They can be read to the resident or filled out by the resident's informal caregiver (or professional caregivers if no informal caregiver was noted in the patient record), preferably together with the resident.

A questionnaire was developed for the closest family caregiver (as noted in the health record) [3] and a separate one for the most involved professional caregiver [4] in order to measure indicators of quality of care for residents who passed away in the facility within the last six months. We performed a cognitive testing for all questionnaires in the corresponding responder group (i.e., residents, family, and professional caregivers). We tested the comprehensibility and response burden: recommendations resulted in minor linguistic changes for both residents and family caregivers.

2.3. Step 2: Pilot Testing

2.3.1. Design

We used a mixed-method design, including a quantitative application of the quality indicators and qualitative interviews with the nursing home staff using the instrument, in order to evaluate the face validity, feasibility, discriminative power, and usefulness of the instrument.

2.3.2. Setting and Participants

Nursing homes were recruited on a voluntary basis through a call for participation via involved community-based organizations. From the 24 candidates, we selected a purposive sample of nine nursing homes, while considering the number of beds (between 64 and 290 beds), the organizational structure (i.e., six profit and three non-profit) and the geographical location (every Flemish province was represented).

Nursing homes were able to measure the quality indicators via questionnaires through a cross-sectional inclusion design. This method allows for nursing homes to gather information on residents who were currently living in the nursing home as well as those who had passed away. Following inclusion criteria were used:

Residents who were currently living in the nursing home and:

- lived for a minimum of one month in the facility;

Residents who had passed away and:

- lived for a minimum of one month in the facility; and,
- passed away four weeks to six months earlier in the nursing home.

2.3.3. Measurement Procedure

All nursing homes followed the same measurement procedure based on a previously developed and tested method in order to measure the quality indicators via questionnaires [16]. Before the start of the pilot test, a coordinator per nursing home was appointed in consultation with the researchers. The researchers visited the coordinator (in the nursing homes) in order to explain the study, expectations, measurement procedure, how to work with the online questionnaires, going through the detailed instruction manual. The coordinator responsibilities include the supervision of the measurement procedure, communication within the nursing home (e.g., informing the staff about the instrument and procedure, announcing start date), drafting the list for including residents (in concordance with the researcher), and distribution of the questionnaire among residents, family caregivers and staff (Figure 2). The coordinator was also asked to keep a diary and note thoughts regarding the workload, setbacks, and/or other findings (Figure 2).

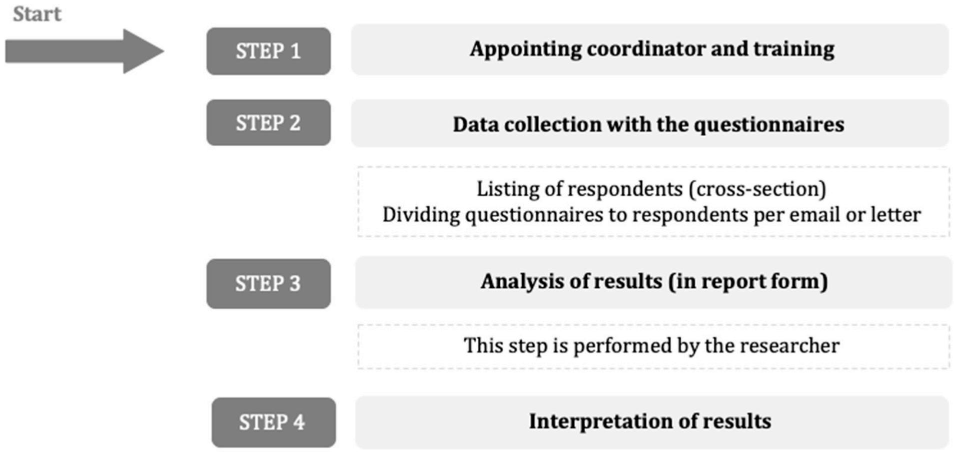

Figure 2. Measurement procedure.

Nursing homes were asked to include minimum of 2/3 of all residents at random and all deceased residents who met the inclusion criteria. We developed an inclusion matrix, depending on the number of residents per nursing home. We used online questionnaires via Limesurvey because nursing home staff were responsible for the distribution of questionnaires and to ensure responders privacy. No IP addresses were saved to guarantee anonymity. Residents could fill out the questionnaire via portable computers or tablets available in the nursing homes; family members received a link to the questionnaire via email; inhouse caregivers accessed the online questionnaire via computers in the nursing homes or on their private computers.

2.3.4. Feedback and Evaluation

Per nursing home, a report was created, summarizing the individual and overall performance scores in a structured and standardized way. Nursing home coordinators were responsible for communicating the results to the nursing home staff (step 3 and 4 in Figure 2). After the report was sent to the nursing homes, the researchers visited the nursing homes for an evaluation interview with the coordinator, while using an interview guide with open-ended questions. The coordinators kept a diary during the measurement and delivered it in advance to the researcher. During the interview, the workload of the coordinator and the nursing home staff was evaluated and barriers and facilitators in the use of the quality indicators were identified. Coordinators could also share their thoughts on future use of the instrument and wider implementation. The researcher kept a diary of evaluation points, remarks, and questions for further qualitative evaluation during the whole period of the pilot test.

2.3.5. Analyses

Data collection was closed after one month. Performance scores (non-adjusted mean) per quality indicator were calculated while using the defined numerators and denominators (range 0–100). In order to evaluate feasibility and discriminative power for individual quality indicator, we used descriptive and psychometric analyses in Microsoft Excel and SAS. Furthermore, the interviews were conducted with all coordinators in order to evaluate the face validity and usability of the indicators and the feasibility of the procedure. Together with the diaries of the coordinators and the field notes of the researcher, these interviews were analyzed while using a thematic framework approach, which was based on the barriers and facilitators for implementation framework of Grol and Wensing [10,39,40]. Table 1 presents an overview of all evaluation aspects, accompanying methods, and criterions.

Table 1. Overview of the evaluation and accompanying methods and criterions.

Aspect	Definition	Evaluation Method	Criterion to Judge Aspect as Adequate
Individual quality indicators (QI's)			
Face validity	The extent to which QI's are subjectively viewed as covering the concept it purports to measure	Qualitative: interview: feedback on every single quality indicator was asked in terms of face validity	Subjective confirmation of validity of quality indicator scores
Feasibility	The extent to which the QI's are measurable	Quantitative: psychometric analyses	Not more than 10% missing values per question
Discriminative power	The extent to which a QI discriminates between good and bad quality	Quantitative: psychometric analyses	Not more that 95% of answers in an extreme category Meaningful range between QI scores (min–max $\geq$20%)
Usefulness	The extent to which the QI scores can be used to improve care	Qualitative: interview question "Were you able to define improvement point based on the quality indicator scores and feedback report?"	Subjective confirmation of usefulness
Overall quality indicator measurement			
Feasibility	The extent to which the measurement procedure is feasible for caregivers in nursing homes	Qualitative: interview question "Do you have the feeling you are able to measure the quality indicators without any support in the future?"	Subjective information on work-load for caregivers
		Qualitative: interview question "How did you feel about the length of the questionnaire?"	Subjective information on survey completion time for caregivers

2.4. Ethical and Language Issues

This study is approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (protocol: QPACWZC01 BUN: 143201838240). All of the respondents (i.e., residents, family, and nursing home staff) received an online questionnaire, including cover letter and informed consent. Only questionnaires with signed informed consent were used to calculate performance scores. No IP addresses, names, or other personal identifiers were saved in the online questionnaire system.

All of the indicators and questionnaires were developed and evaluated in Dutch. All of the interviews and trainings were performed in Dutch. The English translation was done specifically for this article. Dutch versions of the indicators or questionnaires are available on request.

3. Results

3.1. Step 1: Indicator Development

3.1.1. Phase 1 and 2: Literature Study and Expert Interviews

Based on the existing QPAC quality indicator set for specialized palliative care, the additional literature search (phase 1) and interviews with relevant stakeholders (n = 10) (phase 2), we identified 26 candidate quality indicators in eight domains of quality of palliative care for elderly persons in nursing homes. Table 2 shows the difference between the Q-PAC domains (specializes palliative care) and the domains for the nursing homes based on literature search and stakeholder interviews in phase 2.

Table 2. Eight thematic domains for quality indicators.

Original QPAC Set [24]		**QPAC for Nursing Homes**	
1	Physical aspects of care	Physical aspects of care	1
2	Psychological, social and spiritual aspects of care	Psychological, social and spiritual aspects of care	2
3	Care planning, information and communication with patients	Autonomy and dignity	3
		Care planning and communication with residents	4
4	Care planning, information and communication with family	Communication with family	5
5	Care planning, information and communication between caregivers	Communication between caregivers	6
6	Circumstances surrounding death	Care and circumstances surrounding death	7
7	Coordination and continuity of care		
8	Support for family	Care for family	8

3.1.2. Phase 3: Expert Consensus

Based on their individual evaluation of the 26 candidate quality indicators, seven quality indicators were immediately accepted and included. None were immediately rejected, so the remaining 19 quality indicators were debated in a one-day plenary discussion until consensus was found. Nine of 19 quality indicators were eventually accepted and three were newly developed during the meeting and added to the draft set. After the discussion, a set of in total 19 quality indicators were drafted and per email consented by all experts (Tables 3 and 4). In Supplementary Table S1, the full list of quality indicators, as was tested in the pilot phase, is presented with accompanying numerator, denominator, question, and source.

Table 3. Participants in expert consultation rounds.

	Total
Professional caregivers from care homes	**7**
Head nurse/Referent nurse	3
Paramedic	1
Care personnel	1
Physician	1
Quality coordinator	1
Representatives from residents and next-of-kin	**3**
Flemish Expertise Centre for Dementia	1
Alzheimer League, family council	1
Flemish elderly council	1
Palliative care research and policy	**5**
KU Leuven—LUCAS research group	2
Flemish Federation Palliative Care	1
Local Palliative home care network Westhoek-Oostende	1
Flemish agency for care and health	1

Table 4. Quality indicators for palliative care in nursing homes.

Domain: Physical Aspects of Care					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
PC-1	Being in pain	Percentage of residents with a pain score of 3 or more in the last three days	Residents	30.7	37.1 (19.1–56.3)
Domain: Psychological, Social and Spiritual Aspects of Care					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
PC-2	Feeling worried or anxious, or a burden	Percentage of residents who indicate they were most of the times or always feeling worried or anxious, or a burden to others	Residents	9.2	23 (4.3–27.3)
PC-3	Being around people who care about you	Percentage of residents who indicate that they were most of the times or always able to be around people who cared about them	Residents	57.1	42.9 (29.8–72.7)
Domain: Autonomy and Dignity					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
PC-4	Personal wishes and beliefs respected	Percentage of residents who indicate that their caregivers most of the times or always respecting their personal wishes and beliefs	Residents	63.3	55.7 (35.2–90.9)
PC-5	Decisions about life and care	Percentage of residents who indicate that they most of the times or always can make their own decisions about their life and care	Residents	44.2	35.4 (31.3–66.7)
PC-6	Treated with respect	Percentage of residents who indicate that they most of the times or always were treated with respect	Residents	68.6	47.2 (43.8–90.9)
Domain: Care Planning and Communication with Residents					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
ACP-1	Information comprehensible and not contradictory	Percentage of residents who indicate that they most of the times or always receive comprehensible information and almost never of never contradictory information	Residents	79.5	21.4 (72.3–93.8)
ACP-2	Conversation with family	Percentage of residents for whom the next-of-kin indicates that more than once a conversation took place with the caregivers, the next-of-kin and, when possible, the resident	Next-of-kin	47.6	100 (0–100)
ACP-3	Knowledge about care goals and life wishes	Percentage of residents for whom their professional caregiver indicates that they have knowledge about the residents' care goals and life wishes.	Professional caregiver	63.8	40 (47.1–87.1)
ACP-4	Encouraging ACP	Percentage of residents for whom their professional caregiver indicates that they often or very often encourage residents and their next-of-kins to involve in advance care planning.	Professional caregiver	37.7	72.5 (10.8–83.3)
Domain: Communication with Family					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
ACP-5	Next-of-kin involved in decisions	Percentage of next-of-kin who indicate that they often or very often felt involved in the decisions taken about the resident.	Next-of-kin	64.7	75 (25–100)
EOL-1	Information about approaching death	Percentage of next-of-kin who indicate that they received the right amount of information on the approaching death of the resident.	Next-of-kin	73.5	35.7 (64.3–100)
Domain: Communication between Caregivers					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
PC-8	Information in resident file	Percentage of residents for whom the professional caregiver finds sufficient information in the resident file when needed.	Professional caregiver	69.3	37.6 (52.7–90.3)
Domain: Care and Circumstances Surrounding Death					
N	Short title	Description of the indicator	Respondent	Mean score (%)	Range (min–max)
EOL-3	Comfortable in last week of life	Percentage of next-of-kin who indicate that many or a lot of measures were taken to make the resident comfortable in the last week of life.	Next-of-kin	67.6	100 (0–100)
EOL-4	Recognizing the approaching death	Percentage of residents for whom the professional caregiver indicates they could recognize the approaching death well or very well by physical changes.	Professional caregiver	91.7	16.7 (83.3–100)
EOL-5	Satisfied by care delivered	Percentage of residents for whom the professional caregiver indicates they are satisfied with the care delivered to the resident.	Professional caregiver	95.8	16.7 (83.3–100)
EOL-6	Support by specialized palliative care	Percentage of residents for whom the professional caregiver indicates a palliative care referent or specialized team was involved in the care for the resident.	Professional caregiver	68.8	100 (0–100)

Table 4. *Cont.*

Domain: Care for Family					
PC-7	Attention for wishes and feelings of next-of-kin	Percentage of next-of-kin who indicate that the professional caregivers had attention for their wishes and feelings.	Next-of-kin	67.6	30 (50–80)
EOL-2	Supported immediate after death	Percentage of next-of-kin who indicate that they felt sufficiently supported by the professional caregivers immediate after the death of the resident.	Next-of-kin	85.3	66.7 (33.3–100)

PC = Palliative care; ACP = advance care planning; EOL = end of life.

3.2. Step 2: Pilot Test

3.2.1. Responder Characteristics

Nine nursing homes tested the quality indicator set and measurement procedure. In total, 294 residents, 393 professional caregivers (345 for residents who currently lived in the facility and 48 for deceased residents), and 34 family caregivers completed the whole questionnaire and hence were included for the pilot study. We asked nursing homes to list the total number of inclusions, but four of them did not perform this assignment correctly; hence, we lack information on the response rates in this study. In total 214 of the residents were female and the majority (53%) of residents was between 85- and 94-years old. Table 5 presents an overview of characteristics.

Table 5. Characteristics per response type in the pilot test.

Response Type	Total	Female (%)	Age of Resident				Dementia [B] (%)	Length of Stay [C]		
			<75 (%)	75–84 (%)	85–94 (%)	>94 (%)		<12 (%)	12–24 (%)	>24 (%)
Residents	**294**	**214 (73)**	26 (9)	74 (25)	157 (53)	37 (13)	NA	NA	NA	NA
Resident him/herself	114	83 (73)	11 (10)	24 (21)	67 (59)	12 (11)	NA	NA	NA	NA
Together with family caregiver	63	43 (68)	5 (8)	14 (22)	38 (60)	6 (10)	NA	NA	NA	NA
Family caregivers in the name of the resident	116 [A]	87 (75)	10 (9)	35 (30)	52 (45)	19 (16)	56 (48)	37 (33)	22 (20)	52 (47)
Professional caregivers	393	305 (73)	27 (7)	97 (25)	218 (55)	51 (13)	204 (49)	125 (32)	60 (15)	208 (53)
Residents who lived in the facility	345	257 (74)	25 (7)	88 (26)	193 (56)	39 (11)	162 (47)	109 (32)	54 (16)	182 (53)
Deceased residents	48	31 (65)	2 (4)	9 (19)	25 (52)	12 (25)	29 (60)	16 (33)	6 (13)	26 (54)
Family caregivers	34	22 (65)	1 (3)	7 (21)	17 (50)	9 (26)	16 (47)	14 (41)	5 (15)	15 (44)

A: 5 missings for length of stay. B: Questioned only when the family caregivers completed the questionnaire in the name of the resident. C: Length of stay in months.

3.2.2. Psychometric Analyses: Feasibility and Discriminative Power

None of the indicators had too many missing (>10%) answers. The quality indicators showed good discriminative power, as there were no indicators that had 95% or more answers in an extreme category (Table 3). Only two indicators had a variation range (min-max) smaller than 20 percentage points between different nursing homes, i.e., 'Recognizing the approaching death' and 'Satisfied by care delivered' and, hence, showed problems with sensitivity to change.

3.2.3. Qualitative Analyses; Feasibility, Usefulness and Face Validity

We interviewed all nine coordinators of the included nursing homes. With regard to face validity, all of the coordinators confirmed that the appeared to reflect their practice and seemed valid. As indicated by one on the coordinators: "*The results indicate clear work points and results are recognizable*". They also agreed the results were easy to interpret and useful in terms of improving their service, but they indicated that they struggled in establishing concrete improvement goals that are based on the quality indicator scores. The coordinators evaluated the length of all four questionnaires as feasible, but four coordinators declared that they would prefer paper questionnaires for residents and family, as this may improve response rates. As indicated by one of the coordinators: "*We would prefer paper questionnaires . . . we* [staff in de nursing home] *don't have professional email addresses and I didn't want to send* *the questionnaires to their private email. Also, our residents don't know how to use a computer or tablet and therefore some residents who normally could fill in a questionnaire alone, now couldn't*".

Moreover, all of the coordinators indicated that they would use the instrument again and evaluated the instruction manual as useful and sufficient and assumed the instrument could be executed without the researchers. One of the coordinators said: "*Training was okay, the manual is clear and I think we could have managed without* [the manual]". Additionally, all of the coordinators indicated that the workload was feasible and worthwhile, although they declared that preparing the list of respondents was time-consuming, as they had to acquire their own approach.

Based on field notes, the interviews with the coordinators, and diaries of the same coordinator, we made an overview of facilitators and barriers regarding the use of the instrument (Table 6) in general terms and per step of the measurement procedure, as described in Figure 2.

Table 6. Facilitators and barriers based on the interviews and dairies regarding the use of the instrument.

Barrier (b) or Facilitator (f)	**Quote from Caregivers or Field Notes**	**Diary by Coordinator**	**Interview with Coordinator**
The use of the instrument in general terms			
Lack of time and staff to perform quality measurement (b)	*"To sell the instrument: make it a sort of an obligation, otherwise it will not happen, I think. So much extra is added [next to the regular work], and also many projects that are already there anyway"* (coordinator nursing home)	X	X
Readiness of the team to perform quality monitoring together (f)	*"[experience with implementation of the quality assessment] it was ok. It also depends on the enthusiasm and commitment of the persons who are doing it."* (coordinator nursing home)		X
Step 1: Appointing coordinator			
Presence of a good coordinator to guide the quality measurement (f)	*"Appointment of the coordinator: one is not enough. Depends on the size of the nursing home."* (coordinator nursing home) *"Announced [the quality assessment] during team meeting. They [coordinators] had made a step-by-step plan and mailed it to the staff, how they could easily find it and fill it in … everything went smoothly"* (coordinator nursing home)	X	X
Step 2: Data collection with the quality indicators			
Bad timing regarding the start of measurement (i.e., sick staff, loss of coordinator) (b)	Some of the coordinators became absent during the procedure and the person who took over didn't have all the needed paperwork. (field notes researchers). Some nursing homes forgot to record the total of included participants, didn't sent out the recruited number of questionnaires or didn't sent questionnaires to family caregivers. The reason they indicated was the moment of the measurement was not convenient (field notes researchers).		X
Lack of computer literacy in all participants (b)	*"They [family and residents] had no e-mail and some [family] had to come to the nursing home to fill it [the questionnaire] in."* In some nursing homes professional caregivers didn't had a work email and in one of these homes, the coordinator had to aid each included professional caregivers with opening the link [which made available on the desktop] to the questionnaire (field notes researchers).		X
Lack of technology in the nursing homes (b)	*"It was a lot of time investment, there was only one iPad available in the nursing home, so we had to arrange a lot. WIFI connection was also not reliable, which limited usability."* (coordinator nursing home)	X	X
Feasible workload (f)	All coordinators found the overall workload feasible (field notes researchers) *"A lot of work in preparation by the coordinator so the coordinator should certainly have time to prepare. Once it runs [there is] little follow-up work."* (coordinator nursing home)	X	X
Step 3: Analysis of results by researchers			
Low(er) response rate because of measurement procedure (b) AND Inclusion of deceased residents due to low mortality (b)	*"With a longer measurement period, they [respondents] could fill in more"* (coordinator nursing home)	X	X
Fast (within two weeks) analysis of questionnaires because of the use of digital data (f)	Because we used online questionnaires the researchers didn't need to input any data but could directly analyse resulting in fast feed-back to the nursing homes		X
Step 4: Interpretation of results by coordinator and nursing home team			
Easy to interpret results (f)	*"The results indicate clear work points. Results are recognizable"* (coordinator nursing home)		X
Struggle to go from interpretation to establishing improvement goals (b)	Most coordinators indicate they recognize the results, but they cannot (yet) make clear improvement goals. (field notes researchers)		X

4. Discussion

In this study, we developed and evaluated a quality indicator set and a tailored measurement procedure consisting of 19 indicators to monitor the quality of palliative care in Belgian nursing homes. The composition of this indicator set is based on previously developed quality indicators for specialized palliative care, but, after adaptation to the nursing home context by experts and stakeholders, the themes differ somewhat: more emphasis is placed on autonomy and dignity of the nursing home residents. From this first pilot study, the quality indicators seem to be valid and the measurement procedure feasible for caregivers in nursing homes who are interested in improving the quality of end-of-life care within their center. From the psychometric analyses, we found that most of the quality indicators were feasible and they showed good discriminative power. The instrument appeared to reflect practice and hence confirmed face validity, according to coordinators during the qualitative interviews. The measurement procedure was evaluated by the interviewed coordinators as feasible and they indicated the measurement of the quality indicators could be performed based on the manual without extra help of the researchers. Overall, this study shows that the quality indicators are ready for further use in a large implementation study in Flemish nursing homes in order to further evaluate their feasibility, usefulness, discriminative power, and potential for quality improvement.

An evaluation of the quality of care with quality indicators best includes process as well as outcomes indicators of care in one monitoring cycle [16,41]. The quality indicator set for palliative care that we developed for nursing homes uses both types of indicators. We also included objective as well as subjective quality indicators. The psychometric analyses in this pilot study showed good results for all of the indicators on discriminative power expect for ′recognizing the approaching death′ and ‘satisfied by care delivered’, which are both indicators subjectively measured by caregivers. Both of the indicators might have been influenced by response bias, due to social desirability or a tendency to overestimate their skills [42] and were discarded from the quality indicator set. From this finding we might conclude that, when using self-assessment instruments for quality monitoring, caregivers should report as much as possible on objective information of care, i.e., information that can be found in the patient file. Such biases can best be monitored by regularly evaluating the quality indicator set for psychometric criteria, in order to keep the quality data sensitive to changes in quality of care over time and between health care services.

An important strength of our study is the rigorous, systematic development method while using stakeholders and the mixed-method design, including the RAND/UCLA method for indicator development, quantitative analysis of data, and qualitative interviews with the coordinators in the nursing homes to evaluate the instrument. Hence, we were able to evaluate the instrument and its measurement procedure in terms of face validity, feasibility, discriminative power, and usefulness. Additionally, because the thoroughly follow-up with the involved coordinators before, during and after the pilot, barriers and facilitators influencing the course of the measurement were identified. The small database is one of the limitations of this study. Psychometric analyses were limited and a study on further implementation is necessary to evaluate and validate the instrument including the quality indicators. The absence of response rates is another limitation of our study. Although coordinators drafted a list of included residents, we were unable to match them with the questionnaires because of GDPR policies. Additionally, although we aimed to include as many residents as possible while using three versions of the questionnaire in the resident’s evaluation, we have no insights regarding whether residents with cognitive problems, such as dementia, were sufficiently involved in the quality monitoring.

Worldwide initiatives have been taken to monitor and improve the quality of palliative care in different settings [43–47]. Several studies have pointed out that the quality of dying and end of life care is not optimal across Western countries [48–50]. Some of these studies also used quality indicators in order to evaluate quality of palliative care in this setting, albeit being mostly focused on cancer patients, hospital and home setting, and administrative data in order to gather information on care processes and patient outcomes.

Therefore, these measures are labeled as objective indicators and, although they provide a good basis for quality monitoring, they are not enough to point out strengths and weaknesses in specific long-term care organizations. Additionally, user perspective needs to be considered through subjective quality measures [51]. With our instrument, we focused on nursing homes and tried to combine both objective and subjective measures into different stakeholder perspectives in order to reach a comprehensive picture on quality of palliative care. Only this way, important themes for elderly persons, such as dignity and autonomy, can be properly addressed in order to improve the quality of care in the light of also improving the quality of life for residents in nursing homes. According to our qualitative analysis in this pilot study, coordinators indeed found the results of their measurement recognizable for their nursing home, supporting the face validity of these indicators (i.e., they are measuring what they aim to measure) from a caregiver point of view. This is an important finding, because, in order to reach effective change in health care, the value of timely and recognizable feedback is a crucial incentive for caregivers in order to continuously engage in these monitoring and improvement processes [11,40,45,52–54].

In light of care improvement in the field of palliative care in a nursing home context, a large-scale research project, ‘PACE steps to success’, has recently been implementing a combination of tailored improvement initiatives focusing on communication, advanced care planning, and knowledge and skills on end of life care while using a train-the-trainer implementation model. Although the intervention did not show significant effect on their primary outcome (comfort in the last week of life for residents), the process evaluation showed that the implementation rate was highly variable between countries and teams, and several challenges arose, such as attitude and motivation of staff, and skills and expertise of the trainer appointed to the individual nursing homes [26,48]. Our previous implementation research in palliative care already showed that caregivers are willing to invest in quality improvement trajectories and learn from other teams, but they need support from their management and financial reimbursement or staff to engage in these activities [40]. In this pilot study, we found the same barriers and facilitators pointing out the importance of setting the right preconditions for implementation in the nursing home context, throughout research and policy. This might be done by primordially evaluating nursing home readiness in order to increase the use and correct application of the quality indicators [55].

5. Conclusions

In this study, we developed and evaluated a quality indicator set and a tailored measurement procedure consisting of 19 indicators to monitor quality of palliative care in Belgian nursing homes. We combined both objective and subjective measures into four questionnaires for different perspectives in order to reach a comprehensive picture on quality of palliative care, end-of-life care and advance care planning in nursing homes. Care teams in nursing homes are able to monitor themselves based on these indicator scores. We found, while using both quantitative as qualitative analyses, the developed instrument had good face validity, feasibility, discriminative power, and it is useful in terms of quality monitoring according to caregivers, though establishing concrete improvement goals based on quality indicator scores remains difficult for them. The quality indicators are ready for further use in a large implementation study and process evaluation in Flemish nursing homes in order to further evaluate their feasibility, usefulness, discriminative power, and potential for quality improvement.

Supplementary Materials: The following are available online at https://www.mdpi.com/1660-4601/18/2/829/s1, Table S1: list of quality indicators with numerators, denominators and questions.

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Assessing Nursing Homes Quality Indicators' between-Provider Variability and Reliability: A Cross-Sectional Study Using ICCs and Rankability

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Abstract: Nursing home quality indicators are often used to publicly report the quality of nursing home care. In Switzerland, six national nursing home quality indicators covering four clinical domains (polypharmacy, pain, use of physical restraints and weight loss) were recently developed. To allow for meaningful comparisons, these indicators must reliably show differences in quality of care levels between nursing homes. This study's objectives were to assess nursing home quality indicators' between-provider variability and reliability using intraclass correlations and rankability. This approach has not yet been used in long-term care contexts but presents methodological advantages. This cross-sectional multicenter study uses data of 11,412 residents from a convenience sample of 152 Swiss nursing homes. After calculating intraclass correlation 1 (ICC1) and rankability, we describe between-provider variability for each quality indicator using empirical Bayes estimate-based caterpillar plots. To assess reliability, we used intraclass correlation 2 (ICC2). Overall, ICC1 values were high, ranging from 0.068 (95% confidence interval (CI) 0.047–0.086) for polypharmacy to 0.396 (95% CI 0.297–0.474) for physical restraints, with quality indicator caterpillar plots showing sufficient between-provider variability. However, testing for rankability produced mixed results, with low figures for two indicators (0.144 for polypharmacy; 0.471 for self-reported pain) and moderate to high figures for the four others (from 0.692 for observed pain to 0.976 for physical restraints). High ICC2 figures, ranging from 0.896 (95% CI 0.852–0.917) (self-reported pain) to 0.990 (95% CI 0.985–0.993) (physical restraints), indicated good reliability for all six quality indicators. Intraclass correlations and rankability can be used to assess nursing home quality indicators' between-provider variability and reliability. The six selected quality indicators reliably distinguish care differences between nursing homes and can be recommended for use, although the variability of two—polypharmacy and self-reported pain—is substantially chance-driven, limiting their utility.

Keywords: nursing homes; long-term care; benchmarking; quality indicators; health care; quality of health care

1. Introduction

Quality indicators are used worldwide to monitor, assess and report the quality of care provided in healthcare settings by measuring specific health care structures (e.g., staffing), processes (e.g., patient referrals) or outcomes (e.g., nosocomial infections) that reflect quality of care [1,2]. Healthcare providers can use them for continuous quality monitoring or for benchmarking, i.e., to compare healthcare

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providers, to measure quality against accepted standards or to measure developments over time. Benchmarking these indicators allows evaluation and comparison of healthcare providers' quality of care levels. However, concerns have been expressed regarding the value of quality indicators and publicly reported benchmarking [3–6]. Therefore, to ensure that quality indicators provide useful information, they need to be evaluated by criteria including but not limited to validity, feasibility and relevance. Particularly in the context of publicly reported benchmarking, quality indicators have to reliably assess differences in quality of care between healthcare providers. Quality indicators should thus be able to show (1) between-provider variability and (2) reliability. Between-provider variability refers to the quality indicator's ability to indicate differences in quality of care beyond chance, i.e., to identify higher-performing and lower-performing healthcare providers [7]. The quality indicator's reliability is its capacity to accurately and consistently measure the particular quality it indicates [8,9]. If both characteristics apply to the quality indicators used, they can be used for benchmarking, which has the potential to support the maintenance and improvement of quality of care [10].

In several countries (e.g., the United States, Australia, Canada), nursing home quality indicators have been measured and reported publicly for some time [11]. Quality indicators cover a wide variety of themes, most commonly physical restraints, falls, pressure ulcers and weight loss. They tend to be assessed either with routinely used instruments (e.g., Resident Assessment Instrument-Minimum Data Set (RAI-MDS) in the United States and Canada) or through specific data collections (e.g., the National Aged Care Mandatory Quality Indicator Program in Australia). Depending on the country, the results may be reported to the nursing home administration, regionally and/or nationally [12–15]. In Switzerland, despite legislation providing legal bases for the measurement and public reporting of quality indicators in nursing homes since 1994, their measurement at the national level started only in 2019, with the first quality indicator results still not published as of October 2020 [16]. Their selection and development included a review and expert consultations, considering a variety of criteria (e.g., relevance, feasibility, reproducibility) [17,18]. In 2016, based on a broad stakeholder consultation, the first set of six quality indicators indicating percentages of specific health processes or outcomes among nursing home residents were selected: the percentage of residents with polypharmacy (one quality indicator), experiencing pain (two quality indicators), being subjected to physical restraints (two quality indicators) and with weight loss (one quality indicator). The details of the selection process are reported in Appendix A. After the selection was made, we conducted an analysis to evaluate whether the six quality indicators' between-provider variability and reliability were adequate for national and publicly reported benchmarking.

Methods for assessing between-provider variability include intraclass correlation 1 (ICC1) and rankability. To assess each indicator's capacity to differentiate between facilities, we used the ICC1, which reflects "the proportion of variance that is accounted for by the group level" [19]. While this method has been used in other settings to evaluate quality indicators' between-provider variability (e.g., hospital quality indicators), it has not yet been used in long-term care contexts [20]. A second metric to assess between-provider variability is rankability, i.e., "the part of heterogeneity between … clinics [or nursing homes] that is due to true differences" [21]. Finally, it is also important to assess the group mean via intraclass correlation 2 (ICC2), which describes the reliability of each quality indicator [22]. Therefore, this study aims to use ICC1 and rankability to report on the six selected nursing home quality indicators' between-provider variability and ICC2 to report on their reliability.

2. Materials and Methods

2.1. Design and Sample

This multicenter pilot study used routine resident data from a convenience sample of 152 nursing homes located across Switzerland's three major language regions (German, French, Italian). In 2017, 1561 Swiss nursing homes provided both medical care and social services to more than 157,716 older adults. Around 80% of these people are long-term residents, with an average length of stay of 2.5 years [23]. Inclusion criteria at the nursing home level were for each facility to be licensed as a nursing home and to have agreed to work with a specific version of the assessment instrument including the items needed for the six national quality indicator measurements (Appendix B for further information). At the resident level, all long-term residents residing in the nursing home at the date of the data export were included.

2.2. Variables and Measurements

Each resident's birth year (YYYY format), admission date to the nursing home (YYYYMMDD format), sex (male/female) and care level (scale of 1–12) were used. Care level—calculated based on an assessment performed by the nursing home staff—was allocated a number from 1 to 12, with each higher number representing an additional 20 min of care time per day. We calculated length of stay in days from admission to data export day, and residents' age as the difference in years between birth year and year of the assessment. We also collected variables specifying each patient's depressive (depression rating scale; DRS) and cognitive status (cognitive performance scale; CPS). The DRS is calculated on a scale from 0 to 14: scores of 3 or above indicate evidence of minor to major depression [24]. The CPS is calculated on a scale from 0 ("intact") to 6 ("very severe impairment") [25]. The size of the nursing home (number of beds) was also included.

We used the following variables to calculate the six quality indicators, all of which were collected for the recall period "in the last 7 days": number of active ingredients taken; frequency and intensity of self-reported and observed pain; frequency of trunk fixation use or seating that prevents the residents from rising; frequency of bedrail use; and percentage of weight loss during the last 30 or 180 days. We also used a variable specifying whether the resident's latest assessment was that at admission (yes/no) and whether the nursing home staff evaluated that he or she had a life expectancy of under 6 months (yes/no/information not collected). In case of use of a physical restraint, we also used a variable specifying the context in which the measure was applied (use of the measure on the request or in agreement with a resident capable of judgment/use of the measure on a resident incapable of judgment/context not yet clarified).

The six selected quality indicators were defined as follows: *polypharmacy* is the percentage of residents who took 9 or more active ingredients over the last 7 days. The cut-off value of 9 is in line with other international measures of polypharmacy in nursing homes [26]. *Pain* is measured by 2 quality indicators: *self-reported pain* is the percentage of residents with daily moderate or higher pain intensity or those with nondaily very strong pain intensity in the last 7 days. *Observed pain* is the percentage of residents who showed daily moderate or higher pain intensity or those who showed nondaily very strong pain intensity in the last 7 days. *Physical restraint* is also measured through 2 quality indicators. The first measures the percentage of residents with daily fixation of the trunk or with seating that prevented them from rising in the last 7 days; the second measures the percentage of residents with daily use of bedrails or other devices on all open sides of their bed so that they could not leave the bed independently in the last 7 days. The sixth quality indicator is *weight loss*, measuring the percentage of residents with weight loss of ≥5% in the last 30 days or of ≥10% in the last 180 days.

Quality indicators are described in a numerator/denominator format. Their results are expressed as a rate for each nursing home (e.g., percentage of residents with observed pain in a specific nursing home). The numerator includes all residents for whom the outcome of interest (e.g., pain) is indicated; the denominator includes all residents except those who fit predetermined exclusion criteria. For the self-reported pain quality indicator, for example, residents were excluded if they did not give a valid answer to questions related to pain frequency or intensity. For both physical restraint quality indicators, residents capable of judgement who either requested or agreed to the measure were excluded. For the weight loss quality indicator, we applied two exclusion criteria: resident's life expectancy estimated by the staff to be under 6 months or current assessment of the resident is the admission assessment. Definitions, numerators, denominators, items measured and exclusion criteria for all quality indicators are displayed in Table 1.

Table 1. Description of the six Swiss quality indicators.

Theme	Definition	Numerator	Denominator	Items Measured	Exclusion Criteria
Polypharmacy	Percentage of residents who took 9 or more active ingredients in the last 7 days	All residents who had taken 9 or more active ingredients in the last 7 days	All long-term care residents	Number of active ingredients in the last 7 days	No exclusion criteria
Self-reported pain	Percentage of residents with daily moderate or higher pain intensity or residents with nondaily very strong pain intensity in the last 7 days	All residents who reported the following pain in the last 7 days: - Daily moderate, strong or very strong, unbearable pain OR - Nondaily very strong, unbearable pain	All long-term care residents, excluding those who did not give a valid answer regarding frequency or intensity of self-reported pain	Frequency and intensity of self-reported pain in the last 7 days	No valid answer to questions on frequency OR intensity of self-reported pain
Observed pain	Percentage of residents who showed daily moderate or higher pain intensity or residents who showed nondaily very strong pain intensity in the last 7 days	All residents where the following pain was observed in the last 7 days: - Daily moderate, strong or very strong, unbearable pain OR - Nondaily very strong, unbearable pain	All long-term care residents	Frequency and intensity of observed pain in the last 7 days	No exclusion criteria
Physical restraint, trunk fixation or seating that prevents the resident from rising	Percentage of residents with daily fixation of the trunk or with seating that prevented the resident from rising in the last 7 days	All residents who had daily in the last 7 days: - Trunk fixation OR - Seating that prevents the resident from rising	All long-term residents, excluding those who wanted or agreed to the use of this measure	Frequency of use in the last 7 days and context of the measure	Residents capable of judgment who either requested or agreed to the measure

Table 1. *Cont.*

Theme	Definition	Numerator	Denominator	Items Measured	Exclusion Criteria
Physical restraint, bedrails	Percentage of residents with daily use of bedrails or other devices on all open sides of the bed that did not allow the resident to leave the bed independently in the last 7 days	Residents with daily application of bedrails or other devices on all open sides of the bed, which does not allow the resident to leave the bed independently	All long-term residents, excluding those who requested or agreed to the use of this measure	Frequency of use in the last 7 days and context of the measure	Residents capable of judgment who either requested or agreed to this measure
Weight loss	Percentage of residents with weight loss of 5% or more in the last 30 days or of 10% or more in the last 180 days	Residents with a weight loss of 5% or more in the last 30 days or 10% or more in the last 180 days	All residents, excluding those with a life expectancy estimated by the staff as lower than 6 months or residents who were last assessed at admission to the nursing home	Weight loss of 5% or more in the last 30 days or of 10% or more in last 180 days	Residents with: - Life expectancy under 6 months - Last assessment at admission

2.3. Data Collection

Resident data were collected by the nursing homes via updated versions of routinely used resident assessments instruments between July 2016 and August 2017. All quality indicator information was obtained through routine data collection processes already in place, including observations (e.g., physical restraints) or conversations with residents (e.g., self-reported pain). At the time of the study in Switzerland, three assessment instruments were in use: (1) Nursing Home Resident Assessment Instrument (RAI-NH), (2) the Planification Informatisée des Soins Infirmiers Requis (PLASIR/PLEX) (computerized planning of required nursing care) and (3) the BewohnerInnen-Einstufungs-und Abrechnungssystem (BESA) (residents classification and billing system) [27]. Further information on these instruments is available in Appendix B. Each assessment instrument provider had to recruit a minimum of 50 nursing homes to ensure the sample would have an equal number of nursing homes working with each instrument. The goal was to have a total study sample consisting of minimum 10% of all Swiss nursing homes. To ensure that all residents present in each nursing home at the time of the data export were assessed at least once, data were collected for a minimum of 6 months in each nursing home.

2.4. Statistical Analysis

We examined the data on each quality indicator for completeness, plausibility and missing values. Missing data were dealt with by listwise deletion; for each quality indicator, the number of valid residents depended on the exclusion criteria. We also computed resident characteristics and prevalence rates for the six studied quality indicators. Risk adjustment for the indicators was assessed in a preparatory study using hierarchical multiple regression models, with the Akaike information criteria and odds ratios assessed for each quality indicator. All indicators were risk-adjusted for the resident's cognitive performance and care dependency with additional adjustment for polymedication with age and for both pain indicators with depression and gender. Risk adjustment variables are provided in Table 2. Statistical analyses were conducted by N.S., confirmed by C.B. and supervised by M.S., who has a track record of statistical analyses in healthcare quality measurement.

Table 2. Risk adjustment variables, prevalence rates and missing values for the six Swiss quality indicators.

Theme	Risk Adjustment Variables	Prevalence Rate, Mean %, SD [1]	Missing, % (n)
Polypharmacy	- CPS [2] - care level - age	43.0 (12.9)	0.0 (0)
Self-reported pain	- CPS - care level - depression - gender	19.7 (11.8)	13.4 (1525)
Observed pain	- CPS - care level - depression - gender	14.9 (10.4)	0.7 (81)
Physical restraint, trunk fixation or seating that prevents the resident from rising	- CPS - care level	3.4 (5.2)	0.0 (0)
Physical restraint, bedrails	- CPS - care level	13.0 (11.3)	1.6 (132)
Weight loss	- CPS - care level	7.9 (6.8)	0.1 (2)

Abbreviations: [1] SD: standard deviation, [2] CPS: cognitive performance scale.

2.4.1. Between-Provider Variability: ICC1 and Rankability

To assess each quality indicator's capacity to distinguish between providers, we computed ICC1, caterpillar plots and rankability. The ICC1 shows the proportion of variation in the quality indicator that is attributed to the group level [28]. In this context, ICC1 values typically range from 0.0 to 0.3, where values over 0.05 indicate relevant between-provider variability [19,29,30]. The ICC1 is the ratio of variance among providers (*VG*) over the total variance, i.e., the group variance (*VG*) and the within-group or residual variance (*VR*). As we analyze binary outcomes, VR is the latent scale variance of the logit model $\pi^2/3$, leading to the following equation: $ICC1 = VG / (VG + \pi^2/3)$ [29,31].

2.4.2. Reliability: ICC2

Variances for the ICC1 were calculated using a conditional generalized linear mixed model with 95% confidence intervals to assess the uncertainty of the estimate [32]. Additionally, to check the distribution of nursing home estimates and explore between-provider variability visually, we computed caterpillar plots based on empirical Bayes estimates with 95% confidence intervals [33,34]. Each quality indicator's caterpillar plot shows that indicator's estimate for each nursing home (e.g., weight loss), as well as whether it deviates positively or negatively from the grand mean across all nursing homes. We calculated ICC1 figures with the rptR package in R (Version 3.6.6., R Core Team, 2020) [31,34]. We also explored quality indicators' rankability, i.e., the part of variability between nursing homes measured by quality indicators that results from true differences in quality of care [35]. High rankability for a particular indicator allows performance ranking for that indicator, e.g., polymedication [20]. Rankability (ϱ) is defined as: $\varrho = VG/(VG + median(s^2))$, with $median(s^2)$ indicating the variance of the individual facility effect estimates from a fixed effect regression model. Rankability (range: 0–100%) refers to observed differences that might result from quality of care disparities and is classed as low (<50%), moderate (50–75%) or high (>75%) [28,35]. Finally, we assessed the six quality indicators' group mean reliability via ICC2. ICC2 is the ratio of group variance to total variance/*k*, where *k* is the number of nursing homes, i.e., $ICC2 = VG/((VG+ \pi^2/3) \times (1/k))$ [19].

ICC1 and ICC2 are generally interdependent: the higher a quality indicator's ICC1, the higher its ICC2. The ICC2 typically ranges from 0.6 to 1.0, with values closer to 1 indicating higher measurement reliability.

2.5. Data Management and Ethical Considerations

At the end of the data collection period, each instrument developer anonymized all resident-level data and transferred all records to the Swiss Federal Office of Public Health, which pseudonymized them at the nursing home level. The study data were then transferred to the research group, which carried out the analysis. Data protection and confidentiality were ensured during every phase of the study. The Ethics Committee of Northwest and Central Switzerland declared that according to Swiss legislation, the study did not require ethical clearance (EKNZ Req-2017-00052).

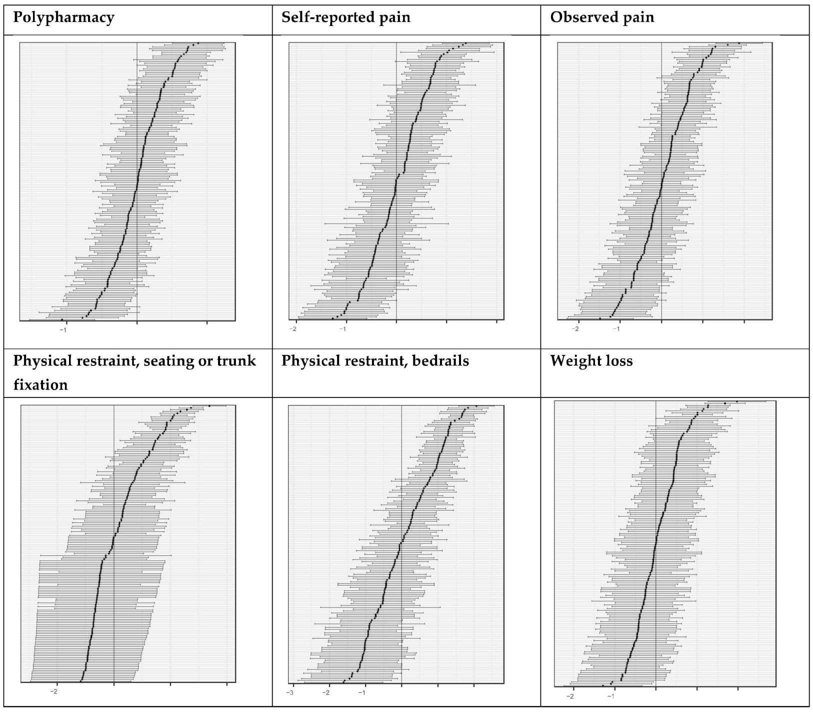
3. Results

3.1. Sample and Quality Indicators Description

A total of 152 nursing homes participated in the study (56 for RAI-NH, 46 for PLAISIR/PLEX, 50 for BESA; mean size: 102.3 beds (standard deviation (SD): 51.2)). These housed 11,412 residents (mean age: 86.1 years (SD: 8.36); 72.8% female). The median length of stay was 859 days (interquartile range (IQR): 375–1646 days), with a median care level of 6.0 (IQR: 4–9). The mean prevalence of each quality indicator and missing item data per quality indicator are displayed in Table 2.

3.2. Between-Provider Variability: ICC1 and Rankability

The between-provider variability of this study's six selected quality indicators was relatively high: all ICC1 values were above 0.05, ranging from 0.068 (polypharmacy) to 0.396 (physical restraint, trunk fixation or seating that prevents the resident from rising). Our caterpillar plots illustrate that each quality indicator can discriminate sufficiently between the higher- and lower-performing nursing homes (Figure 1). On the one hand, we were able to identify better-performing nursing homes, i.e., those housing submean proportions of residents with the indicator result; e.g., 17 nursing homes had significantly fewer residents with polypharmacy. Only in the case of the *physical restraint, trunk fixation or seating that prevents the resident from rising* quality indicator was it not possible to differentiate higher-performing nursing homes, as many facilities had no such cases, resulting in a low mean. On the other hand, we were able to identify lower-performing nursing homes, i.e., those having significantly higher proportions of residents with the quality indicator result than the mean; e.g., 13 had a higher percentage of residents with weight loss. Rankability values ranged from low, at 0.144 (polypharmacy) and 0.471 (self-reported pain); to moderate, at 0.692 (observed pain) and 0.720 (weight loss); to high, at 0.865 (physical restraint, bedrails) and 0.976 (physical restraint, trunk fixation or seating that prevents the resident from rising). ICC1 and rankability results are provided in Table 3. Unadjusted results are provided in Appendix C.



Polypharmacy

Self-reported pain

Observed pain

Physical restraint, seating or trunk fixation

Physical restraint, bedrails

Weight loss

Figure 1. Caterpillar plots based on empirical Bayes estimates of the six quality indicators. In each plot, the horizontal lines represent the nursing homes: the dot in the middle of each line represents the percentage of nursing home residents to whom the quality indicator applies; the whiskers represent the 95% confidence interval (CI). The vertical line represents the (standardized, i.e., centered to 0) sample mean of the specified quality indicator. If the whiskers (i.e., the CI) do not touch the vertical line (i.e., the mean), the result of the nursing home in the quality indicator specified (e.g., the percentage of residents with weight loss in this nursing home) differs significantly from the sample mean (e.g., the mean percentage of residents with weigh loss across all nursing homes). Lower-performing nursing homes with quality indicator values above the mean, e.g., more residents with weight loss, are on the top-right side of the plot. Those with quality indicator values below the mean, e.g., fewer residents with weight loss, are on the negative (lower left) side of the plot. If the CI touches the sample mean, the nursing home's result does not differ significantly from the mean.

Table 3. Risk-adjusted results of intraclass correlation 1 (ICC1), intraclass correlation 2 (ICC2) and rankability of the six quality indicators.

Theme	ICC1 [1] (95% CI [2])	ICC2 [3] (95% CI)	Rankability (ϱ)
Polypharmacy	0.068 (0.047–0.086)	0.917 (0.889–0.935)	0.144
Self-reported pain	0.134 (0.104–0.166)	0.896 (0.852–0.917)	0.471
Observed pain	0.223 (0.131–0.325)	0.941 (0.879–0.965)	0.692
Physical restraint, trunk fixation or seating that prevents the resident from rising	0.396 (0.297–0.474)	0.990 (0.985–0.993)	0.976
Physical restraint, bedrails	0.371 (0.297–0.425)	0.989 (0.984–0.991)	0.865
Weight loss	0.137 (0.085–0.180)	0.899 (0.856–0.922)	0.720

Abbreviations: [1] ICC1: intraclass correlation 1, [2] CI: confidence interval, [3] ICC2: intraclass correlation 2.

3.3. Reliability: ICC2

The reliability results of the six quality indicators were high according to usual standards: ICC2 ranged from 0.896 (self-reported pain) to 0.990 (physical restraint, trunk fixation or seating that prevents the resident from rising). ICC2 results are found in Table 2. Unadjusted results are provided in Appendix C.

4. Discussion

For each of six selected quality indicators, this study uses ICC1, rankability and ICC2 to evaluate two important properties: between-provider variability and reliability. Our results show that four of the six quality indicators (observed pain, physical restraint, trunk fixation or seating that prevents the resident from rising and bedrails, malnutrition) have high ICC1, moderate to high rankability and high ICC2 values. This indicates respectively that between-nursing home variability was high and that these four quality indicators were generally reliable. Two indicators—polypharmacy and self-reported pain—also showed high reliability and variability beyond chance, however to a lesser extent, which makes them less ideal for comparing nursing homes. These two quality indicators represent similar challenges for nursing homes. Even with focused efforts, polypharmacy is difficult to tackle for facilities and reducing the polypharmacy rate might be complex because of structural circumstances (e.g., physician system, legal regulations). Similarly, lowering the percentage of residents with pain is complex (i.e., difficulties in and possibilities for treating chronic painful conditions) for nursing homes. Therefore, from a measurement viewpoint, while four quality indicators can be recommended without hesitation for publicly reported benchmarking, two do not fully achieve this status.

Internationally, reports of nursing home quality indicators' between-provider variability are rare. To our knowledge, the study by Rantz et al. (2004), who reported a between-provider variability evaluation for 23 nursing home quality indicators used in the United States, is the only published study to do so. That study grouped nursing homes according to resident outcomes, tested the groups for significant differences and performed pairwise comparisons [36]. Of the 23 quality indicators tested, the authors concluded that only ten could distinguish the group of nursing homes with good resident outcomes from that whose corresponding outcomes—including for polymedication and weight loss—were poorer. In contrast, ICC1 and rankability provide measures to assess each indicator's ability to differentiate between facilities. ICC1 does so while addressing clustering and multiple testing, neither of which featured in the study by Rantz et al. However, Rantz et al. were by no means exceptional in this respect: our literature review could not identify a single study using ICC1, rankability or caterpillar plots based on empirical Bayes estimates to evaluate between-provider variability in the long-term care sector, although all have been used in other fields.

Among publicly reported nursing home performance figures, a small number of countries (e.g., the Netherlands) have reported the reliability of isolated quality indicators, while Germany and the United States have published studies or reports assessing the reliability of entire nursing home quality indicator sets (respectively, of 10 and more than 100 quality indicators) [37–40]. These studies used single item-level and/or weighted kappas and percent agreement between "gold standard" nurses and nursing home nurses to assess the selected quality indicators' interrater and intrarater reliability. Reliability results varied widely between quality indicators. The use of Cohen's kappa to assess nursing home quality indicators' reliability only provides information on the reliability of individual measures. Using ICC2 allows us to acquire information on the reliability of quality indicators at the group level, which we argue is more interesting, as the facility mean is targeted rather than the reliability of the measure at the individual level [29]. While this level of reference makes the ICC2 ideal for nursing homes benchmarking, we could identify no other studies using it as a reliability measure.

Despite having widely different cut-off values, our results show that ICC1 and rankability correlated strongly: high ICC1 values were reflected by high rankability values; e.g., our highest ICC1 value, 0.396, was linked to our highest rankability value, 0.976 (for physical restraint, trunk fixation or seating that prevents the resident from rising). The same applies for low figures: our lowest ICC1, 0.068 corresponded with the lowest rankability, 0.144 (for polypharmacy). This relationship has been explored with a similar correlation for the ranking of binary hospital quality indicators [20]. Although an ICC1 of 0.05 has been regarded as the lower threshold for quality indicators, considering the rankability found in our study, this threshold might be higher, at roughly 0.15. Indeed, if both rankability and ICC1 results are higher than the threshold, there is evidence of differences in quality of care between nursing homes, and these quality indicators can therefore be recommended.

Several issues surround the use of quality indicators that have not been adequately evaluated or simply do not meet acceptable standards. Quality indicators that cannot distinguish quality of care differences are not usable to publicly benchmark healthcare providers: they can lead to the publication of erroneous information, inappropriate comparisons or misguided quality improvement efforts, i.e., resulting from nursing home administrators' or policy-makers' use of them to set quality improvement targets. Further, inaccurate benchmarking results can lead to unjustified rewards or sanctions both by governments and by other stakeholders, particularly residents' families [3,41]. Conversely, regular, accurate reporting on meaningful quality indicators contributes to accountability and transparency in the healthcare system [10]. Therefore, ensuring nursing home quality indicators' can identify between-provider variability and reliability for benchmarking is a highly important step in their evaluation.

Although quality indicators can be extremely useful to identify quality improvement targets at the nursing home and policy levels, they cannot be used without considering the context. For example, as each quality indicator shows only one very limited aspect of a healthcare provider's care, no single quality indicator can be used to characterize providers' overall quality of care. Instead, sets of reliable quality indicators can show nursing home administrators their facilities' rankings compared to other providers, thereby allowing them to identify, prioritize and allocate resources to quality improvement targets. However, while quality indicators are excellent tools for comparing quantifiable outcomes, they do not identify poor results' underlying problems, indicate whether results are clinically meaningful or guide nursing homes regarding their improvement (i.e., regarding which specific factors require action or at which levels) [42,43]. Perhaps most importantly, while well-developed and well-evaluated quality indicators can provide valuable information to nursing homes, nursing home administrators often lack the skills, knowledge, leadership or professional and organizational capacities to put that information to good use [43]. Therefore, nursing homes need to work towards developing feasible strategies to identify and act on genuine quality improvement efforts based on quality indicator results.

Despite this pilot study's large sample size, which includes around 10% of all Swiss nursing homes (1561 nursing homes in Switzerland in 2017), the included nursing homes' mean bed count (102 beds) was somewhat higher than the Swiss average (62 beds) [23]. Even based on this rather homogeneous sample in comparison to the full sample of Swiss nursing homes, all six selected quality indicators showed between-provider variability, indicating they could be used in Swiss nursing homes. The indicator of self-reported pain had 13.4% missing values due to respondents not wanting or not being able to answer, which precludes a proportion of nursing home residents from being represented by this indicator. Therefore, it is important to evaluate both self-reported and observed pain, since the latter includes all residents. We report ICC1 and ICC2 in this study. While the value of the ICC1 is unchallenged in assessing between-provider variability, the ICC2 has generally been less frequently used and more recent literature has identified difficulties of the ICC2 when ICC1 values are very low [44]. This is not the case in our study; however, the generally high ICC2 values might indicate less sensitivity. The rankability scores seem to provide a more nuanced picture.

5. Conclusions

Based on the six selected nursing home quality indicators' ICC1, rankability and ICC2 values, we determined that all six quality indicators can reliably distinguish differences in quality of care between nursing homes, although two operate at a lower level. Even though all are suitable as quality indicators for benchmarking and public reporting, for two of them, the observed variability is substantially driven by chance, limiting their utility. Still, they can serve nursing homes to assess their quality in this area and initiate quality improvement projects where needed. This pilot study showed that both ICCs and rankability are meaningful methods both to evaluate nursing home quality indicators' between-provider variability and reliability and to validate them. Assessing quality indicators' measurement properties is an essential step towards building sets of quality indicators that are useful in nursing home practice, policy and research. Public reporting of quality indicators increases transparency of the quality of care provided in nursing homes and provides an assessment of the national system. In practice, such indicators allow nursing homes to compare themselves with other facilities. For lower-performing nursing homes, this can be a starting point in identifying domains where quality improvement might be needed. Identifying higher-performing nursing homes helps to identify best care practices in these domains and enable learning from them. Regular evaluation of nursing home quality indicators, including between-provider variability and reliability, should be carried out and reported in all applicable contexts.

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Appendix A

Selection Process of the Four Themes of the Swiss Quality Indicators

The selection of the four themes covered by the six Swiss quality indicators was based on a multistep method-guided process started in 2008 [17]. This process was managed by a Steering Committee under the leadership of the Swiss association of nursing homes (CURAVIVA), with the participation of the Swiss Federal Office of Public Health, the Swiss Conference of Cantonal Health Directors and the Swiss Federal Statistical Office. The first step consisted of a literature review on the themes measured by quality indicators in the nursing home sector at the international, national and cantonal levels [45–48]. Based on this review, the Steering Committee selected five themes: physical restraint, weight loss, behavioral and psychological symptoms of dementia, medication (polypharmacy and antipsychotics) and pain.

The following phase consisted of the development of definitions, the development of evidence-based measurements and the operationalization of the measurements and answer options for the five selected themes. According to the RAND/UCLA methodology, development was supported by a multiexpert consultation for each theme chosen [49]. In 2014, the results of this development and of the quality indicator definitions at the time were sent to the appropriate offices of the Swiss federal government, cantons, nursing home associations, professional societies and associations, insurance companies, assessment instruments and other experts for consultation [50]. The Steering Committee then selected the 6 quality indicators with the highest acceptance rate (based on the national consultation) and prepared them for national measurement. The six selected quality indicators cover 4 themes: physical restraint (2 quality indicators), weight loss, polypharmacy and pain (2 quality indicators). Criticism of the nonselected themes included doubts about their validity as quality indicators (e.g., antipsychotic use) or the fear that some themes, if used, could send misleading signals (e.g., behavioral and psychological symptoms of dementia). The topics chosen show similarities to the quality indicator set recommended at roughly the same time in Germany [51]. Furthermore, based on a literature review, the Steering Committee also recommended variables to be tested for exclusion criteria and risk adjustment. Switzerland's approach is to start with a limited set of well-evaluated quality indicators, then to strengthen and complete this set over time with additional quality indicators.

Appendix B

Table A1. Overview of the assessment instruments used in the pilot study.

Assessment Instrument [1]	Nursing Home Resident Assessment Instrument	Planification Informatisée des Soins Infirmiers Requis [2]	BewohnerInnen-Einstufungs-und Abrechnungssystem [3]
Abbreviation	RAI-NH	PLAISIR/PLEX	BESA
Distributor in Switzerland	Q-Sys	Eros	BESAcare
Language availability	German, French, Italian	French	German, French, Italian
QI variables integration	Updated version of the instrument	Additional module	Updated version of the instrument
Data collection by	Healthcare staff	Healthcare staff or external evaluators (choice of each NH)	Healthcare staff
Start of the data collection (month)	July 2016	July 2016	July 2016
Data export (month)	August 2017	February 2017	August 2017

[1] At the time of the study, only three assessment instruments were in use by Swiss nursing homes. Each nursing home has the right to choose a preferred assessment instrument. These are used to carry out routine resident data collection to help evaluate aspects of residents' needs and care (e.g., amount of care needed, cognitive functions, mobility). One such assessment must be carried out at each resident's admission, then at least once every 6 months. The data gathered serve as a basis for care planning and health insurance claims [27]. [2] Computerized planning of required nursing care. [3] Residents classification and billing system.

Appendix C

Table A2. Unadjusted results of intraclass correlation 1 (ICC1), intraclass correlation 2 (ICC2) and rankability of the six quality indicators.

Theme	ICC1 (95% CI)	ICC2 (95% CI)	Rankability (ϱ)
Polypharmacy	0.055 (0.037–0.068)	0.898 (0.865–0.918)	0.120
Self-reported pain	0.119 (0.087–0.149)	0.953 (0.931–0.962)	0.437
Observed pain	0.147 (0.113–0.177)	0.963 (0.949–0.971)	0.575
Physical restraint, trunk fixation or seating that prevents the resident from rising	0.343 (0.235–0.405)	0.988 (0.980–0.991)	0.970
Physical restraint, bedrails	0.245 (0.197–0.286)	0.980 (0.973–0.983)	0.783
Weight loss	0.135 (0.095–0.165)	0.959 (0.941–0.969)	0.715

Abbreviations: ICC1: intraclass correlation 1, CI: confidence interval, ICC2: intraclass correlation 2.

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Article

The Validity of Connecting Conversations: A Narrative Method to Assess Experienced Quality of Care in Nursing Homes from the Resident's Perspective

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Abstract: It is important to assess experienced quality of care in nursing homes, as this portrays what is important to residents and helps identify what quality improvements should focus on. Connecting Conversations is a narrative method that assesses experienced quality of care from the resident's perspective in nursing homes by having separate conversations with residents, family, and professional caregivers (triads) within a learning network. This study assessed the validity of performing the narrative method, Connecting Conversations. Trained nursing home staff (interviewers) performed the conversations in another nursing home than where they were employed. In total, 149 conversations were performed in 10 nursing homes. Findings show that experts deemed the narrative assessment method appropriate and complete to assess experienced quality of care (face validity). The questions asked appeared to capture the full construct of experienced quality of care (content validity). Additionally, there was a range in how positive conversations were and first results indicated that a nursing home scoring higher on satisfaction had more positive conversations (construct validity). More data are needed to perform additional construct validity analyses. In conclusion, Connecting Conversations shows promising results for its use as a valid narrative method to assess experienced quality of care.

Keywords: narrative; quality assessment; validity; interviews; relationship-centered care; quality of care; triad; resident perspective

1. Introduction

Worldwide, there is an increase in older people and, hence, an increasing demand for long-term care services, such as nursing home care [1,2]. Nursing homes are a type of long-term care service with 24–hour care and functional support for the most vulnerable people in our society with complex health needs [3]. The Institute of Medicine defined six domains to help define and assess quality of care: safety, effectiveness, efficiency, timeliness, patient-centeredness, and equitability [4]. It is challenging to assess quality of care, as providing care is a service that is characterized by its intangible, heterogeneous, multifaceted, perishable, and interactive characteristics [5,6]. Therefore, measures have been developed to assess a range of quality indicators, mostly focused on safety and effectiveness, such as the incidence of pressure ulcers [7]. As the data collected with quality measures are used for quality improvement, policy-making, accountability, and transparency, it is important to ensure that the quality indicators truly measure the construct they aim to measure [8–10].

Over the past decade, the nursing home culture has shifted from a mere medical approach to a more holistic, person- and relationship-centered approach, acknowledging the resident's perspective, experiences, and caring relationships [11–13]. This holistic approach requires additional assessments of quality of care from the resident's perspective, as amongst others, this can help care teams to improve quality, and it can support residents to enhance their quality of life in the nursing home [14,15]. Quality of care from the resident's perspective is a process of care experiences with expectations before, care interactions during, and an assessment of the experience afterward in a certain context, as presented in the Individually Experienced Quality of Post-Acute and Long-Term Care (INDEXQUAL) framework [16]. Expectations are influenced by personal needs, previous experiences, and word-of-mouth [5]. The experiences in the caring environment are formed by the caring relationships among the resident, their family, and professional caregivers, and their interactions [17,18]. Therefore, it is important to include the professional caregivers' and families' perspectives as well when assessing quality of care from the resident's perspective [19,20]. After the experience, an assessment is given of what happened and how it happened (perceived care services), how this impacted the resident's health status (perceived care outcomes), and how this made the resident feel (satisfaction) [21,22].

Until now, the most common approach to assess residents' quality of care has been with quantitative satisfaction, patient-reported experience, and patient-reported outcome measures, such as the Consumer Quality Index or the Net Promoter Score [7,22–26]. These measures however are not sufficient to capture quality of care from the resident's perspective, as they only assess individual elements of care experiences and are lacking the meaning behind the response to these items [21,27]. To capture the full process of residents' quality of care, it is valuable to use narratives, as these possess emotions, explain logic, provide information about the caring relationships, and capture an experience [28]. Narrative inquiry has been characterized by three dimensions: (1) personal and social (interaction); (2) past, present, and future (continuity); and (3) place (situation), and respondents receive the opportunity to share their stories and elaborate on points for improvement [29,30]. Therefore, narratives can help discover what is meaningful to residents and help to improve quality of care tailored to the individual [31]. Research has shown that care staff can use narratives to evaluate and improve care services based on care recipients' stories [32].

The development of assessment methods is a stepwise approach in which the constructs and components are defined, the method is pilot- and field-tested, and reliability and validity are assessed [10]. Determining the reliability and validity of assessment methods is important to assure the quality of the method and the corresponding data, and to provide potential users transparency when selecting an appropriate assessment method [10]. Reliability and validity of narratives are usually assessed with four key components related to trustworthiness: credibility, transferability, dependability, and conformability, mainly focused on the process of data collection and analysis [33]. However, these components have been developed for qualitative research in general, not specifically for a qualitative assessment method [34].

Reliability is a prerequisite of validity and has been defined as "the degree to which measurement is free from measurement error" [35]. For qualitative assessment methods, the data are in a narrative form and subjective, and the interviewer is considered to be part of the method and can contribute to the reliability through training and practice [34,36,37]. Therefore, reliability of narrative methods in terms of consistency can be analyzed by evaluating the procedures of how the assessments are performed [38].

Validity has been defined as "the degree to which an instrument truly measures the construct(s) it purports to measure" [35]. It evaluates whether an assessment method actually measures a construct and whether the scores of the method are consistent with a theoretical framework of that construct [10].

The question is how validity of narrative assessment methods should be evaluated and whether the concepts of face, content, and construct validity can be used, as these have been developed to evaluate quantitative assessment methods [35]. Valid methods assessing quality of care contribute to the credibility of the quality-of-care data [39,40].

In the Netherlands, the use of narratives in nursing homes is occurring more frequently nowadays, as policy guidelines recommend the use of residents' experiences for quality monitoring and improvement [41]. However, to date, little research has been done on the reliability and validity of these narratives and, if this has been addressed, this has usually been done by means of trustworthiness for qualitative research [10,42,43]. The data collected with these narrative quality assessment methods are being used in daily nursing home practice for quality improvements and policy-making, and therefore it is inevitable to determine their validity.

Recently, the narrative method "Connecting Conversations" was developed aimed at assessing the entire process of experienced quality of care in nursing homes from the resident's perspective [44] Connecting Conversations trains nursing home staff to perform separate conversations with a resident, family member, and a professional caregiver of that resident (triad). Its theoretical foundation is based on relationship-centered care and the full care experience as defined in the INDEXQUAL framework [16,45]. Connecting Conversations' feasibility has been assessed by evaluating the consistency of the procedure in terms of performance completeness, protocol adherence, and satisfaction and has been published separately in this special issue of IJERPH as well [44]. This study aimed to evaluate the validity of performing the narrative method, Connecting Conversations.

2. Materials and Methods

The study used a mixed-methods cross-sectional design and data collection was performed from October 2018 to February 2019.

2.1. Connecting Conversations

Connecting Conversations is a narrative method that assesses experienced quality of care in nursing homes from the resident's perspective. Separate conversations are performed with the resident, a family member, and a caregiver involved in the daily care of that resident (a triad) by a nursing home staff member (interviewer) employed in another care organization than where he or she performs the conversations. This provides for a learning network, creating the opportunity for interviewers to learn from each other and another environment, and it enhances an equal relationship between the participants in the triad and the interviewer. The method is based on appreciative inquiry, which focuses on what is going well and how this can be done more, instead of only focusing on problems and the negative [45].

The six main Connecting Conversations questions are about the resident's life; satisfaction with care provision; most positive experience; description of an average day in the nursing home; and relationships between the resident, family, and caregiver, based on the INDEXQUAL framework [16]. Interviewers received simple visuals (green, yellow, and red smiley) to support residents in answering the questions when needed. To ensure that interviewers have all the knowledge and skills to perform the conversations, a 3-day training is provided by UMIO, an executive branch of the university, in which interviewers learn to perform the conversations. During day 1 and 2 interviewers are taught that the questions in the protocol should be used to trigger respondents to share their stories and can be supported with conversation techniques, such as responding with probing questions, paraphrasing, and creating purposeful silences. Day 3 is focused on sharing experiences, reflecting, and learning with and from each other. Specific details on the narrative method have been published separately in this special issue of IJERPH [44].

2.2. Interpretation and Operationalization of Validity for Connecting Conversations

In total, three concepts were assessed for Connecting Conversations: (1) face validity, (2) content validity, and (3) construct validity [10]. Table 1 presents the definitions of these concepts for a narrative method, the operationalization of these concepts for "Connecting Conversations" and how they were translated into an analysis [35].

Table 1. Validity definitions, operationalization, and analyses for Connecting Conversations.

Concept	Definition	Operationalization for Connecting Conversations	Analysis
1. Face validity	The degree to which a narrative assessment method looks as though it is an adequate reflection of the construct to be measured [35]	The degree to which experts, interviewers and client representatives judged Connecting Conversations actually assesses residents' experienced quality of care in nursing homes	Three separate group discussions in which evaluations by key stakeholders, client representatives, and trained interviewers were interpreted
2. Content validity	The degree to which a narrative assessment method adequately represents the construct under study [35]	The degree to which Connecting Conversations has a sample of questions that covers the full concept of residents' experienced quality of care as defined by the INDEXQUAL framework	Analyzed whether transcripts could be coded with the themes from the INDEXQUAL framework of experienced quality of long-term care for one full triad per interviewer
3. Construct validity	The degree to which the stories of a narrative assessment method are consistent with hypotheses, e.g., with regard to internal relationships, relationships with scores of other assessment methods, or differences between relevant groups [35]	The degree to which data collected with Connecting Conversations can be interpreted as ratings of experienced quality of care, varying from negative to positive	Analyzed the %-positively coded segments per transcript for one full triad per interviewer. Hereafter, compared %-positive to the actors within a triad and between triads
		The degree to which results from Connecting Conversations are similar to results from the Net Promoter Score (NPS), assessing residents' loyalty/satisfaction	The %-positive coded segments were compared to the NPS score for all full triads of one nursing home scoring high and one scoring low on the NPS score

2.3. Setting and Participants

Care triads and interviewers were recruited from the nursing homes within the Living Lab in Ageing and Long-Term Care South-Limburg [46].

2.3.1. Care Triads

In the Netherlands, there are different types of nursing home wards that offer long-term somatic care for residents with physical disabilities, long-term psychogeriatric care for residents with dementia, or temporary rehabilitation care [47]. This study included triads with residents living in both somatic and psychogeriatric wards. Ten nursing homes each selected one ward if 15 or more residents lived in a ward or two wards if less than 15 residents lived in a ward.

Within each ward, five triads (wards <15 residents) or ten triads (wards >15 residents) were recruited randomly by the research team in collaboration with a contact person of the ward. Random selection aimed to avoid selection bias and ensured a true sample of residents' experiences on the ward could be captured. One triad consisted of a nursing home resident, a family member, and a caregiver of that resident. Inclusion criteria were that the resident was living in the nursing home and received long-term care at the time of the conversation; the family member was the nursing homes' first contact person for the resident; and the caregiver was involved in the residents' daily care provision at least one day a week.

Random selection of triads was performed by generating a random sequence list of all residents' room numbers in a specific ward. The contact person of the ward asked residents of the first 5 (or 10) randomized room numbers if they were interested in participating. When a resident refused, the next was approached until 5 (or 10) residents (and thereby, triads) were recruited. The reasons for randomizing all room numbers, prior to asking whether participants would be interested to join were threefold. First, this assured all residents received an equal chance of being included for the conversations. There is risk of selection bias when recruiting residents for conversations, as well-spoken, more involved residents and families are more likely to respond to the recruitment call. This occurred during pilot testing of the narrative method. By randomizing all resident room numbers, each has an equal chance of being selected and invited to participate. Second, the opportunity to give the resident a voice was not limited by the willingness of the family member to participate. Third, once a participant has been randomly selected and is willing to participate, he or she will have the certainty that this will happen. This avoids getting their hopes up and eventually them not being selected for the conversations. Only once a resident agreed to participate, the family and professional caregiver were approached. If the resident was unable to have the Connecting Conversations because of cognitive impairment, the triad was included as a dyad (family–professional caregiver). If no family member was available or the family did not want to participate, the triad was also included as a dyad (resident–professional caregiver). If a professional caregiver did not want to participate, he or she recommended another caregiver closely involved in the resident's care to participate.

2.3.2. Interviewers

Any staff member interested in becoming an interviewer could apply, and managers selected interviewers based on their intrinsic motivation and involvement in quality assurance by providing hands-on care or within a policy position. Additionally, a health scientist and psychologist employed at the university attended the training and performed conversations as well. Selection aimed at including 12 to 20 interviewers, as this was a suitable group size for participation in the intensive, highly interactive training.

2.4. Data Collection and Procedure

2.4.1. Procedure

Interviewers' demographic characteristics were collected at the start of training day 1. These were age in years, sex, job title, and years of working experience in the nursing home setting. The research team assigned interviewers to another nursing home than where they were employed to perform Connecting Conversations. Each interviewer was instructed to perform conversations with five full triads on a ward. Interviewers scheduled their own conversations with a contact person in their assigned nursing homes. They could perform multiple one-hour conversations a day. Family members who were unable to attend a face-to-face conversation were interviewed by phone. Interviewers audio recorded and documented a summary per question on a tablet.

2.4.2. Face Validity

Key stakeholders, client representatives, and interviewers were invited to express to what degree they judged Connecting Conversations to be an appropriate method to assess experienced quality of care in nursing homes. Key stakeholders (up to two per institution) were from the Dutch Ministry of Health, the Dutch Health Care Institute, the Dutch Client Council, the Dutch Professional Association of Nurses, the Dutch Health and Youth Care Inspectorate, and the board members of Nursing Homes. Up to three client representatives per care organization were invited through the seven care organizations within the Living-Lab of Aging and Long-Term Care [46].

Two separate interactive group discussions were scheduled, one for key stakeholders and one for client representatives, which were documented in meeting minutes. Participants discussed two questions: (1) To what extent do you judge Connecting Conversations to be an appropriate method to assess quality of care in nursing homes from the resident's perspective? and (2) To what extent do you judge the questions asked with Connecting Conversations to fully cover the concept of experienced quality of care in nursing homes from the resident's perspective? Interviewers evaluated all three training days and field notes were taken. First, information on the background and development of Connecting Conversations was presented. Thereafter, participants were invited to express their thoughts on the design of Connecting Conversations and provide the research team with constructive feedback.

2.4.3. Content Validity

To assess the degree to which Connecting Conversations has a sample of questions that covers the full concept of residents' experienced quality of care as defined by the INDEXQUAL framework, separate conversations with resident–family–caregiver triads were performed and audio-recorded, according to the Connecting Conversations protocol.

2.4.4. Construct Validity

In the Dutch national quality framework for nursing homes, the Net Promoter Score (NPS) is currently the minimally required assessment for residents' experiences in nursing homes [41]. Therefore, all participating nursing homes were offered the choice of whether they wanted the NPS to be measured in their nursing homes alongside Connecting Conversations. The NPS is a one-item measure that assesses loyalty, as a derivate for satisfaction, by asking residents one question: "on a scale of 0–10, would you recommend this nursing home to your family and friends?" A score of 9 or 10 is a promoter, and scores of 6 or below are detractors. The final NPS score is a % calculated as the different between the % of promoters and the % of detractors [26]. In general, a more positive score (>0) is considered good and a more negative score (<0) is considered poor. The NPS was considered a suitable comparator to validate Connecting Conversations' data, as it also assesses the more subjective side of quality of care from the resident's perspective. It differs from Connecting Conversations as it only provides a basic one-score rating, without reaching the underlying explanation of why this score has been given.

2.5. Data Analysis

2.5.1. Face Validity

Field notes and meeting minutes were formatted and analyzed by the first author. Data were categorized into two components: appropriateness and completeness. Within appropriateness, feedback on the appropriateness of the method was extracted, such as opinions on the choice for a narrative form or the three separate conversations. Within completeness, feedback on the number and content of questions was extracted, such as the formulation of the questions or missing topics. Two researchers evaluated the comments during two face-to-face discussions during which the categorized findings were interpreted.

2.5.2. Content Validity

A sample of all collected data was selected for validity analysis to avoid overrepresentation of an interviewer or ward. One completed triad per interviewer, which was audio recorded, was randomly selected. The random sample of transcripts was coded with the 15 themes from the INDEXQUAL framework, as this framework covers the themes of experienced quality of long-term care. Directed content analysis was performed [48]. Both researchers independently coded the transcripts with the sub-themes from the INDEXUQAL framework [16]. Coding was supported with a code tree that defined each INDEXQUAL theme (Table 2). The INDEXQUAL framework consists of four main themes divided into 15 sub-themes. For each sub-theme, a question was formulated that enhanced the coders understanding of the code tree. If a section was unrelated to the INDEXQUAL sub-themes, it was left un-coded. Discrepancies between both researchers regarding the assignment of a code were discussed with the research team until consensus was reached.

Table 2. Code tree Individually Experienced Quality of Long-Term Care (INDEXQUAL).

Theme	Sub-Theme	Interpretation
Context	Nursing home	What are the characteristics of the nursing home?
	Person	Who was and who is the resident?
Expectations	Expectations	What did the R–F–C expect from the nursing home care?
	Word-of-mouth	What did the R–F–C hear from others about nursing home care?
	Personal needs	What needs does the resident have? (sense of security, belonging, continuity, purpose, achievement, significance)
	Past experiences	What prior experiences did the R–F–C have with care?
Experiences	Experiences (daily routine)	What does an average day of the resident look like?
	Relationship-centered care	How are the relationships in the nursing home? (more general than themes below)
	• Resident–Family	How is the relationship between R–F?
	• Resident–Caregiver	How is the relationship between R–C?
	• Family–Caregiver	How is the relationship between F–C?
	Care environment	How is the subjective nursing home environment experienced?
Experienced quality of care	Perceived care services	What happened during a specific experience?
	Perceived care outcomes	How is the resident's health status?
	Satisfaction	How did it make the R–F–C feel?

R: resident, F: family, C: caregiver.

2.5.3. Construct Validity

On a scale of 1 (bad) to 10 (perfect), responders are known to give a range of answers between 1 and 10. When using narratives, the range in answers provided is less standardized. Therefore, transcripts were coded with two codes: positive and negative, by two researchers independently. Segments were only coded if a clear emotional value was provided, for example positive segments included words such as "satisfied," "happy," "great" and negative ones such as "unfortunate," "frustrating," "angry." Neutral segments such as "she reads a lot" were not coded. Per transcript, the total number of positive coded segments was calculated as a percentage of the total number of coded segments: e.g., if 50 segments were coded, of which 30 were positive and 20 were negative, the %-positive would be 60%. For each triad, the %-positive was plotted into a graph to visualize the range in %-positive between the different conversations (resident–family–caregiver) and different triads.

Additionally, the %-positive of triads performed in a participating nursing home with a high NPS (>0) in 2018, and a nursing home with a low NPS (<0) in 2018 were compared. Both NPS scores were compared to the nursing homes' %-positive. Validity was apparent if the %-positive was lower in the nursing home with the lower NPS score compared to the %-positive of the nursing home with the high NPS score. This analysis was performed on all full triads available for both nursing homes. Qualitative data were analyzed with MAXQDA version 18.1.1. (VERBI Software, Berlin, Germany) and quantitative descriptive data with SPSS version 25 (IBM Nederland B.V, Amsterdam, The Netherlands) [49,50].

2.6. Ethical Considerations

The study protocol was approved by the medical ethics committee of the regional medical center Zuyderland (17-N-86). Information about the aim of the study, the expected burden of the conversations, and confidentiality was provided to all residents, family members, and caregivers in the triads in advance by letter. Before the start of each conversation, written informed consent was provided by all participants. Residents with legal representatives gave informed assent themselves before and during the conversations, and their legal representatives gave written informed consent [51]. Participation was strictly voluntarily and participants were allowed to withdraw from the study at any moment. In order to guarantee privacy and anonymity of participants, no names or organizations were documented.

3. Results

In 2018, 16 interviewers attended the training and performed 149 Connecting Conversations (46 residents, 46 family members, 57 caregivers) in 10 different nursing homes (4 psychogeriatric, 5 somatic, 1 acquired brain injury <65 years). In total, 34 full triads were performed, 11 family–caregiver dyads, and 11 resident–caregiver dyads. Of these conversations, 125 were successfully audio recorded and 21 were not due to technical failure (n = 17), or participants refusal to audio record the conversation (n = 4). All interviewers attended the first two training days and 13 (81%) attended the third evaluation training day. Interviewers' demographics are presented in Table 3.

Table 3. Interviewer demographics and data collection.

Interviewers (N = 16)	
Mean age in years (SD)	40 (11)
% Female	14 (88)
Occupation	
Nurse (%)	10 (63)
Policy advisor (%)	3 (19)
Nurse aid (%)	1 (6)
Psychologist (%) [1]	1 (6)
Health scientist (%) [1]	1 (6)
Mean contracted hours per week (SD)	32.3 (5.2)
Mean years working experience (SD)	13.8 (9.7)

[1] Not employed in the nursing home, but at the university.

Interviewers had planned to perform five completed triads each; however, multiple triads were not completed. Reasons for an incomplete triad included: cognitive inability of the resident to participate in the conversation (n = 11), unavailability of a family member to participate (n = 11), and challenges recruiting triads within a ward due to scheduling issues and lack of time (n = 23 triads). Table 4 presents a summary of the main findings for the validity analyses.

Table 4. Main findings face, content, and construct validity.

Concept	Interpretation Connecting Conversations	Main findings
1. Face validity	The degree to which experts, interviewers, and client representatives judged Connecting Conversations truly assesses residents' experienced quality of care in nursing homes	Key stakeholders (n = 7), interviewers (n = 16), and client representatives (n = 10) evaluated the design of and questions asked with Connecting Conversations to be the right formula to assess experienced quality of care in nursing homes from the resident's perspective
2. Content validity	The degree to which Connecting Conversations has an appropriate sample of questions to cover the full concept of residents' experienced quality of care as defined by the INDEXQUAL framework	All themes and sub-themes from the INDEXQUAL framework were present in the 11 randomly selected triads. Word-of-mouth was seldom identified
3. Construct validity	The degree to which data collected with Connecting Conversations can be interpreted as true ratings of experienced quality of care. Thus, there is a variety in conversations from being not positive to very positive	%-positive ranged between and within triads • Residents, 6% * to 100% positive • Family, 23% to 100% positive • Caregivers, 31% to 100%
	The degree to which results from Connecting Conversations are similar to results from the Net Promoter Score (NPS), assessing residents' loyalty/satisfaction	A nursing home scoring low on the NPS also scored a lower %-positive compared to a nursing home scoring high on the NPS, showing a general tendency There was insufficient data for a correlation analysis

* 6% positive means 94% negative coded segments.

3.1. Face Validity

Key stakeholders (n = 7), interviewers (n = 16), and client representatives (n = 10) evaluated whether the design of and questions asked with Connecting Conversations were fitting to assess experienced quality of care in nursing homes from the resident's perspective. All expressed the importance of taking time to perform conversations and the benefit of having three separate conversations. Additionally, key stakeholders highlighted the strength of the method being based on the INDEXQUAL framework: "it is important to include the resident's experiences, but also the families' and caregivers' experiences" and client representatives confirmed, "to a large extent, the relationship with a resident determines the experienced quality of care." Interviewers were able to reflect on the questions after having performed conversations and evaluated that "they are the correct questions to ask and very clear." The main concern of key stakeholders and interviewers was whether residents with cognitive impairment would be capable to have these conversations; client representatives however did not express this concern. Interviewers, for example, suggested it would be good to "receive some more guidance and supportive tools."

3.2. Content Validity

Of the 16 interviewers, 11 completed at least one full triad with audio recordings. The 11 triads were performed in somatic wards for older people (n = 5), psychogeriatric wards for older people (n = 5), and an acquired brain injury ward for people <65 years old (n = 1).

Table 5 presents how often each INDEXQUAL sub-theme was coded with the INDEXQUAL framework. The larger the grey circle, the higher the number of coded segments. Additionally, Table 5 presents quotes for each sub-theme to enhance understanding of how the data fit the framework. Analysis showed that all themes and almost all sub-themes from the INDEXQUAL framework were present in the random selection of triads. These findings suggest that the six Connecting Conversations questions cover the full concept of experienced quality of care. Word-of-mouth is the only sub-theme that rarely occurs. Residents did not address the relationship between their family and professional caregivers, which makes sense, as they are not directly asked about this. Perceived care services, perceived care outcomes, and satisfaction were identified the most; in line with the INDEXQUAL framework that places these themes in the after "assessment" phase. Numerically, less segments were coded for residents (n = 404) compared to those for family members (n = 636) and caregivers (n = 621).

Table 5. Connecting Conversations content validity coded with INDEXQUAL themes.

Theme	Sub-Theme	R	F	C	Quote
Context	Nursing home	◦	•	◦	"It is eventually small-scale living." (F)
	Person	◍	◍	◍	"She always enjoys to talk." (C)"I am used to speaking dialect and that is what I feel comfortable with." (R)
Expectations	Expectations	◦	•	•	"What is being organized here, I have been totally amazed. I did not expect that." (F)
	Word-of-mouth		◦		"Her husband also has that. They all think it is too busy." (F)
	Personal need	◍	◍	◍	"But, close by, that is precisely what I long for. That I really live in my own village. And that is very important to me." (R)
	Past experiences	•	⊘	•	"I also think through the years, she used to live elsewhere. The family therefore has certain expectations of care that cannot always be achieved." (C)
Experiences	Experiences (daily routine)	⊘	⊘	⊘	"In the evening she usually goes to bed on time, because she has dialysis and then she has to be downstairs at 7.30 a.m." (F)
	Relationship-centered care	◉	◦	◦	"The contact with the people from the other neighborhood here . . . she really misses that connection." (C)
	Resident–Family	•	⊘	•	"It's nice every time they visit." (R)
	Resident–Caregiver	⊘	⊘	◍	"She likes all staff, so a 10." (F)
	Family–Caregiver		⊘	⊘	"Yes, actually good too; the daughter is also the first contact person." (C)
	Care environment	◍	◍	⊘	"Because, they don't always have time for us." (R)
Experienced quality of care	Perceived care services	⬤	⬤	⬤	"Yes, you are looked after, but that is all. You have to nag the entire week because you don't have absorbent products and then suddenly there are six packs on the rack." (R)
	Perceived care outcomes	◍	⬤	◍	"She always used to love to read, but reading is not possible anymore." (F)
	Satisfaction	⬤	⬤	⬤	"Sometimes a bit annoyed." (C)

C: caregiver, F: family, R: resident. The larger the colored circle, the higher the number of coded segments (calculated based on 20 percentiles). ◦ 1–7 \| • 8–26 \| ⊘ 27–37 \| ◍ 38–62 \| ⬤ 63–150 coded segments.

3.3. Construct Validity

For each transcript within a triad, both positive and negative segments could be identified and coded. An example of a positive and a negative segment are presented below.

- Positive segment Resident-Caregiver (triad 008) - Interviewer: "How is the contact between you and Mister Johnson?" Caregiver: "Actually, it is very good. I experience it as being pleasant. He is very grateful that I am there for him and help him."
- Negative segment Care environment (triad 002) - Interviewer: "Is there anything that could be better?" Resident: "Yes, the care provision. They are busy. They see everything but yeah … And the music is loud. I cannot stand that. Then I often ask if it can be softer."

Figure 1 presents the range in quality ratings between conversations and triads. Each row represents a different triad and portrays the %-positively coded segments of the resident, family, and caregiver in that triad and the "x" shows each triad's mean %-positive. For residents, %-positive ranged from 6% to 100%, for family it ranged from 23% to 100%, and for caregivers it ranged from 31% to 100%. These findings indicate that Connecting Conversations' data capture a large variety in scores range from low %-positive to high %-positive. The median %-positive over the 11 triads is 54% and caregivers (64%) seemed more positive than residents (46%) and family members (53%).

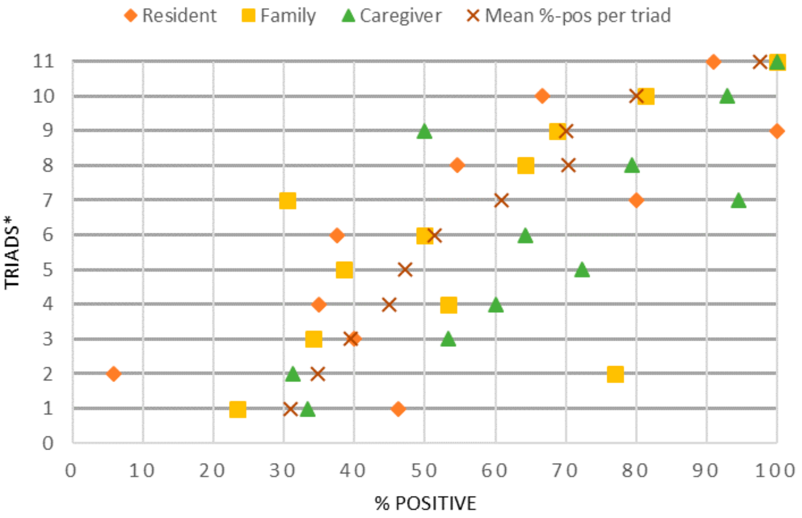

Figure 1. %-Positive coded segments of each resident, family, and caregiver per triad. * Each row represents one completed Connecting Conversation triad, presenting the %-positive for the resident, family, caregiver, and the mean %-positive for these three.

We compared %-positives to the NPS-score for two nursing homes (Table 6). Nursing home A scored high above average on the NPS score (34) and shows that this nursing home scored a higher %-positive coded segment (72%). Nursing home B scored greatly below average on the NPS score (−50) accompanied with a lower %-positive (57%). This indicates that there is a convergence between resident satisfaction measured on a one-item scale (NPS) and the qualitative data (%-positive) collected with Connecting Conversations. There were insufficient data to perform a correlation analysis.

Table 6. NPS score and Connecting Conversations %-positive.

Measure	**Nursing Home A**		**Nursing Home B**	
	Score	***n***	**Score**	***n***
NPS score (residents)	34	38	−50	16
% Positive Connecting Conversations (residents)	62%	4	49%	3
% Positive Connecting Conversations (triads R–F–C)	72%	12	57%	9

4. Discussion

This study assessed the validity of performing the narrative method "Connecting Conversations," which aims to assess experienced quality of care in nursing homes by performing separate conversations with a resident, family, and professional caregiver of that resident. Results indicated that Connecting Conversations is a promising method to assess experienced quality of care in nursing homes from the resident's perspective and appears valid. Experts reported that both the design and questions asked were deemed appropriate and complete to assess experienced quality of care (face validity). Thematic content analysis showed the full construct of experienced quality of care appeared to be captured with the conversations (content validity). When addressing construct validity, a range from negative to positive conversations became apparent. In addition, first results indicated a nursing home scoring low on satisfaction also scored a lower %-positive coded segments compared to a nursing home scoring high on satisfaction (construct validity).

Our findings show that narratives can be used to evaluate care services, confirming the conclusion from another study [32]. In nursing research, narratives are usually used to collect stories about someone's experiences in a certain context [52]. However, stories collected with Connecting Conversations provided information on the full construct of experienced quality of care attached with a judgement of that quality, operationalized as %-positive. Quality of care is a complex concept and therefore it is recommended to assess multiple components including resident experiences, clinical outcomes, and employee satisfaction; for example, experienced quality of care assessed with Connecting Conversations, accompanied with the quantitative standardized quality indicators assessed with the National Prevalence Measurement of Quality of Care and employee satisfaction assessed with the single-item measure for overall job satisfaction [53–55]. By combining quantitative and qualitative data, we are able to capture a holistic view on quality of care [6,54]. This can contribute to more tailored policy-making and quality improvement at nursing homes' operational (care triads), tactic (care teams), and strategic (care organization) levels, aimed at achieving higher quality of care within a nursing home [56].

Findings show residents living in nursing homes themselves are often capable of having conversations about their experienced quality of care, even when verbally challenged. The interpretation of stories shared by residents with moderate to severe cognitive impairment does need to be done cautiously. Research has shown this may be less valid, as residents may have difficulties correctly understanding questions and remembering past experiences [57]. Connecting Conversations strengthened this by having three separate conversations, i.e., by including the families and caregivers stories as well, known as data triangulation [33]. Findings show the benefit of including all three perspectives, as the %-positive between actors in a triad often differed. Additionally, research has confirmed that with trained interviewers and clearly formulated questions residents with cognitive impairment can more often be included in the conversations [14,58–60]. The interviewer may need to be provided with more support when conducting the conversations with the most vulnerable residents by means of more supportive questions and visuals, or by performing additional observations [61–63].

For this study, several methodological considerations need to be addressed and some suggestions for future research. First, coding %-positive was binary (positive or negative). In practice, this range is larger as "I am extremely happy" is interpreted as fully positive compared to "I am quite happy," which is still positive, but to a lesser extent. We made no distinction between both types of positive quotes. Future research should focus on more in-depth analysis of the different intensities of positive and negative wordings, by means of for example text-mining [64,65]. This can contribute to an even better understanding of the similarities and differences between experienced quality of care according to residents, their families, and professional caregivers. Second, validity can only be present if an assessment method is reliable [66]. For quantitative assessment methods, reliability analyses are usually focused on the outcome of the method in terms of consistency, stability, and repeatability [10]. Future research should explore possibilities to assess reliability of the outcome for narrative methods by means of for example inter-rater reliability or test–retest [10]. Third, there were insufficient data to perform a correlation analysis with satisfaction outcomes. Additional assessments should be performed to analyze this and other types of construct validity, such as the known-groups method, to explore whether the method can distinguish nursing homes that are doing well compared to nursing homes that require more quality improvements [10]. This is challenging as there is no standard evaluation available for narrative methods and existing evaluations will need to be adapted.

The current study introduced a different approach than trustworthiness to evaluate the validity of a narrative method that assesses quality of care with face, content, and construct validity measures. It can be used by other researchers as a starting point to further explore validation of narrative assessment methods and can help to select appropriate qualitative methods that assess quality of care. When using the current study as an example, several steps should be taken into consideration. First, it is important to a priori clearly define the construct to assess, as analysis on validity focuses on this. Second, a selection should be made of which concepts of validity will be assessed and how these will be assessed. Third, these concepts should be clearly defined and operationalized to the narrative method under study, as transparency supports the thoroughness of the research [67,68].

5. Conclusions

The narrative method Connecting Conversations is deemed a promising method to assess experienced quality of care in nursing homes from the resident's perspective. Using validated narrative methods can contribute to credible quality assessments that can help determine what is going well and what needs to be improved when delivering care. It is important to use validated quality assessment methods, as the accuracy of the collected data is a first step toward more effective quality improvement initiatives and policy-making. Therefore, it would be beneficial to standardize the reliability and validity analysis of qualitative assessment methods. For Connecting Conversations, research should collaborate with practice and policy to explore how to embed the narrative assessment method in practice and how the data can be used to improve experienced quality of care in nursing homes.

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The Feasibility of Connecting Conversations: A Narrative Method to Assess Experienced Quality of Care in Nursing Homes from the Resident's Perspective

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Abstract: Currently, residents living in nursing homes and their caring relationships are being placed more centrally in the care experience. Experienced quality of care is influenced by the interactions between residents, family and caregivers, who each have their own experiences and needs. Connecting Conversations is a narrative method aimed at assessing experienced quality of care in nursing homes from the resident's perspective by having separate conversations with residents, family and caregivers (triads), adopting an appreciative inquiry approach. This study presents how to use Connecting Conversations and its feasibility. Feasibility was assessed as performance completeness, protocol adherence and interviewers' experiences. Conversations were conducted by trained nursing home staff (n = 35) who performed 275 Connecting Conversations in another nursing home than where they were employed (learning network). Findings show it is feasible to perform separate appreciative conversations with resident–family–caregiver triads by an interviewer employed in another nursing home; however, protocol adherence was sometimes challenging in conversations with residents. Interviewers valued the appreciative approach, the learning network and the depth of the separate conversations. Challenges were experienced with scheduling conversations and receiving time and support to perform the conversations. Stakeholders should continue collaboration to embed Connecting Conversations into daily practice in nursing homes.

Keywords: narrative; quality assessment; feasibility; interviews; relationship-centered care; quality of care; triad; resident perspective

1. Introduction

The proportion of people over 60 years is expected to almost double from 12% (2015) to 22% (2050) [1]. The aging population has resulted in an increasing number of older people with chronic diseases requiring long-term care [2]. The most vulnerable people with complex health needs live in nursing homes in which they receive 24-h care and functional support [3]. Nursing homes are struggling to maintain and improve their quality of care due to the increase in aging population and strain on resources, the complexity of residents' needs, the changes in residents' expectations and the challenges in staff-mix [4–7]. According to the Institute of Medicine, a component of the US National Academy of Sciences, quality of care needs to be safe, effective, efficient, timely, patient-centered and equitable [8]. It is challenging to fully operationalize these generic concepts to the nursing home setting and therefore quality indicators are often used [9]. To assess these quality indicators, such as the prevalence of pressure ulcers or malnutrition, standardized quantitative methods are used, such as the nursing home minimum data set (MDS) or the national prevalence measurement of quality of care (LPZ) [10,11]. More recently, initiatives such as the Worldwide Elements to Harmonize Research in Long-term Care Living Environments (WE-THRIVE) have occurred, aiming to achieve global common data elements for quality of care to enhance standardized assessments in long-term care [12]. Additionally, specific areas of health care, for example palliative care, have identified their own indicators for quality of care [13]. Stakeholders use quality of care data for different purposes, for example, professional caregivers may use them to learn, reflect and improve care provision, nursing home managers to monitor and improve their performance, and policy makers for transparency and accountability [14,15].

In service science, quality is often defined as the comparison of the consumer's expectations and the actually delivered service, assessed with the outcome 'satisfaction' [16]. Care provision in nursing homes can be considered a type of service delivery in which the resident's expectations and experiences gain a much more important role than in the more traditional quality of care definitions. Evaluations of care services more frequently are trying to fully recognize residents' needs and experiences with the complete service experience before, during and after receiving care [17]. This means evaluation does not only focus on the actual activity, but also incorporates, for example, how the resident was approached during this activity. By mapping the full customer journey, the sum of all experiences (touchpoints) can be described and moments of truth can be identified that can positively or negatively influence an experience [18]. This holistic view can help care organizations to sustain caring relationships and retention, and receive positive word-of-mouth [17].

In line with this service science perspective, residents and their caring relationships are being placed more centrally in the care experience, as can be seen in care models such as person-centered care and relationship-centered care [19,20]. Person-centered care focusses on residents as each being unique human beings with their own needs and wishes, and relationship-centered care goes one step further by focusing on all people involved in the residents' care experiences, including family, and the impact of their reciprocal relationships [21–23]. This concept is known as balanced centricity in service sciences, implying that experiences are created by multiple stakeholders whose needs deserve to be acknowledged [24]. Residents, family and caregivers each have their own experiences and needs and by including all involved stakeholders when assessing quality of care, quality improvement initiatives can focus more on what matters most from a holistic perspective [25–28]. Additionally, this contributes to a resident's quality of life and well-being, families feeling valued by making a useful contribution and caregivers' job satisfaction [29,30]. In line with this holistic view on quality of care, the Dutch policy guidelines for quality of care in nursing homes have been revised to focus more on person- and relationship-centered care, well-being, safety and learning together with and from each other's practices, highlighting the importance of assessing quality of care from the resident's perspective [31].

Studies have revealed the complementary value of assessing quality of care by having conversations with residents, their families and professional caregivers, as each have their own needs and stories [25,32]. The addition of the story behind quality rating is often missing when resident experiences and outcomes are only assessed with quantitative patient-reported experience (PREMs), patient-reported outcome (PROMs) and satisfaction measures [33–35]. Stories about experiences, so-called narratives, help people to make sense of their world, relationships and themselves, and can support nursing homes to focus on what really matters [35,36]. They can help to identify what is most important to residents and can support quality improvement initiatives for individual residents [37]. Narratives are able to capture an experience that is enriched by incorporating emotions, explaining logic and providing details about the caring relationships [38]. As quality of care is a complex concept, there is a need to assess multiple quantitative and qualitative indicators, and this information should be used in continuous quality improvement cycles [14].

Narratives are already being used as methods to assess for example children's speech [39] or perform mental health research with young children [40] and in nursing homes as interventions, such as life reviews, to improve residents' life satisfaction [41,42]. However, the use of narratives as a method to structurally assess elements of quality of care in long-term care is relatively new. This is gradually occurring more frequently; however, little is known about how to use them and their feasibility in practice [43,44]. Recently, the narrative method Connecting Conversations has been developed aimed at assessing experienced quality of care in nursing homes from the resident's perspective. It was developed according to the steps in the development and evaluation of a measurement method by De Vet, Terwee, Mokkink and Knol [43], including defining the construct to be measured [45], mapping the needs of key stakeholders [46], one cycle of pilot-testing and two cycles of field-testing. This study aimed to present how to use the narrative method 'Connecting Conversations' in practice and its feasibility. Validity findings have been published separately in this special issue of IJERPH as well[47].

Theoretical Foundation

Quality of care from the resident's perspective, i.e., experienced quality of care, is a process in which expectations occur prior to receiving care, interactions occur during the care experience and an assessment is given after the care experience within a certain context, as defined by the Individually Experienced Quality of Post-Acute and Long-Term Care (INDEXQUAL) framework [45]. Relationship-centered care and caring relationships, individual needs of the resident, family and caregiver (a triad) and their interactions are considered to be at the core of a care experience [22,48,49]. Therefore, to assess experienced quality of care, it is important to ask not only residents, but also family and caregivers how the resident experiences the quality of care, by performing separate conversations [46]. Additionally, the resident's full customer journey should be considered during quality assessments, as stories, experiences and preferences between residents differ [12,28].

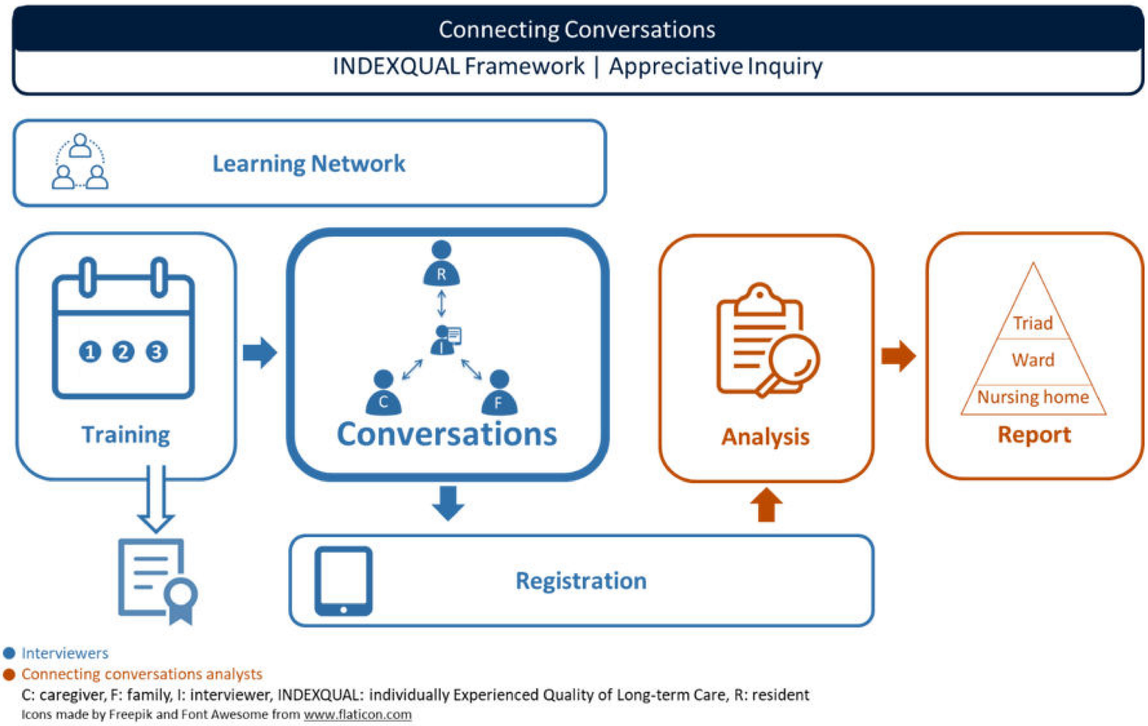
It could be beneficial to adopt a positive approach when performing these conversations, as nursing homes often adopt a problem-focused approach magnifying what is not going well; whereas focusing on what is working best and how to build on this can be more rewarding [46,50]. Appreciative inquiry is a positive approach identified as the opposite of problem-solving and helps participants to really engage and focus on discovery (appreciate the best of what is), dream (imagine what could be), design (determine what should be) and destiny (create what will be) [51]. This approach has proven to have positive outcomes on the nursing home culture and interactions by care staff [50,52,53]. The INDEXQUAL framework, relationship-centered care and appreciative inquiry are the theoretical foundation of Connecting Conversations.

2. Materials and Methods

The study used a cross-sectional design and data collection was performed in two cycles of field-testing: (1) October 2018 to February 2019 and (2) October 2019 to January 2020. First, a description of the content of Connecting Conversations is provided, followed by the operationalization of feasibility, details of the participants, data-collection and data-analysis used to assess feasibility.

2.1. Connecting Conversations

The narrative method Connecting Conversations aims to assess experienced quality of care in nursing homes from the resident's perspective. Figure 1 presents the structure of 'Connecting Conversations'. The content of each blue element is performed by a trained interviewer. The orange elements are currently performed by the research team, as these are still under development. Separate conversations are performed with a resident, family member and professional caregiver of that resident, a so-called care triad. These conversations are registered in an app on a tablet. Interviewers follow a mandatory three-day training to be able to perform the conversations in another nursing home than where they are employed, facilitating a learning network. The research team analyses and reports back the data to the nursing homes. All elements are described in detail in Appendix A. Table 1 provides a brief description of each element.



● Interviewers
● Connecting conversations analysts
C: caregiver, F: family, I: interviewer, INDEXQUAL: individually Experienced Quality of Long-term Care, R: resident
Icons made by Freepik and Font Awesome from www.flaticon.com

Figure 1. Connecting Conversations.

Table 1. A summarized description of the Connecting Conversations elements.

Element	Main Description
Training	Interviewers need to follow a mandatory three-day (3 h/day) training to assure the quality and reliability of performing and registering Connecting Conversations. The training focusses on connecting, practicing and sharing experiences, and has adopted an appreciative inquiry approach. Successful attendance results in a certificate.
Conversations	Semi-structured questions are asked in separate conversation with a resident, family member and professional caregiver of that resident, who each answer from the resident's perspective. Questions are based on the INDEXQUAL framework and are formulated from an appreciative inquiry approach. Main topics: resident's life, satisfaction with care provision, most positive experience, description of an average day in the nursing home and relationships between the resident, family and caregiver.
Registration	The Connecting Conversations app supports interviewers to perform, register and view the conversations. Main features app: documenting informed consent, participant demographics, summative answers, audio recording and viewing collected data.
Learning network	The learning network provides a platform for interviewers in which they can learn from and with each other through continuous interaction [54]. Interviewers from different care organizations follow the training together and perform conversations in each other's care organizations, thus not where they themselves are employed. This provides for independent interviewers and the opportunity for interviewers to learn from daily practices in another nursing home environment.
Analysis	The written texts, as reported in the app, are analyzed by two researchers with content analysis [55].
Report	The analyzed data are presented on ward level in a factsheet with supporting 'quotes'. Additional reports on triad and nursing home level can be delivered upon request.

2.2. Interpretation and Operationalization of Feasibility for Connecting Conversations

To determine to what extent it is feasible to use Connecting Conversations in practice, feasibility has been defined as the extent to which Connecting Conversations was conducted as planned and how interviewers experienced Connecting Conversations. This definition has been operationalized into three elements: completeness, protocol adherence and interviewer experiences as presented in Table 2. Feasibility analyses only focused on the Connecting Conversations elements performed by the interviewer: conversations, registration, training and learning network.

Table 2. Feasibility definitions, operationalization and analyses for Connecting Conversations.

Feasibility Concept	Definition	Operationalization for Connecting Conversations • Element Analyzed	Analysis
Completeness	Extent to which Connecting Conversations was completed as planned	All planned triads were randomly selected and completed in the learning network as planned Interviewers completed the training and all planned conversations • Conversations • Learning network	• Description of successes and challenges of random selection of triads on a ward and the learning network • Completed conversations rate [1], including documentation of incomplete and missing triads, and the duration of the conversations • Description of recruited interviewers and attendance rate [1] training
Protocol adherence	Extent to which the conversations were performed as planned	All interviewers followed the Connecting Conversations' protocol as taught during the training. • Conversations • Training	• All six questions were asked as formulated in the protocol [1] • Per conversation at least one probing question and one time paraphrasing was used [1] • The respondent talked more than the interviewer [1]
Interviewer experiences	Interviewers' satisfaction with Connecting Conversations and experienced facilitators and barriers	All interviewers evaluated all components of Connecting Conversations: training, scheduling conversations, performing conversations and registering conversations. • Conversations • Registration • Training • Learning network	Deductive coding of interviewer experiences, categorized into elements that were appreciated and that were considered challenging

[1] Interpret as total percentage of participants: <60% not acceptable, 60%–80% acceptable, >80% good.

2.3. Setting and Participants

This study was performed within the Living-Lab in Ageing and Long-Term Care. The living-lab is a collaboration between seven long-term care organizations and four educational institutes, all located in the southern part of the Netherlands [56].

2.3.1. Care Triads

Each of the seven care organizations selected one somatic (for people with physical deterioration) and one psychogeriatric (for people with cognitive decline) ward. Within the selected wards, random selection of residents was necessary to increase the reliability and validity of the assessment and avoid biased selection of only the most well-spoken and satisfied residents with closely involved families.

Residents were randomly selected from the nursing home ward by generating a random sequence list of all residents' room numbers of the selected wards. The contact person of the ward approached residents of the first five (cycle 1) or six (cycle 2) randomly generated room numbers to participate. When a resident refused, the next was approached until the total number of triads was recruited. A family member and professional caregiver closely involved with the selected residents daily care provision were invited, once the resident agreed to participate. Triads were included as dyads if a resident was unable to have the Connecting Conversations because of cognitive impairment (family–professional caregiver dyad) or if no family was available or unwilling to participate (resident-professional caregiver dyad). To provide all residents the opportunity to have a conversation, conversations were attempted with each resident. Only when the resident did not respond at all or merely mumbled answers that could not be understood, the results of the conversation were not included for that triad.

2.3.2. Interviewers

Any interested staff member employed at one of the seven care organizations within the living-lab was invited to apply and each care organization's management performed final selection. There were three main selection criteria for interviewers: (1) familiar with the nursing home environment, either by providing hands-on care, such as nurses or recreational coaches, or more managerial, such as ward managers or policy makers; (2) good communication skills and natural empathetic abilities; and, (3) involved in or a strong interest in quality assurance. Selection aimed at including two interviewers per care organization per cycle. Additionally, researchers in geriatric nursing science employed at the university, such as health scientists or psychologists, were allowed to participate as well. A minimum of 14 interviewers (two per care organization) and a maximum of 20 interviewers could participate, as this was the maximum attendance to ensure involvement and interaction during the training. The interviewers attended the training and performed the conversations during their working hours, and did not receive any additional incentives.

2.4. Data-Collection and Procedure

2.4.1. Connecting Conversations

Appendix A presents the interview guide of questions asked during the separate conversations. Family and professional caregivers were asked to answer the questions, as they believed the resident would. Interviewers were provided a list of probing questions and supportive visuals for the questions asking for a grade to support them during the conversations.

2.4.2. Procedure

The research team assigned interviewers to another care organization than where they were employed, considering travel distance, to enhance the learning network. This prevents confirmation bias, as the interviewer has no prior knowledge of the resident or the performance of the nursing home [57]. Interviewers scheduled five (cycle 1) or three (cycle 2) full triads with a contact person in their assigned care organization. Multiple conversations could be performed a day, estimated at one hour per conversation. Family members could be interviewed by phone, if scheduling a face-to-face conversation was not possible.

2.4.3. Completeness

For completeness, data from cycle 1 and 2 were collected by documenting the number and duration of performed conversations. Interviewer characteristics were collected at the start of training day 1 with a survey: age in years, sex, job title and years of working experience in the nursing home setting.

2.4.4. Protocol Adherence

Data from cycle 1 were used to assess protocol adherence. The data were collected by audio recording performed conversations with a tablet.

2.4.5. Interviewer Experiences

Interviewers from cycle 1 and 2 were invited to informally evaluate Connecting Conversations at the end of each training day. The trainer asked if interviewers were satisfied with the content, felt engaged, felt confident and if anything should be done differently. After completing all conversations, interviewers were invited to complete a written customer journey about Connecting Conversations, which described all touchpoints that the interviewer experienced during Connecting Conversations in a pre-developed format [18]. The five touchpoints in this journey were (1) the training, (2) scheduling conversations, (3) performing conversations, (4) documenting conversations and (5) miscellaneous for any other comments. Information was gathered adopting an appreciative inquiry approach, asking about what went well during these touchpoints, what could be improved and interviewers' overall satisfaction. To enhance understanding of what went well and what could be improved, interviewers were invited to attend a group interview or an individual interview, depending on their preference and availability.

2.5. Data-Analysis

2.5.1. Completeness

Descriptive statistics were used to calculate completeness of all performed conversations, mean duration of conversations and interviewers' characteristics.

2.5.2. Protocol Adherence

Interviewers' protocol adherence was evaluated for three elements: (1) the core theme of all six questions was asked; (2) the addressed conversation techniques 'probing questions' and 'paraphrasing' were applied at least once during each conversation; and, (3) respondents talked more than the interviewer, calculated by the total number of words spoken by the responder divided by the total number of words in the full transcript [58]. These analyses were performed for all conversations of which audio recordings were available (cycle 1). All audio recordings were transcribed verbatim and two researchers scored the transcripts independently. Discrepancies between both researchers regarding if a protocol element was adhered to or not were discussed with a third member of the research team until consensus was reached.

2.5.3. Interviewer Experiences

Interviewers' evaluations of Connecting Conversations were analyzed and summarized by one researcher with the computer software MAXQDA v20.0.7 [59]. Findings were evaluated with another researcher during two face-to-face discussions. During these discussions, the findings were interpreted and focus was on which elements interviewers appreciated and which were considered challenging. Points for improvement provided during field testing cycle 1 were implemented prior to the start of field-testing cycle 2. The main findings of the evaluations were presented back to the interviewers for validation.

2.6. Ethical Considerations

The medical ethics committee of Zuyderland, the Netherlands, approved the study protocol (17-N-86) and concluded that the study was not subject to the Medical Research Involving Human Subjects Act. Information about the study was provided to all interviewers, residents, family members and caregivers in advance by letter. All participants provided written informed consent to contribute to the study and residents with legal representatives gave informed assent themselves before and during the conversations, and their legal representatives gave written informed consent [60]. Participation was strictly voluntarily and participants could withdraw from the study at any moment. Anonymity of participants was guaranteed and therefore no names or organizations were documented, unless participants provided consent to share their individual data with the nursing staff for quality improvement initiatives.

3. Results

In total, 35 interviewers attended the training and performed 275 Connecting Conversations (89 residents, 83 family members, 103 caregivers) in 18 different nursing homes (8 psychogeriatric, 9 somatic and 1 acquired brain injury). When residents refused to participate, the most common reason was that they considered this to be too intensive or they were not interested.

3.1. Completeness

Random selection of residents' room numbers was performed successfully in 14 of the 18 nursing homes. The exchange of interviewers between nursing homes, i.e., the learning network, was deemed feasible, as each interviewer performed at least three conversations in their assigned nursing home. Reasons for unsuccessful random selection and challenges with the learning network were organizational challenges in the nursing home. These consisted of a lack of a designated contact person to manage the selection and scheduling of the conversations, a lack of staff and high time pressure, and a lack of understanding of the added value of the conversations and random selection. During cycle 2, the research team made some improvements to the execution of the study compared to cycle 1. They started recruitment earlier and in a more structured manner, with a standardized protocol, a central e-mail address for questions, clearer instructions and timely follow-up to guide the process more thoroughly. Table 3 presents details on the completeness of collected data and interviewer characteristics in total, and separately for field-testing cycles 1 and 2.

Completeness was 76% of all planned triads/dyads. For 10% (n = 14) of the conversations, the resident was not able to communicate and for 15% (n = 20) of the conversations, family was not willing or available to participate. Additionally, 24% (n = 32) of the triads could not be recruited due to insufficient triads willing to participate on the ward or challenges scheduling conversations with the visiting interviewer. During cycle 2, completeness rates were notably higher than during cycle 1 (84% and 71%, respectively). Median duration of conversations was 17 min.

3.2. Protocol Adherence

Table 4 presents the results of the protocol adherence analysis of 125 transcripts performed by 15 interviewers during field-testing cycle 1 (one interviewer had no successful audio recordings).

Results show the questions were asked correctly for 88% of the cases (agreement rate 85%). Compared to the resident group (73%), the completeness of each separate question asked appears higher in the family (92%) and caregiver group (94%). Completeness of all six questions asked was 39% for residents opposed to 74% and 73% for family and caregivers, respectively. Interviewers indicated that in some cases they went off protocol, because the resident had difficulties answering the open-ended questions. When less than four questions were asked correctly, this was because the resident was experiencing difficulties to have a conversation due to cognitive impairment. In almost all conversations, interviewers used at least one probing question (99%) and in a majority of the conversations, paraphrasing was done (69%). In 86% of the conversations, the responder spoke more than the interviewer did; for conversations with family and caregivers, this was almost always (97%–98%).

Table 3. Connecting Conversations' care triads and interviewer demographics.

Care Triads	Total	Field-Testing Cycle 1	Field-Testing Cycle 2
Planned conversations n			
→ Total	405	240	165
→ Triads R-F-C	135	80	55
Performed conversations n (%)			
→ Total	275 (68) [3]	149 (62) [5]	126 (76) [7]
→ Resident (R)	89 (66)	46 (58)	43 (78)
→ Family (F)	83 (61)	46 (58)	37 (67)
→ Caregiver (C)	103 (76)	57 (71)	46 (84)
→ Total triads/dyads	103 (76)	57 (71)	46 (84)
→ Full triads R-F-C	68 (50) [4]	34 (43) [6]	34 (60) [8]
→ F-C combination [1]	14 (10)	11 (14)	3 (5)
→ R-C combination	20 (15)	11 (14)	9 (16)
→ Full triads missing	32 (24)	23 (29)	9 (16)
Mean/Median minutes conversations (range)			
→ Total	19/17 (3–79)	18/15 (3–54)	21/18 (4–79)
→ Resident (R)	21/17 (4–79)	18/14 (6–54)	24/22 (4–79)
→ Family (F)	21/19 (6–48)	21/22 (6–39)	21/18 (7–48)
→ Caregiver (C)	17/14 (3–55)	15/14 (3–41)	19/16 (4–55)
Interviewers' characteristics			
Total interviewers n	35	16	19
Mean age in years (SD)	40 (11)	40 (11)	42 (11)
Females (%)	31 (89)	14 (88)	17 (89)
Occupation n (%)			
→ Nurse	10 (29)	6 (38)	4 (21)
→ Baccalaureate-educated nurse	9 (26)	4 (25)	5 (26)
→ Policy advisor	5 (14)	3 (19)	2 (11)
→ Care manager	2 (6)	0	2 (11)
→ Recreational coach	2 (6)	0	2 (11)
→ Psychologist [2]	3 (9)	1 (6)	2 (11)
→ Health scientist [2]	2 (6)	1 (6)	1 (5)
→ Nurse aid	1 (3)	1 (6)	0
→ Complaints officer	1 (3)	0	1 (5)
Mean contracted hours per week (SD)	32.4 (5.2)	32.3 (5.2)	32.6 (5.3)
Mean years working experience (SD)	13.1 (11.0)	13.8 (9.7)	12.4 (12.1)
Training attendance all 3 days n (%)	30 (86)	13 (81)	17 (89)
Training attendance 2 out of 3 days n (%)	5 (14)	3 (19)	2 (11)

[1] Residents missing because on psychogeriatric ward and not cognitively capable to have the conversation. [2] Not employed at the nursing home, but at the university. [3] Of which 241 with audio recordings. [4] Of which 52 with audio recordings. [5] Of which 125 with audio recordings. [6] Of which 24 with audio recordings. [7] Of which 116 with audio recordings. [8] Of which 28 with audio recordings.

3.3. Interviewer Experiences

Overall, interviewer experiences were very positive; however, they also experienced some challenges. Evaluations were mostly individual interviews (n = 29) and one group interview (n = 6) was performed. First, the valuable aspects interviewers experienced are presented followed by facilitators that can contribute to properly perform assessments with Connecting Conversations.

3.3.1. In-Depth Attention

"Real attention is given to someone". Interviewers were positive about the conversations, as became apparent from evaluations such as "I really enjoyed doing this" and "the conversations show a valuable overview of someone's experienced quality of care". Interviewers were surprised by the in-depth content of the conversations and found it "really special, the stories you hear and the directions they take". Registration with the app was considered a real asset, interviewers explained, and it was "so easy to use". Interviewers specifically valued the audio-recordings: "it was nice that audio recordings were made, so I could fully engage in the conversation without feeling the stress of needing to immediately write everything down”.

Table 4. Protocol adherence results [1].

	Total	Resident (R)	Family (F)	Caregiver (C)
	N = 125	N = 36	N = 38	N = 51
Question 1 quality of life n (%)	107 (86)	24 (67)	36 (95)	47 (92)
Question 2 satisfaction caregivers n (%)	113 (90)	29 (81)	34 (89)	50 (98)
Question 3 most positive n (%)	116 (93)	30 (83)	36 (95)	50 (98)
Question 4 average day n (%)	113 (90)	26 (72)	37 (97)	50 (98)
Question 5 relationships n (%) [2]	102 (82)	24 (67)	34 (89)	44 (86)
Question 6 relationships n (%) [3]	106 (85)	25 (69)	33 (87)	48 (94)
Average questions asked %	88	73	92	94
All six questions asked n (%)	79 (63)	14 (39)	28 (74)	37 (73)
Four or five questions asked n (%)	30 (24)	10 (28)	8 (21)	14 (27)
Less than four questions asked n (%)	14 (11)	12 (33)	2 (5)[4]	0
Probing questions n (%)	124 (99)	36 (100)	37 (97)	51 (100)
Paraphrasing n (%)	86 (69)	22 (61)	29 (76)	35 (69)
≥50% responder words spoken n (%)	108 (86)	23 (64)	37 (97)	50 (98)

[1] Interpret as total percentage of participants: <60% not acceptable, 60-80% acceptable, >80% good. [2] Relationships: resident (resident–caregiver), family (family–caregiver), caregiver (caregiver–resident).[3] Relationships: resident (resident–family), family (family–resident), caregiver (caregiver–family). [4] This interview was performed by one interviewer that did not adhere to protocol.

3.3.2. Narrative Appreciative Inquiry

“Different from other conversations because of the questions being asked and the positive approach”. Interviewers experienced the benefit of adopting an appreciative approach, as “often, in other conversations, only the negative side is addressed” and “the questions trigger to think positively”. They also appreciated the positive nature of the training and showed this by being actively engaged and enthusiastic. Most were pleasantly surprised by the dynamic set-up of the training and felt they had really learned to perform appreciative conversations. They appreciated how the trainer created a safe environment, the “balance between theory and practice” and how they became “aware of their own listening skills”.

3.3.3. Three Perspectives

“There is a clear difference between perspectives”. Interviewers valued taking the time to have separate conversations with the resident, a family member and a caregiver of that resident and experienced that “the triad gives three different perspectives”. They really encountered the differences and similarities between the perspectives and that it is important to hear each side to a story.

3.3.4. Learning Network

“Valuable to be in another organization”. Interviewers enjoyed having the training together with colleagues from other care organizations and learning from each other. They also enjoyed performing the conversations in another care organization than where they were employed. Some were surprised by the openness of the responders, which was created by the interviewers’ independent status within the nursing home: “I am a stranger to them who comes to interview them, and nevertheless they express themselves and their feelings to quite some extent”. Interviewers also reflected on observations they made whilst visiting the other nursing home. For example, an interviewer shared she saw all caregivers taking their lunchbreak at the same time, leaving residents all alone in the living room. She realized in her ward they also do that, and has now installed an early and a late lunch shift.

3.3.5. Commitment

“I really enjoyed participating. My manager would really like to embed Connecting Conversations in the whole care organization”. A majority of interviewers has remained engaged with Connecting

Conversations after finalizing their conversations. For example, one interviewer had challenging experiences performing conversations as her assigned nursing home faced challenges to schedule conversations on multiple occasions. A follow-up session, however, kept her involved and motivated to stay engaged. Other interviewers have also positively shared their experiences with their managers and quality policy officers, resulting in an increasing demand for Connecting Conversations throughout care organizations.

3.3.6. Scheduling

"It was challenging to reach the contact person and to find suitable days for the conversations, also taking your own work schedule into consideration". Whereas the valuable aspects of Connecting Conversations are clearly visible, care organizations should be aware that it is a challenging process to implement this new way of assessing quality of care. There was a large variety between interviewers feeling supported or challenged to perform the conversations. This was mainly influenced by the support of one's own manager and the support of the care organization that was being visited. As interviewers performed conversations elsewhere, they were dependent on a contact person within the visiting care organization who facilitated recruitment of triads and scheduling of conversations. The contact person was considered a crucial element to successfully complete all conversations.

Based on all feasibility findings, Table 5 presents the facilitators that need to be considered when implementing Connecting Conversations. The elements have been formulated as facilitators, yet when absent, they will be experienced as barriers for successful implementation. First, organizations should adopt a clear vision in which they support this new way of assessing quality of care and provide resources for this. Second, several prerequisites are important to gather rich and valid stories: random'selection of triads, external interviewers in the learning network, sufficient time and resources and a contact person on the ward. Last, when performing the conversations, it is important to be as inclusive as possible.

Table 5. Facilitators to implement Connecting Conversations.

	Facilitators	**Reason Why Important**
Vision	Adopt an appreciative inquiry approach when introducing, implementing and embedding Connecting Conversations into the nursing home	To enhance commitment and enthusiasm; and set an example of the method's positive impact: 'practice what you preach'
	Have a clear purpose for what the results will be used	To decide on the magnitude of the assessment and the format of the report(s)
Prerequisites	Random selection of triads on a ward	To avoid selection bias
	Assure interviewers have conversations elsewhere than where they are employed (external interviewers)	To enhance the learning network and provide respondents a safe environment to share their stories
	Provide sufficient time for training, conversations and the learning network	To ensure quality of the conducted conversations
	Assign a contact person in the nursing home who is responsible for facilitating the visiting interviewer (scheduling conversations; informing residents, family and staff on the ward)	To enhance completeness and to create a safe environment for the visiting interviewer
Performance	Make an effort to have conversations with each selected resident, regardless of his or her (cognitive) health status	To embrace an inclusive approach, in which residents are provided with self-determination
	Think in solutions when scheduling conversations, for example by allowing full-time employed family to have the conversation by phone or during evening hours	To embrace an inclusive and appreciative approach

4. Discussion

Connecting Conversations assesses experienced quality of care in nursing homes from the resident's perspective. This article presented how to use the narrative method 'Connecting Conversations' and its feasibility. Main findings show it is feasible to perform separate appreciative conversations with a resident, family member and caregiver of that resident by a trained interviewer employed in another nursing home. Protocol adherence was sometimes considered challenging during conversations with residents, as residents did not always seem to understand the questions. Interviewers mostly valued the appreciative approach, the collaboration between care organizations in the learning network and the time they received for in-depth separate conversations with residents, family and caregivers. Challenges were experienced with scheduling the conversations and not all interviewers received the time and support from their care organizations to perform the conversations.

Findings show it is possible to create a learning network in which care organizations exchange staff as interviewers, under the prerequisites that time and support is provided. Whereas it is often said that narratives are considered big time investments [61], our findings show a median duration of only 17 min per conversation and henceforth it is very feasible to perform these conversations. A successful learning network is characterized by sharing knowledge, balancing interests and self-development [62]. This can contribute to the self-development and reflective learning of the interviewers, which henceforth can increase the quality of care in one's own nursing home [63]. By integrating this appreciative manner of having conversations into the nursing staff's routines, focus can be shifted from time-based tasks for residents to continuously connecting with residents [61].

Additionally, findings show appreciative inquiry is a useful approach to engage in conversations about quality of care. By adopting an appreciative evaluation of quality of care, a shift is made towards the positive, embracing caregivers to recognize valuable stories and use these positive insights in their future care provision [51]. Appreciative inquiry has successfully been used in other nursing home initiatives too, for example in the implementation of the sensory garden in Norwegian nursing homes [64] or the My Home Life program in the United Kingdom [65,66]. To anchor an appreciative culture, management should reinforce communication and interactions between people, instead of standardized rules and procedures, on all levels of nursing home organizations: strategic, tactic and operational [67]. Leadership could contribute to this, by, for example, assigning Connecting Conversation champions who adopt a key role in successfully developing and supporting quality improvement initiatives based on the collected narrative data [68]. This, in turn, can contribute to increased quality of care and a positive psychosocial climate [69].

Protocol adherence findings confirm the importance of a proper training for interviewers in which they learn how to adhere to the protocol and apply the appreciative approach and conversation techniques. Interviewers' skills, motivation, reliability, flexibility and productivity contribute in achieving completeness of planned triads [70]. As interviewers are part of a narrative quality assessment method, they play a major role in the reliability of the quality data [71]. Interviewers are not just recorders of the experiences, as they also have an experience of the shared experience [72]. Therefore, to increase the richness of the collected quality of care experiences, it is recommended to invest in proper selection and training of interviewers.

This study shows that a majority of the randomly selected residents living in nursing homes are capable of having a conversation about their experiences. However, complete protocol adherence appeared to be challenging, as in more than half of the conversations, the interviewer was unable to ask all six questions according to protocol. Studies often exclude residents living in nursing homes with a certain degree of dementia or other cognitive declines [73–76]. It is important to include the resident's voice and others have confirmed that in most cases, with well-trained interviewers and adapted questions, this is possible [77,78]. For Connecting Conversations, it is recommended to adjust the protocol for residents with cognitive impairment, by for example reformulating the six overarching questions into multiple shorter and easier sub-questions. For an even more inclusive approach, it is recommended to perform additional observations when residents are indeed unable to have the conversation (i.e., very severe dementia or aphasia), to assure their experiences are also fully captured, for example with the Maastricht Electronic Daily Life Observation (MEDLO) tool [32,79]. Other methods that exist for this include Dementia Care Mapping (DCM) or Person. Interaction. Environment. Care Experience in Dementia (PIECE-DEM)[80,81]. The challenges of these observation methods are that they are considered time-consuming and they have not been developed based on the principles of the INDEXQUAL framework of experienced quality of care, but on other theoretical frameworks.

Narratives are considered worth the time investment because they can have a positive impact on the caring relationships between residents, family and their caregivers, and residents' feelings of autonomy and well-being [61,82]. However, for future implementation, there is room for improvement regarding analysis and reporting of the results. The stories from three perspectives provide rich information that can be used on multiple levels, and the forms of analysis and reporting are dependent on the reason why experienced quality of care is assessed [15,82]. On an operational level, results can provide care teams with directories for continual learning and quality improvements for individual triads and teams. On a tactical level, managers need input on what is going well and what needs improvement within their ward or nursing home. To discover trends on an organization-wide strategic level, other analysis techniques could be more helpful, such as text mining, aimed at analyzing and identifying trends in large amounts of qualitative data [83]. On all these levels, the model of relationship-centered organizations may be a fitting framework to adopt, as it focusses on the web of relationships between care professionals, their actions and cycles of reflection, which is supported by inquiry-centered leadership and a culture of continual learning [84].

Findings show promising results for expanding the use of the narrative assessment method Connecting Conversations in practice. For successful implementation, there are many important determinants that need to be operationalized to the specific intervention and setting, including knowledge and cognition, attitude, routines, social influence, organizational characteristics and resources [85]. Additionally, recent research has shown that developed interventions in the care sector are in need of self-sustaining business models and therefore it is important to develop a suitable business model for Connecting Conversations, keeping its contextual factors into consideration [86]. For high completeness rates, it is important to clearly communicate with the participating interviewers and nursing homes, have clear protocols in place, follow-up in a timely manner and continuously be available to answer questions and provide support.

The current study has not incorporated experiences of how respondents within the triads experienced the new way of assessing quality of care with Connecting Conversations. It is recommended for future research to ask them to describe their experiences with this new way of assessing quality of care from the resident's perspective, as they are considered the key players in the conversations. Additionally, future research should focus on evaluating Connecting Conversations' validity and reliability. Further development should combine research with practice and policy to focus on how the information from Connecting Conversations can be reported back to care organizations so the data can be used to improve quality of care in nursing homes. Stakeholders should collaborate to successfully and sustainably embed Connecting Conversations into daily practice in nursing homes.

5. Conclusions

To our knowledge, Connecting Conversations is one of the first narrative methods aimed at assessing experienced quality of care in nursing homes as a customer journey, within a triad, from the resident's perspective in an appreciative way. It would be useful for nursing homes to implement a full quality assessment formula in which clinical and safety indicators, staffs' job satisfaction and residents' experienced quality of care are structurally assessed to gain a holistic view on quality of care. This can contribute to providing and receiving the best possible care and working conditions for residents, family and staff.

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Appendix A

This appendix presents a full description of Connecting Conversations, as briefly presented in Figure 1 and Table 1. Connecting Conversations aims to assess experienced quality of care in nursing homes from the resident's perspective.

Appendix A.1. Conversations

Table A1 presents the semi-structured questions that are asked during Connecting Conversations, providing interviewers guidance throughout the conversations. Family and professional caregivers are asked to answer the questions, as they believe the resident would. Questions 1 to 4 replace "you" with "your loved one" for family and "resident's name" for caregivers. Questions 5 and 6 are adapted to reflect the respondents' relationships, thus family are asked about their contact with the resident and the caregivers; and caregivers are asked about their contact with the resident and the family.

Table A1. Connecting Conversations' Questions.

1a 1b	On a scale of 1 to 10, how would you grade your life at this moment? What is needed to make that a [grade +1]?
2a 2b	On a scale of 1 to 10, how would you grade the caregivers that are involved with your daily care provision? What is needed to make that a [grade +1]?
3	What is the most positive experience you have experienced here?
4	What does an average day look like for you?
5a 5b	What is pleasant about your contact with the caregivers here? What could be different about your contact with the caregivers here?
6a 6b	What is pleasant about your contact with your family? What could be different about your contact with the family here?
7a 7b	What goes well here? What could be done more here?
8	Is there anything left you would like to share that has not been addressed yet?
Probing questions	Why? What is going well? What could be done more? How did that make you feel? Can you give an example?

All questions are based on the elements of the INDEXQUAL framework, capture the resident's customer journey and are formulated from an appreciative inquiry approach. The critical incidence technique is applied in question 3 by asking explicitly about the most positive experience, aimed at identifying a critical incident [87]. A critical incident combines cognitive, affective and behavioral dimensions by describing the experience itself, the behaviors of everyone involved and the result of these behaviors [88]. Question 4 provides respondents the opportunity to fabricate their own customer journey, which contributes to understanding what is important to the resident, family and/or caregiver [18]. Interviewers are provided with a list of probing questions, to support them during the conversations and supportive visuals for the questions asking for a grade (Figure A1).

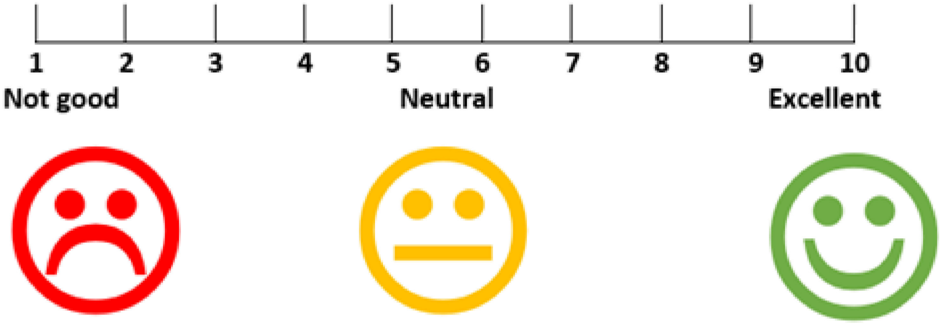

Figure A1. Supportive visual for Connecting Conversations.

Care Triads Recruitment

On a ward consisting of 15–30 residents, six residents with their family and caregivers are randomly selected to participate by the research team. Care organizations are free to select the nursing home ward, however the research team randomly selects the six residents on the ward, to avoid selection bias. A random sequence list of all residents' room numbers of the selected wards is generated. When a resident refuses to participate, the next is approached until the total number of triads is recruited. A closely involved family member and professional caregiver are invited to participate, once the resident has agreed.

Appendix A.2. Registration

Connecting Conversations includes an app for tablets and computers. This app supports interviewers to perform, register and view their Connecting Conversations. The main features of the app are:

- signing informed consent;
- collecting participant demographics;
- presenting semi-structured questions and suggestions for probing questions;
- typing summative answers to each question;
- audio recording and replaying of conversations;
- viewing collected data through a web portal.

Replaying of audio and typing the summative answers can also be done on a computer or laptop by the interviewer, after having performed the conversation. On an online portal managed by the research team, new interviewers and nursing homes can be assigned and the data is securely stored. The raw data as entered into the app are also available for nursing homes upon request, if participants have provided consent for this as it may breach anonymity. Each interviewer has an own secured account in which triads can be created. The app is available in the app Store for tablets and interviewers receive login details during the first training day. Figure A2 presents two screen shots of the app: left shows the list of created triads and right shows the questions, answer fields and audio recording option for a conversation with a resident.

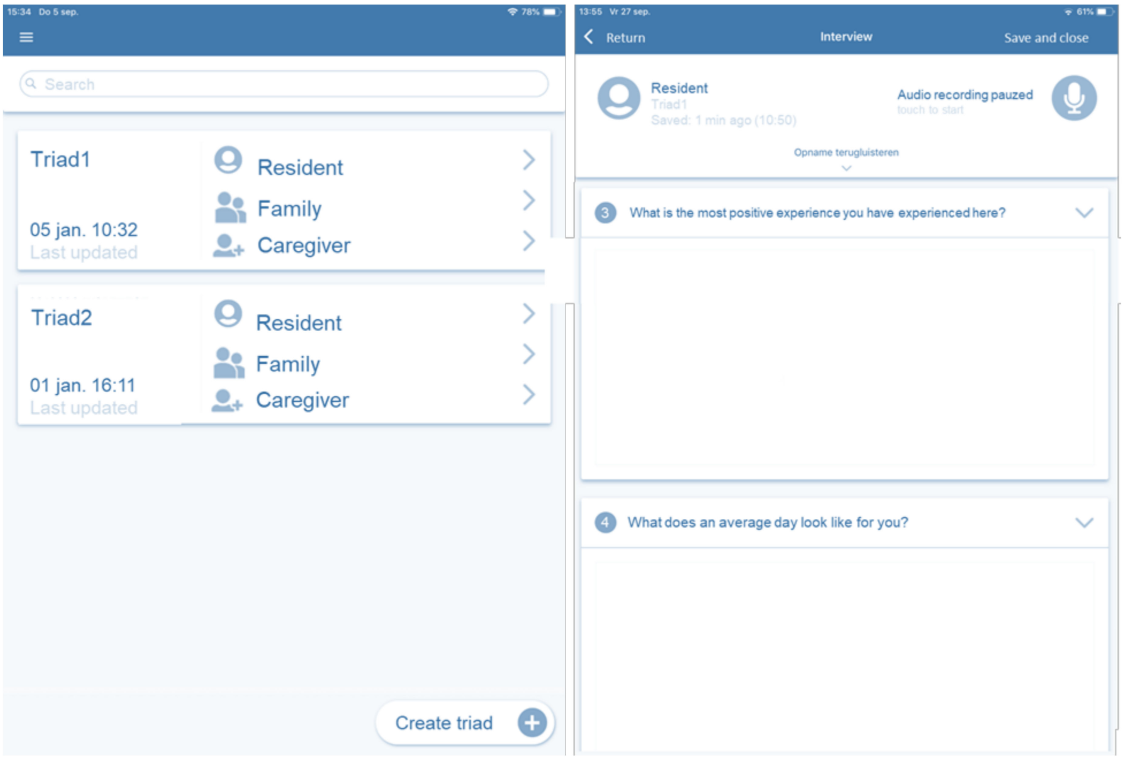

Figure A2. Screen shots from the Connecting Conversations app: triad list (left) and conversation with resident (right).

Appendix A.3. Training

In order to successfully perform and register Connecting Conversations, interviewers need to follow a mandatory three-day training. It aims to assure the quality and reliability of the conversations regardless which interviewer performs a conversation. The training teaches interviewers how to perform Connecting Conversations, focusing on both the theoretical foundations of INDEXQUAL, relationship-centered care, appreciative inquiry and the customer journey, and the practical aspects, such as how to use the app. The training consists of three 3-h sessions in a group of maximally 20 interviewers. Session 1 (day 1) is focused on engaging the group of interviewers, session 2 (day 8) on practicing conversations and session 3 (day 35) on evaluating and reflecting on each other's first experiences with the conversations. Interviewers are taught how to perform appreciative conversations with residents, family and caregivers, and how to ask probing questions, paraphrase and really listen without making assumptions.

The training is provided by an external company experienced in developing and providing innovative, scientific, tailor-made trainings, adopting an appreciative inquiry approach (in the Netherlands we collaborated with UMIO, an executive branch of Maastricht University). A holistic approach has been adopted, by applying the integral theory of consciousness focusing on intentional (I), behavioral (IT), cultural (WE) and social (ITS) quadrants [89]. The training aims to tackle all four components, to achieve successful long-term change. Whereas standard trainings are often aimed at 'predict and control', this training uses a 'sense and respond' approach, providing the group space to adjust the content of the training to their personal needs, which enhances engagement and effective use of time [90].

Appendix A.4. Certificate

Interviewers are rewarded with a certificate if they attend all three sessions and perform at least one triad in another nursing home than where they are employed. Interviewers, who are unable to attend one of the training sessions, receive the opportunity to hand in a compensation assignment. The certificate is valid for 1 years and can be extended after attending a celebration session. A celebration session is organized after all interviewers finalize their interviewers, to share experiences, enhance enthusiasm and future commitment, embrace the learning network, share feedback to further improve, and support interviewers to become Connecting Conversations champions within their organizations.

Appendix A.5. Learning Network

The learning network aims at contributing to sustainable success by providing a platform for interviewers in which they can learn from each other through continuous interaction [54]. Interviewers from different care organizations follow the training together and perform conversations in each other's care organizations, thus not where they themselves are employed. This provides them the opportunity to interact with and learn from each other. Additionally, it supports responders in the triads to answer honestly, as the interviewer is independent and not related to the care organization.

Appendix A.6. Analysis

The written texts as reported in the App, are analyzed by two researchers with content analysis [55]. The texts are formatted in a table consisting of four columns allowing for comparison of answers within an individual triad (Table A2):

(1) the questions asked;
(2) summative answer resident;
(3) summative answer family;
(4) summative answer caregiver.

Table A2. Example answer output Connecting Conversations.

Q2. On a scale of 1 to 10, how would you grade the caregivers that are involved with your daily care provision?	*"9, because they do everything they can. It's just those girls have little time. But they need to see residents within a certain time and cannot just sit around with you."*	*"Insufficient, because in her opinion very many care providers do not treat her as a person, but as a thing that needs to be dressed quickly."*	*"8, because the wishes of the client are met, for example breakfast in bed and care is provided later."*

First, researchers code meaningful segments per triad and label these as 'this is going well' (discover) or 'this needs to be done more frequently' (dream), adopting an appreciative inquiry approach. Second, they check to what extent the resident, family and caregiver expressed similar or different thoughts within a triad (relationship-centered care). Last, similarities and differences between triads are compared and aggregated into trends that are recognized as going well and that could be done more frequently on a ward, resulting in a report for the nursing home. Both researchers discuss their findings and conflicts with a third member of the research team. It is deemed unsustainable to analyze full transcripts for these large amounts of data, as this is very time-consuming and nursing homes want quick quality improvement cycles.

Appendix A.7. Report

The research team is responsible for reporting results back to the nursing homes. The analyzed data are presented on ward level in a factsheet with supporting 'quotes' by a researcher on location. Nursing homes can choose who attends this presentation, for example the ward manager, nursing home manager, quality policy officer of the nursing home and/or the care team. The presentation consists of eight sections presented from an appreciative inquiry approach and tailored to each ward's results presented in Table A3.

Table A3. Outline of report.

1	**Core Principles of Connecting Conversations**
2	Details on how many conversations were performed in which ward
3	To what degree were there many similarities or differences between the resident, family and caregiver within each triad?
4	What is going well on the ward? (discover)
5	Quotes supporting results on Section 4
6	What could be done more frequently on the ward? (dream)
7	Quotes supporting results on Section 5
8	Discussion asking attendees what they think of the results, what they can learn from the results and what they are going to do with the results?

The ward manager is advised to share the results with the care team, family and residents; and to discuss if the results are familiar, how the team can learn from these results and what actions can be taken based on the findings (design and destiny). On request, nursing homes can ask for additional reports, such as a poster with the main results to share on the ward or a written report that can be used for accountability purposes.

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Article

Development and Validation of the Scale for Partnership in Care—for Family (SPIC-F)

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Abstract: This study aims to develop and validate the Scale for Partnership in Care between staff and families of older adult nursing home (NH) residents—for Family (SPIC-F). The components of partnership were identified on the basis of literature reviews and focus group interviews. The content validity of 41 preliminary items was verified by 10 experts, and a pilot study was conducted. The reliability and validity of the instrument was tested on 330 families of older adult NH residents. The final instrument comprised 20 items in three categories: professional caring and support, cooperative relationship and information sharing, and participation in care. Each item is rated on a four-point Likert scale, with total scores ranging from 20–80. The reliability of the instrument was 0.95, and test–retest ICC was 0.83. This instrument could be utilized to develop interventions to establish an efficient partnership and assess its outcomes.

Keywords: instrument development; partnership practice; family caregivers; nursing homes; older adults

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1. Introduction

Population aging is a global phenomenon. As of 2019, the world's population aged 65 or over was 703 million people and is expected to double to 1.5 billion by 2050 [1]. In particular, population aging in Northeast Asia is a notable phenomenon. In 2015, the number of elderly people aged 65 or older living in six Northeast Asian countries accounted for 32% of the world's elderly population and accounted for 56% of Asia [2]. This aging phenomenon has led to an increase in geriatric diseases such as dementia, stroke, and cardio-cerebrovascular diseases, which ultimately lead to an increase in the population in need of care. Globally, the high prevalence of older people and the statistics of increased chronic disease, such as dementia, support these changes [3,4]. The increasing number of older adults in need of continuous protection and care raises various social and economic problems, including the burden on family and the increase in medical care costs [5,6].

Particularly, because policies prioritize home care, older adults can live and receive care in a familiar environment, which can lead family caregivers to experience serious difficulties [5,7]. These difficulties may include physical problems such as chronic headaches and fatigue [7]; mental problems such as stress, depression, and anxiety [5,8]; family conflicts due to care [5]; and the economic burden of care [7].

With such a heavy caregiving burden, families reach their limit in caring for older adults at home [9]. As a result, despite the negative perception of institutionalizing [5], the admission of older adults to nursing homes (NHs) has consistently risen, reaching 345,000 users of NHs in Korea in 2016 [6].

The common belief is that families' caregiving burdens would be diminished by admitting their relatives to NHs, however, families of older adult NH residents still experience different aspects of the caregiving burden [10], such as guilt, confusion with their caregiving role, and role conflicts with NH staff [9,11,12].

Following older adults' institutionalization, families delegate their role as primary caregiver to the NH staff and wish to continue to be involved in the care as the older adults' advocate and watcher [13]. However, learning and adjusting to their changed role in a new environment is a difficult process [14]. Furthermore, there is no clear-cut definition of families' new roles, which might isolate them or place them in a vague position in the caregiving service system [15–17].

Families of older adult residents may provide important information about residents' habits, preferences, and care needs, resulting in the provision of high-quality care to older adult residents [18,19]. Therefore, the family's participation in care is crucial for the wellbeing of the older adult residents [14], and it is important to come up with plans to help families become involved in care as partners rather than passive watchers.

Previous research on partnership in nursing includes studies that explored the meaning and analyzed the construction of partnership [20–23], studies that developed a partnership model [24–27], and studies that examined parental and family involvement [28,29]. Building an efficient partnership between families and staff helps to manage care for older adult residents that enhances their quality of life [18,30].

Despite the awareness of the importance of partnership, efforts to develop a standardized instrument for partnership assessment have been lacking. Tools developed thus far only assess some concepts related to partnership, such as trust [31] or treatment alliance [32], with no instrument encompassing the major components of partnership. Kiriake and Moriyama [33] developed a partnership assessment tool for families of patients with dementia that used a community daycare center. However, it focused on the families of patients with dementia; thus, there are limitations to using this instrument with families of older adults without dementia. Consequently, this tool cannot directly assess the effect of nursing interventions to promote partnership between the staff and families of older adult residents.

Therefore, this study aims to develop a tool for measuring partnership between the families of older adult residents and staff in the nursing home on the basis of the Wiggins' Partnership Care Delivery Model [PCDM] [26,27]. According to Wiggins [26,27], the PCDM is a system of care that has safe patient- and family-centered care at its core, with all the disciplines engaged in a partnership to provide patient-centered care. The components of the PCDM include education and support, collaborative practice, and effective communication. In addition, successful collaboration consists of communication and interpersonal relationships based on trust and time.

Thus, the purpose of this study was to develop and validate an instrument to be administered to families of NH residents to assess their partnership with the NH staff on the basis of PCDM. This will not only identify the degree of partnership between the family member and staff, but also be useful for developing an intervention program for partnership formation in practice. In addition, it can be used as an indicator for quality management of facility care in terms of policy and can be used as basic data for evaluating and preparing improvement plans.

2. Methods

2.1. Study Participants

The participants were family members of older adult NH residents. The inclusion criteria were as follows: (1) families who most frequently visited the NHs after the older adults' admission, (2) those who provided informed consent to participate in the study. Based on an appropriate sample size of 150–200 for exploratory factor analysis (EFA) [34], and at least 150 for confirmatory factor analysis (CFA) [35], we set the sample size to 300. Considering a 20% dropout rate, we collected data from 360 participants, and after excluding 30 questionnaires with inappropriate responses or withdrawal, a total of 330 questionnaires were analyzed.

2.2. Development of Instrument

The Scale for Partnership in Care –for Family (SPIC-F) was developed in four stages based on the guidelines of DeVellis [36] on tool development (Figure 1).

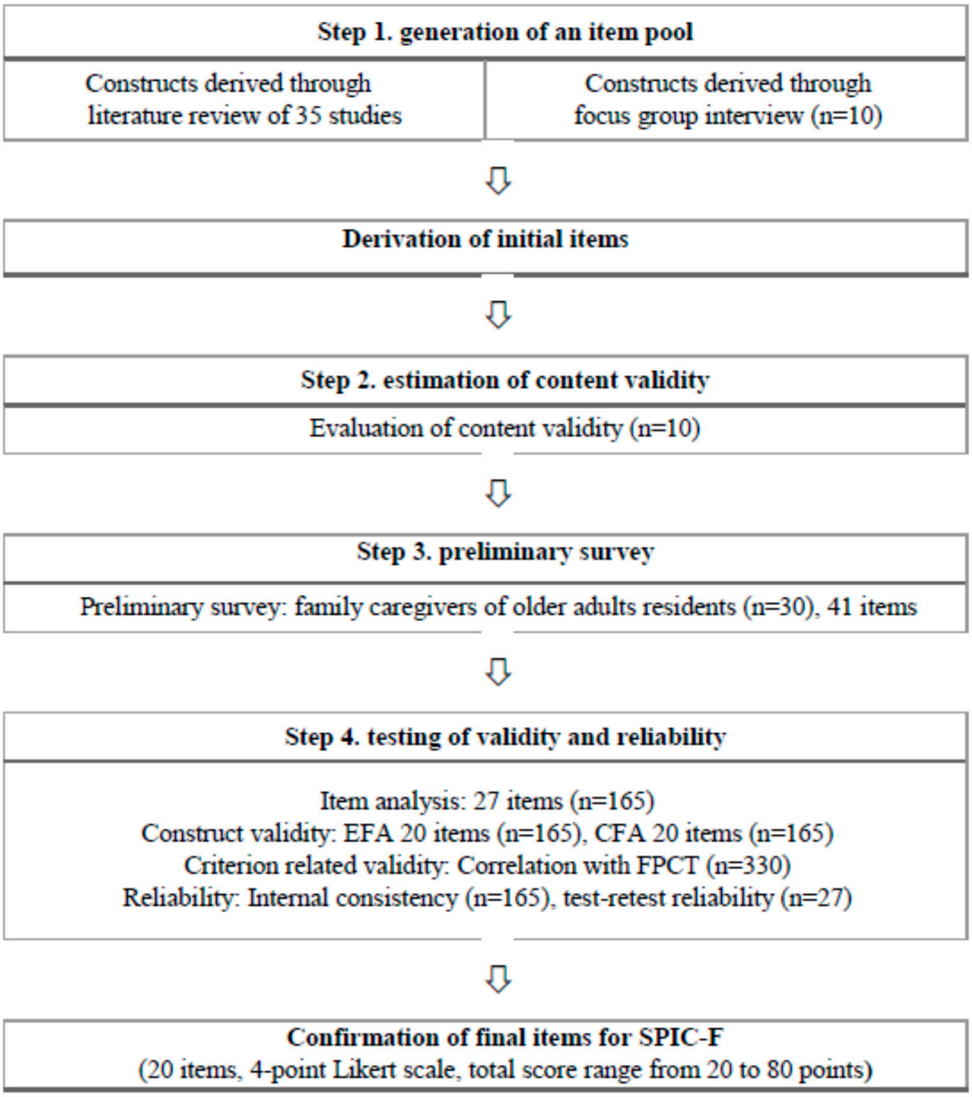

Figure 1. The SIPC-F development process. Notes. EFA = exploratory factor analysis; CFA = confirmatory factor analysis; FPCT = family perceptions of care tool; SPIC-F = scale for partnership in care—for family.

2.2.1. Item Generation

The item generation used a combination of deductive and inductive methods [37]. We used a literature review as the deductive method [38] and conducted a focus group interview (FGI) as the inductive method [39].

To review the literature pertaining to the concept of partnership, two researchers performed searches independently. PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo, Cochrane Library, Dissertation Abstracts, Research Information Sharing Service (RISS), and Korean studies Information Service System (KISS) were searched using the search terms “family”, “staff”, “partnership”, “nursing homes”, and “long-term care facility” to identify articles published between January 1980 and March 2017. The language was set to Korean and English. A total of 35 articles dealing with the construct of partnership were analyzed.

FGIs were conducted with 10 family members of older adult NH residents on September 2 and 30, 2017 to reconfirm the components of partnership identified in the literature review and identify additional components. To ensure an effective interaction between the participants [40,41], each group comprised five participants. The FGIs were conducted in a quiet conference room in the NH and lasted about 90 min on average. Data saturation was reached when no new information was discovered. Individual in-depth interviews were conducted with two FGI participants to complement and verify the results of the FGIs. The collected data were analyzed via qualitative content analysis [42]. Meaningful words, phrases, and sentences were coded by repeatedly reading the interview transcriptions. The differences and similarities among the codes were compared to extract categories that clustered the data in terms of relevance. Considering the connection and relevance among the categories, broader topics that were abstract and significant were extracted as the components of partnership.

The partnership components identified through the literature review and FGIs were relationship, sharing information, sharing decision-making, professional competence, and involvement in care. We developed 32 preliminary self-report items based on the identified components. Each item was rated on a 4-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, and 4 = strongly agree). To prevent fixed responses, items for the same construct were arranged nonconsecutively, and reverse-coded items were included. A higher score indicated a higher level of partnership between staff and families of older adult NH residents.

2.2.2. Content Validity

Content validity was tested by a panel of 10 experts to determine the degree to which each item fit the operational definition of the construct. A panel of experts was formed with five nursing professors in the field of gerontological nursing with five or more years of experience and three nursing home managers and two nurses with 10 or more years of experience in the provision of care at a nursing home. These experts possessed a wealth of knowledge on family caregivers and nursing home residents. The content validity index (CVI) of the preliminary items was rated on a 4-point scale, and ratings of 3 (relevant) and 4 (very relevant) were processed as 1, and ratings of 2 (not relevant) and 1 (not relevant at all) were processed as 0. Only the items with a CVI of 0.78 or higher were selected [43], and any opinions about additional items and revisions were considered.

The CVI of the 32 preliminary items ranged from 0.80 to 1.00 (19 items with CVI of 1.00, 12 with CVI of 0.90, and 1 with CVI of 0.80), and the CVI was above the cutoff of 0.78 for all items [43]. Items that were suggested to be divided into two items were revised accordingly. After revising terms and phrases and adding and subdividing items, a total of 41 items were generated.

2.2.3. Preliminary Study

To enhance the fit of the instrument by reflecting various opinions considering the facility size, a pilot study was conducted with each 10 family members at a facility with up to 29 beds, 30–99 beds, and 100 or more beds, respectively.

A total of 12 men and 18 women participated in the pilot study conducted from March to April 2018. The mean age was 53.1 years, and the mean duration of caregiving prior to institutionalization was 51.0 months, 21 were college graduates or higher. Older adults' mean length of stay in the NH was 48.4 months, and the mean number of participants' monthly visits to the NH was 3.7. At each visit, 18 participants stayed for 1 h or longer.

We asked participants about items that were difficult to understand or answer and about the time needed to respond. There were no problems with comprehensibility, time needed for response, item arrangement, and appropriateness of item length in the pilot study; thus, the main survey was conducted with 41 items.

2.3. Data Collection and Ethical Considerations

This study was approved by the institutional review board (IRB No. HYI-17-085-1) at the researcher's affiliated university. Data were collected from July to October 2018 at 14 NHs (four NHs with 29 beds or less, six NHs with 30–99 beds, four NHs with 100 or more beds) in Seoul, Gyeonggi, Gangwon, Gyeongbuk, and Chungnam, Korea.

In order to reduce measurement errors, a preliminary study was conducted to confirm item comprehension, time needed for response, item arrangement, and appropriateness of item length. Two research assistants were then trained to assist with both the distribution and collection of the questionnaires in the participating nursing homes. In addition, since some items of the tool included a description of the facility staff's capabilities, self-filled surveys were conducted anonymously in a quiet, independent space so that the response was not affected by the staff.

Prior to data collection, the participants were adequately informed about the purpose and procedures of the study, study participants' rights, voluntary participation, and confidentiality, and data were collected from those who voluntarily signed the written consent form. In addition, the survey was conducted 2 weeks after initial survey for test–retest.

2.4. Instrument

Criterion validity was tested using the Family Perceptions of Care Tool (FPCT) originally developed by Mass and Buckwalter [44] and translated into Korean by Park [45]. It was used as evidence that families with a good cooperative relationship with the facility staff have high satisfaction with care provided by the facility [18,46–48]. This tool measures family's perceptions of care in four aspects (staff consideration, management effectiveness, physical care, activities). The Cronbach's α was 0.94 in Park's [45] study and 0.88 in this study.

2.5. Statistical Analysis

Data analyses were performed using the SPSS/WIN program version 25.0 (IBM Corp, Armonk, NY, USA) and the AMOS/WIN program version 25.0.

The 330 participants recruited for the man survey were randomized into an EFA or a CFA group (165 in each) using the random case sampling feature of SPSS, according to the study by Hinkin [34], who suggested that different sets of participants should be used for EFA and CFA. Participant's general characteristic were analyzed using frequency, percentage, mean, and standard deviation. The homogeneity between the EFA and CFA groups was analyzed with t-tests and χ^2 tests. For item analysis, the mean, kurtosis, and skewness of each item were examined, and items with an item-total correlation coefficient above 0.30 were selected [49]. The Kaiser-Meyer-Olkin (KMO) test and Bartlett's test of sphericity were performed to determine whether the data were appropriate for EFA. In EFA, factors were extracted with principal component analysis (PCA) with Varimax rotation. Factors with an eigenvalue greater than 1.00 were extracted, and items with a commonality greater than 0.40 and factor loading (FL) greater than 0.50 were selected [50].

In the CFA, the criteria for model fitness were as follows: χ^2 (p) ($p > 0.05$), normed χ^2 (CMIN/df) ≤ 3, goodness-of-fit index (GFI), and adjusted GFI (AGFI) ≥ 0.80, comparative fit index (CFI) and normed fit index (NFI) ≥ 0.90, root mean square residual (RMR) ≤ 0.05, and root mean square error of approximation (RMSEA) ≤ 0.10 [50]. The criteria for convergent validity were as follows: FL ≥ 0.50; composite reliability (CR) $\geq \pm 1.97$ ($p < 0.05$); average variance extracted (AVE) ≥ 0.50; and composite construct reliability (CCR) ≥ 0.70. The discriminant validity was tested using AVE and square of correlation coefficient between variables ($\Phi 2$). The criterion for discriminant validity was AVE $> \Phi 2$ [51].

As for criterion validity, concurrent validity was assessed using Pearson's correlation analysis with families' satisfaction with the care provided at NHs, as families with a good cooperative relationship with NH staff were found to have high satisfaction with the care provided [18,46–48].

Reliability was verified with item-total correlation (ITC) and internal consistency (Cronbach's α). The stability of the instrument was analyzed by the test–retest reliability was assessed using intra-class correlation coefficient (ICC).

3. Results

3.1. Validity and Reliability Testing

3.1.1. Participant Characteristics

The mean age was 53.67 (SD ± 11.04) years, and 62.1% were women. The majority of the participants (80.3%) considered their economic status to be middle class, 45.8% perceived themselves to be in moderate health, and 70.9% reported high stress. Forty percent of the participants were in a 30–99-bed facility, and 60.0% were adult children of the older adult residents. The mean duration of caregiving prior to institutionalization was 53.52 (SD ± 89.85) months. There were no significant differences in the general characteristics between the EFA and CFA groups (Table 1).

Table 1. General characteristics of participants. *N* = 330.

Variables	**Category**	**Total**	**Group A for EFA (n = 165)**	**Group B for CFA (n = 165)**	**t or χ^2 (*p*)**
		n (%) or Mean ± SD			
Age (year)		53.67 ± 11.04	54.85 ± 10.44	52.50 ± 11.51	1.94 (0.053)
Gender	Female	205 (62.1)	105 (63.6)	100 (60.6)	0.32 (0.570)
	Male	125 (37.9)	60 (36.4)	65 (39.4)	
Education	≤Middle school	19 (5.7)	8 (4.8)	11 (6.7)	0.51 (0.773)
	High school	90 (27.3)	45 (27.3)	45 (27.3)	
	≥College	221 (67.0)	112 (67.9)	109 (66.0)	
Perceived economic status	Good	28 (8.5)	16 (9.7)	12 (7.3)	3.40 (0.183)
	Moderate	265 (80.3)	126 (76.4)	139 (84.2)	
	Poor	37 (11.2)	23 (13.9)	14 (8.5)	
Perceived health status	Good	43 (13.0)	23 (13.9)	20 (12.1)	0.40 (0.817)
	Moderate	151 (45.8)	73 (44.3)	78 (47.3)	
	Poor	136 (41.2)	69 (41.8)	67 (40.6)	
Perceived stress status	Low	96 (29.1)	46 (27.9)	50 (30.3)	0.24 (0.628)
	High	234 (70.9)	119 (72.1)	115 (69.7)	
Size of facilities	≤29 beds	28 (8.5)	11 (6.7)	17 (10.3)	3.55 (0.170)
	30–99 beds	132 (40.0)	61 (37.0)	71 (43.0)	
	≥100 beds	170 (51.5)	93 (56.3)	77 (46.7)	
Relationship to older adult resident	Spouse	16 (4.8)	8 (4.8)	8 (4.8)	5.24 (0.388)
	Adult child	198 (60.0)	105 (63.6)	93 (56.4)	
	Daughter-in-law	59 (17.9)	30 (18.2)	29 (17.6)	
	Son-in-law	23 (7.0)	11 (6.7)	12 (7.3)	
	Others	34 (10.3)	11 (6.7)	23 (13.9)	
Duration of caring at home (month)		53.52 ± 89.85	51.47 ± 86.13	55.56 ± 93.65	−0.41 (0.680)

EFA = Exploratory factor analysis; CFA = Confirmatory factor analysis; *p* = Level signification.

3.1.2. Item Analysis

The mean score for each item ranged from 2.90 to 3.66, with SD of 0.49–0.83. After deleting 14 items (#2, #4, #7, #14, #15, #17, #23, #25, #30, #31, #33, #38, #40, #41) with an item-total correlation coefficient below 0.30 [49], we decided to perform factor analysis on the 27 items.

3.1.3. Construct Validity

The construct validity of the scale was evaluated with EFA and CFA and assessing convergent and discriminant validity.

EFA

Prior to the EFA, we performed the KMO test and Bartlett's sphericity test. The KMO value was 0.94, indicating adequacy for factor analysis [45], and Bartlett's sphericity value was also statistically significant ($\chi^2 = 2252.85$, $p < 0.001$).

A PCA with Varimax rotation was performed to extract the factors. One item with a commonality of below 0.40 (#8), two items with FL of below 0.50 (#9, #13), two items found to the presence of cross-loading (#1, #24) [50], and two items found to have heterogeneous properties relative to other items in terms of the construct (#5, #11) were deleted.

After deleting these items, EFA was performed with the 20 remaining items. The FL was above 0.50 for all items; thus, no additional items were removed. Three factors had an eigenvalue of 1.00 or higher, and there were three significant factors per elbow point on the Scree plot. Furthermore, the explained cumulative variance of these factors was 65.8%, based on which the number of factors was set to three. The first factor explained 30.4%, the second 22.1%, and the third 13.3% (Table 2).

CFA

CFA was performed to test the construct validity by verifying the number of latent variables and inter-item relationships for the 20 items under the three factors identified through EFA (Figure 2).

We checked whether the items had FL of 0.50 or higher [52] and CR (which determines the significance of FL) of ± 1.965 or higher ($p < 0.05$) [51], and all items satisfied these criteria.

With the exception of χ^2 (p), all fitness indices for the final 20 items satisfied the recommended cutoff requirements: $\chi^2 = 321.72$ ($p < 0.001$), normed χ^2 (CMIN/df) = 1.93, GFI = 0.84, AGFI = 0.80, CFI = 0.93, RMR = 0.02, RMSEA = 0.08, and NFI = 0.86.

Subsequently, we assessed convergent validity, which represents the consistency of the items that measure the latent variable. The cutoff for standardized FL ($\geq$0.50) was satisfied with a range of 0.59–0.85, and the cutoff for CR (>1.965) was also satisfied with a range of 5.87–12.50. The cutoff for AVE (>0.50) was met with a range of 0.68–0.81, and so was the cutoff for CCR (>0.70) with a range of 0.89–0.97; therefore, the convergent validity of the scale was established. Finally, to determine the independence of the factors, discriminant validity was tested with AVE > Φ2. The AVE values for Factor 1 (0.79) and Factor 2 (0.81) were greater than the square of the highest correlational coefficient between the two factors (0.78); thus, the scale's discriminant validity was established.

Table 2. Item analysis and factor analysis of Scale for Partnership In Care—for Family (SPIC-F).

Factor/Item Contents	Mean ± SD	Factor Loadings			Commonality	Explained Variance (%)	ITC	Cron-Bach's α If Item Deleted	Cron-Bach's α	ICC (95%CI) (n = 27)	AVE	CCR
		1	2	3								
Factor 1						**30.4**			**0.93**	**0.80 (0.57–0.91)**	**0.79**	**0.97**
27. Staff encourage the family to visit the facility.	3.08 ± 0.75	**0.79**	0.18	0.16	0.68		0.70	0.95				
28. Staff positively support family involvement in providing care (e.g., conversation, taking a walk, meal assistance, etc.).	3.26 ± 0.58	**0.78**	0.20	0.19	0.69		0.74	0.95				
29. Staff welcome the family when they visit the facility.	3.28 ± 0.69	**0.75**	0.26	0.17	0.66		0.70	0.95				
39. Staff inform the family about the regulations and the policies of the facility before he or she is admitted.	3.31 ± 0.59	**0.74**	0.18	0.22	0.64		0.70	0.95				
34. Staff respect and support the families' decision-making on the older adults residing in the facility.	3.22 ± 0.60	**0.71**	0.40	0.17	0.69		0.77	0.94				
36. Staff provide appropriate care on the condition of the older adults residing in the facility.	3.23 ± 0.58	**0.71**	0.46	0.17	0.74		0.79	0.94				
37. Staff provide care while maintaining the dignity of the older adults residing in the facility.	3.20 ± 0.61	**0.70**	0.35	0.26	0.68		0.77	0.95				
26. Staff inform the family about the condition or changes in the condition of the older adults residing in the facility.	3.35 ± 0.59	**0.67**	0.40	0.19	0.65		0.74	0.95				
35. Staff are sensitive to changes in the state of the older adults residing in the facility.	3.10 ± 0.69	**0.67**	0.34	0.00	0.56		0.63	0.95				
32. Staff involve families when planning care for the older adults residing in the facility.	2.95 ± 0.68	**0.63**	0.31	0.06	0.50		0.65	0.95				
Factor 2						**22.1**			**0.91**	**0.71 (0.36–0.87)**	**0.81**	**0.96**
16. Staff and I communicate smoothly regarding caring for the older adult.	3.28 ± 0.60	0.32	**0.77**	0.22	0.76		0.74	0.95				
20. Staff and I discuss the range of roles that each other should take in caring for the older adult.	3.14 ± 0.64	0.33	**0.77**	0.22	0.75		0.73	0.95				
21. Staff and I respect each other's knowledge and experience with regard to caring for the older adults residing in the facility.	3.30 ± 0.57	0.36	**0.70**	0.30	0.70		0.71	0.95				
19. Staff and I understand and sympathize with each other's difficulties in caring for the older adults residing in the facility.	3.29 ± 0.57	0.49	**0.69**	0.15	0.73		0.75	0.95				
22. Staff and I find solutions together when problems occur regarding the older adults residing in the facility.	3.32 ± 0.60	0.34	**0.68**	0.26	0.65		0.72	0.95				
18. Staff and I share a common goal in caring for the older adults residing in the facility.	3.30 ± 0.63	0.39	**0.67**	0.32	0.71		0.75	0.95				

Table 2. *Cont.*

Factor/Item Contents	**Mean ± SD**	**Factor Loadings**			**Commonality**	**Explained Variance (%)**	**ITC**	**Cron-Bach's α If Item Deleted**	**Cron-Bach's α**	**ICC (95%CI) (n = 27)**	**AVE**	**CCR**
		1	**2**	**3**								
Factor 3						**13.3**			**0.74**	**0.85** **(0.67–0.93)**	**0.68**	**0.89**
10. I am involved in the care of the older adult residing in the facility.	3.24 ± 0.61	0.10	0.09	**0.81**	0.67		0.44	0.95				
12. I pay enough attention to the older adult residing in the facility.	3.27 ± 0.51	0.21	0.15	**0.77**	0.66		0.48	0.95				
3. I provide staff with information on the characteristics of the older adult before he or she is admitted.	3.48 ± 0.57	0.13	0.39	**0.64**	0.57		0.50	0.95				
6. I actively participate when the staff ask for cooperation regarding the older adult residing in the facility.	3.52 ± 0.57	0.19	0.36	**0.56**	0.48		0.51	0.95				
Total							65.8		0.95	0.83 (0.62–0.92)		
KMO = 0.94, Bartlett's test: χ_2 = 2252.85 ($p < 0.001$)												

ITC = Item-Total Correlation; ICC = Intra-class Correlation Coefficient; AVE = Average Variation Extracted; CCR = Composite Construct Reliability.

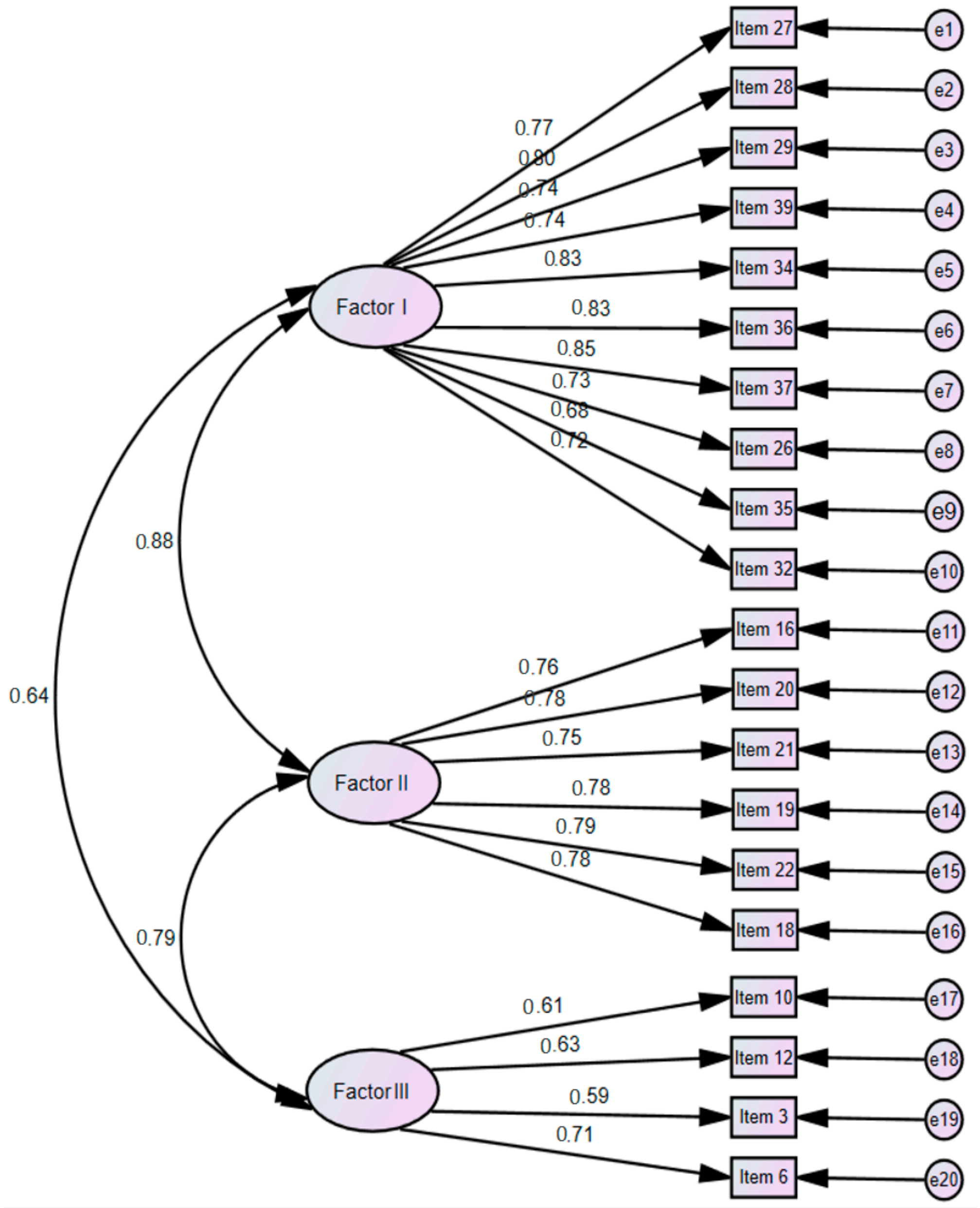

Figure 2. Confirmatory factor analysis of SPIC-F (n = 165) notes. X^2 (p) = 321.72 ($p < 0.001$), df = 167, CMIN/df = 1.93, GFI = 0.84, AGFI = 0.80, CFI = 0.93, NFI = 0.86, RMR = 0.02, RMSEA = 0.08. CMIN/DF = chi-square minimum/degree of freedom; GFI = goodness of fit index; AGFI = adjusted goodness of fit index; CFI = comparative fit index; RMR = root mean square residual; RMSEA = root mean square error of approximation.

3.1.4. Criterion Validity

For criterion-related validity, concurrent validity using Pearson's correlation coefficient test between the SPIC-F and the FPCT. The correlation coefficient was 0.64 ($p < 0.001$), indicating a strong positive correlation between the two instruments, thereby verifying the criterion validity of the SPIC-F (Table 3).

Table 3. Correlation between SPIC-F and Family Perceptions of Care Tool (FPCT). *N* = 330.

Measurement	SPIC-F	Factor 1	Factor 2	Factor 3
	r (*p*)	r (*p*)	r (*p*)	r (*p*)
FPCT	0.64 (<0.001)	0.68 (<0.001)	0.55 (<0.001)	0.28 (<0.001)

SPIC-F = scale for partnership in care—for family; r = Pearson's correlation coefficient; *p* = level signification.

3.1.5. Reliability

The ITC and Cronbach's α were assessed to verify the internal consistency of the instrument (Table 2). The ITC were all > 0.40 with a range of 0.44–0.79 [49], and Cronbach's α was 0.95 for the entire 20 items; 0.93 for Factor 1, 0.91 for Factor 2, and 0.74 for Factor 3, all of which were above the cutoff of 0.70 [36]. The ICC was 0.83 (95% CI [0.62, 0.92]) indicating good to excellent retest stability.

3.2. Finalization of Scale

Finally, the SPIC-F developed in this study contained 20 items with three factors: professional caring and support (10 items), cooperative relationship and information sharing (6 items), and participation in care (4 items). The average time to complete the survey was about 5–10 min. Items were rated on a 4-point Likert scale and the total score range was 20–80, with higher scores indicating higher levels of partnership between families of NH residents and staff. The SPIC-F scale is attached in Appendix A.

4. Discussion

In this study, we identified the components of partnership between families of older adult NH residents and staff and developed an instrument to measure this partnership according to the tool development guideline by DeVellis [36]. The results confirmed that the developed instrument had acceptable validity and reliability.

In our review of the literature, we found that the construct of partnership has been mostly researched in relation to the parents of children and caregivers in acute hospitals [22–25,28,29], and that the studies on families of older individuals involved those living at home and in care facilities [11,19]. Thus, FGIs were conducted with families of older adult NH residents to obtain a clear understanding of partnership and identify factors that reflect the characteristics of NHs. According to the main properties of partnership identified through FGIs, families of older adult NH residents perceived that a partnership with the staff should involve a mutually respectful and equal relationship, sharing information about care, cooperating to make decisions related to care, and being respected in their decisions. Furthermore, families perceived the provision of consistent care without frequent changes of caregiver as important, wished to know the type of care provided or not provided at the NH for better decision-making, and thought that they should fully cooperate with the care provided at the NH. This highlights the need for more communication between the staff and families of older adult residents in order to build an effective partnership [53].

The features of the SPIC-F are as follows. First, we randomized the participants to the EFA or CFA group because the differences in item variance may disappear in correlation analysis because all items are standardized to common variance if EFA and CFA are performed on the same set of subjects when assessing an instrument's validity [34]. Thus, we attempted to establish a more appropriate validation process by using two different samples. Second, a variety of analyses were performed to test of validity and reliability of the instrument. EFA and CFA were performed to test the construct validity. Although the p-value for χ^2 was below the cutoff of 0.05 in the CFA for testing the fit of the model, we nevertheless determined that the model fit satisfied the criteria because χ^2 (p) may be inappropriate even in models with a good fit due to the complexity of the model or influence of the method of estimation; thus, it should not be trusted unconditionally [51]. We established convergent and discriminant validity, and offered strong evidence for the use of the instrument by confirming its criterion validity, internal consistency, and stability. Third, as the tool consists of 20 items, it is convenient and easy to use.

Furthermore, the preliminary survey has made the items easier to comprehend, which can minimize non-response rates. However, because some items of the tool contain contents about the competence of the facility's staff, it is suggested that they be measured by the facility manager or by a third party rather than by the staff who provide direct care to prevent the Hawthorne effect.

The implications for the application of the SPIC-F are as follows. First, the three factors of SPIC-F consist of items reflecting independent and shared roles of families and staff. Considering that partnership involves collaborating to reach a shared goal while acknowledging each other's expertise and agreeing on roles and shared responsibilities [54], and that the SPIC-F encompasses contents about independent and shared roles of families and staff, it could be utilized to develop education and intervention programs to build an efficient partnership. In other words, SPIC-F measures each sub-factor or item to find out the lack of family participation, staffs' professional caring and support, and mutual cooperation, communication, and information sharing among family and staff. On the basis of this, it will be possible to develop a program that can focus on the aspects that are lacking and improve them.

Particularly, through care involvement programs for families of older adult residents, the staff can identify older adults' unmet medical, emotional, and social needs, which in turn could promote older adults' participation in activities [18]. Moreover, the quality of life of older adults in NHs would be enhanced and the conflicts between family member and staff would be reduced by encouraging communication between families and staff, helping families to fulfill their roles in caregiving, and having them provide personal care while visiting the NH [55]. Second, although the SPIC-F measures the level of partnership from the families' perspective, its results could also be utilized when educating facility staff. That is, a low partnership score for the roles of staff could be reflected in the education of staff. Through education, staff would be able to assist older adult residents with their activities of daily living, such as dressing, bathing, or eating, while taking into consideration their needs and preferences [55], promoting person and family-centered care of older adults in NHs [56]. Finally, partnership formation can be used as an indicator of quality care for facility care and can be used as a basis for evaluating and preparing improvement plans. This could also contribute to streamlining health insurance expenditures by further reducing the use of health care by improving the quality of care for the facility.

A limitation of this study is that we used convenience sampling to recruit our participants; thus, this instrument should be validated with subjects from various regions. Furthermore, the instrument was developed in Korea and thus includes Korean cultural features; therefore, additional studies are needed to examine whether it can be utilized in other cultures.

5. Conclusions

We developed and validated an instrument to measure partnership between staff and families of older adult NH residents as perceived by families. The SPIC-F consists of 20 items in three categories: professional caring and support (10 items), cooperative relationship and information sharing (6 items), and participation in care (4 items). Each item is rated on a 4-point Likert scale, and the total score range is 20–80, with a higher score indicating a higher level of partnership between staff and families. This instrument was developed by identifying the components of partnership between staff and families and high validity and reliability were established. This instrument is useful for assessing partnership and can be used as a basis for the development and implementation of interventions to effective partnership formation between staff and families of older adult NH residents.

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Appendix A. SPIC-F Scale

Subject: family member of older adult nursing home (NH) resident

Table A1. The following questions are about partnerships with families and staff. For the following questions, please circle the number that best corresponds to your views.

Item	Strongly Disagree	Disagree	Agree	Strongly Agree
Professional caring and support				
1. Staff encourage the family to visit the facility.	①	②	③	④
2. Staff positively support family involvement in providing care (e.g., conversation, taking a walk, meal assistance, etc.).	①	②	③	④
3. Staff welcome the family when they visit the facility.	①	②	③	④
4. Staff inform the family about the regulations and the policies of the facility before he or she is admitted.	①	②	③	④
5. Staff respect and support the families' decision-making on the older adults residing in the facility.	①	②	③	④
6. Staff provide appropriate care on the condition of the older adults residing in the facility.	①	②	③	④
7. Staff provide care while maintaining the dignity of the older adults residing in the facility.	①	②	③	④
8. Staff inform the family about the condition or changes in the condition of the older adults residing in the facility.	①	②	③	④
9. Staff are sensitive to changes in the state of the older adults residing in the facility.	①	②	③	④
10. Staff involve families when planning care for the older adults residing in the facility.	①	②	③	④
Cooperative relationship and information sharing				
11. Staff and I communicate smoothly regarding caring for the older adult.	①	②	③	④
12. Staff and I discuss the range of roles that each other should take in caring for the older adult.	①	②	③	④
13. Staff and I respect each other's knowledge and experience with regard to caring for the older adults residing in the facility.	①	②	③	④
14. Staff and I understand and sympathize with each other's difficulties in caring for the older adults residing in the facility.	①	②	③	④
15. Staff and I find solutions together when problems occur regarding the older adults residing in the facility.	①	②	③	④
16. Staff and I share a common goal in caring for the older adults residing in the facility.	①	②	③	④
Participation in care				
17. I am involved in the care of the older adult residing in the facility.	①	②	③	④
18. I pay enough attention to the older adult residing in the facility.	①	②	③	④
19. I provide staff with information on the characteristics of the older adult before he or she is admitted.	①	②	③	④
20. I actively participate when the staff ask for cooperation regarding the older adult residing in the facility.	①	②	③	④

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Article

Associations between Length of Stay in Long Term Care Facilities and End of Life Care. Analysis of the PACE Cross-Sectional Study

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Abstract: Long term care facilities (LTCFs) are increasingly a place of care at end of life in Europe. Longer residence in an LTCF prior to death has been associated with higher indicators of end of life care; however, the relationship has not been fully explored. The purpose of this analysis is to explore associations between length of stay and end of life care. The analysis used data collected in the Palliative Care for Older People in care and nursing homes in Europe (PACE) study, a cross-sectional mortality follow-back survey of LTCF residents who died within a retrospective 3-month period, conducted in Belgium, England, Finland, Italy, the Netherlands and Poland. Primary outcomes were quality of care in the last month of life, comfort in the last week of life, contact with health services in the last month of life, presence of advance directives and consensus in care. Longer lengths of stay were associated with higher scores of quality of care in the last month of life and comfort in the last week of life. Longer stay residents were more likely to have advance directives in place and have a lasting power of attorney for personal welfare. Further research is needed to explore the underlying reasons for this trend, and how good quality end of life care can be provided to all LTCF residents.

Keywords: long-term care facility; care home; nursing home; length of stay; palliative care; end of life care; epidemiology

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1. Introduction

Long-term care facilities (LTCFs) are becoming a common place of death for older adults [1–3], especially those with dementia [4,5]. Although terminology and typology varies between countries, a LTCF, including care homes and nursing homes, generally refers to a collective institutional setting where care is provided to older adults, who live there, 24 h a day, seven days a week [6].

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Ensuring LTCF residents approaching end of life receive appropriate care is challenging; residents may be frail, with multiple, complex care needs, and may be unable to either establish or communicate their preferences at end of life. Long term care facilities are often staffed by a combination of registered, qualified nurses and care assistants, who may have limited knowledge of end of life care for older adults and limited access to specialist services to support end of life care [7]. In addition, LTCF managers and their staff may lack clarity in defining and identifying end of life, or their role or responsibility in providing subsequent care within the facility [8]. In many European countries, end of life care in LTCFs in not well supported at a national level; in a review of 29 countries only eight had national policies which specifically addressed end of life care in LTCFs [9].

Palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [10]. The term "end of life care" is often used synonymously with palliative care in the UK, and refers to "an extended period of 1 to 2 years during which the patient/family and health professionals become aware of the life-limiting nature of their illness" [11]. Previous studies have found that the adoption of a palliative care approach in LTCFs led to a reduction in deaths outside the LTCF [12], an increase in the numbers of completed advance directives [13], improvements in end-of-life communication between residents, relatives and health professionals [14–16] and improvements in staff knowledge [17–19].

Numerous interventions have been developed to improve the provision and quality of end of life care in LTCFs, including staff education [20,21], inter-professional collaborations and care coordination [22,23], either through individual initiatives or as part of multicomponent interventions, such as the Liverpool Care Pathway [24], Gold Standards Framework for Care Homes [25] or the Steps to Success intervention [26]. The time point at which these initiatives aim to change the care provided to a resident varies; whereas the Liverpool Care Pathways focuses on care in the last days of life [24], interventions focusing on communicating preferences at end of life may be introduced either at admission or four to six weeks post admission. For residents who die shortly after admission, such activities may occur simultaneously.

Although specific guidelines exist for providing end of life care specifically to older adults [27] and those with dementia [28], less research has explored variation in the palliative care delivered to specific subgroups, such as women or older adults with little support from family carers. In particular, it is unclear whether the end of life care received by residents admitted shortly before death differs from the care for those who have lived in a facility for many months or even years [29]. Previous studies exploring care at end of life have found that residents with longer length of stay before death had fewer hospitalisations, were more likely to be receive palliative drug therapy, less likely to be undertreated for non-pain symptoms and more likely to have documented do-not-resuscitate (DNR) orders in place [30–33].

At present, no published research has specifically explored the association between length of stay in a LTCF and the experience of residents at end of life, collected either directly from the resident or by proxy measures. None of the research previously discussed included length of stay as a primary explanatory variable of the end of life care indicators investigated, and none report conducting any prior analysis to explore factors associated with length of stay in the data. Therefore, previous research findings may not control for all characteristics associated with longer lengths of stay, leading to associations between end of life care and resident characteristics, such as age, gender, dementia diagnosis or marital status, being confused with associations with length of stay. In addition, it is common for LTCF residents to fall into one of two broad populations, those with relatively short stays before death and those who have resided in the facility for many years [8]. In previous analysis of length of stay and end of life care in LTCFs, residents with different lengths of stay have commonly been separated into residents residing in the facility either 6 months, 1 year or 2 years before death, leaving the experience of residents with longer lengths of stay unexplored.

A greater understanding of how the experience of residents at end of life varies is a research priority, and can inform the development of interventions aiming to improve the provision and quality of end of life care in LTCFs, and explore variation within a heterogeneous population. In this analysis we used data from the Palliative Care for Older People in care and nursing homes in Europe (PACE) cross-sectional study, which aimed to compare quality of dying and end of life care in deceased residents of LTCFs in six European countries [34]. The purpose of this analysis is to explore whether length of stay in LTCF residents is related to five indicators of end of life care; quality of care in the last month of life, comfort in the last week of life, contact with health services in the last month of life, presence of advance directives and consensus among those involved in care and treatment, using staff-reported data on deceased residents from LTCFs in six European countries.

2. Materials and Methods

2.1. Study Design and Setting

The data used in this analysis are from a cross-sectional, mortality follow back survey of deceased residents; the PACE study [35]. The PACE study was conducted in a sample created, where possible, using national lists of LTCFs in Belgium, England, Finland, Italy, the Netherlands and Poland, recruited using a proportionally stratified random sampling framework [36].

In LTCFs that consented to take part in the study, data were collected on residents who had died in a 3-month retrospective period during 2015. Residents were included in the study if they had died in the facility or after transfer to hospital. For each identified resident, demographic information was collected from either administrative staff or the facility manager (response rate 95.7%), and a postal questionnaire sent to a LTCF staff member regarded as most involved in the resident's care (81.6%). A full description of the study methodology, including ethical approvals, are described elsewhere [35].

2.2. Measurements

A LTCF staff member (nurse or care assistant), identified by a key person appointed by the LTCF manager as most involved in the residents' care, self-reported the main outcomes used in this analysis. Data were collected on (i) quality of care in the last month of life, (ii) comfort in the last week of life, (iii) contact with health services in the last month, (iv) presence of advance directives, and (v) consensus among those involved in care and treatment.

Quality of care in the last month of life (i) was measured using the Quality of Dying in Long-Term Care (QoD-LTC) scale [37]. The questionnaire has 11 items, with higher scores indicating better quality of care. Three subscales, personhood, closure and preparatory tasks, can be generated. Comfort in the last week of life (ii) was measured using the End-of-Life in Dementia Scale Comfort Assessment While Dying (EOLD-CAD) scale [38]. The questionnaire has 14 items, with higher scores indicating higher levels of comfort. Four subscales, physical distress, dying symptoms, emotional distress and wellbeing, can be calculated.

The data on contact with health services at end of life (iii) were number of visits either received or made by a physician during the last month of life, number of admissions to a hospital, geriatric ward, intensive care unit or general ward (for more than 24 h) during the last month of life, and the number of visits to a hospital emergency room (for less than 24 h) during the last month of life. Resident's place of death was categorised as either death in a LTCF or in a hospital.

The presence of advance directives (iv) was determined using four outcomes. Firstly, whether the resident had any written advance directives in place, including a do not resuscitate in case of a cardiac or respiratory arrest order, do not transfer to a hospital order, a request to discontinue the use of, or do not use, other treatments, or a request to try all life sustaining measures. Secondly, whether the resident had a lasting power of attorney for personal welfare. Thirdly, whether a staff member ever spoke with the resident about medical treatments he or she would or would not want in the last phase of life or about the preferred course of care in the last phase of life. The final outcome was whether a staff member spoke with a relative of the resident about medical treatments he or she would or would not want in the last phase of life or about the preferred course of care in the last phase of life, prior to a decision being made.

The degree to which those involved in care were in agreement (consensus) on care and treatment in the last month of the resident's life (v), from the perspective of staff members, was measured among LTCF staff, among representatives/family and among all those involved in the resident's care. Staff members were asked to select one of three choices for each question; full consensus, consensus on major issues or no consensus. In this analysis, the answers were categorised as consensus (full consensus or consensus on major issues) or no consensus (no consensus).

Length of stay was calculated in days using date of admission to the LTCF and date of death. Residents were grouped based on their lengths of stay in seven groups: under 1 month, 1 to 3 months, 3 months to 1 year, 1 to 2 years, 2 to 3 years, 3 to 5 years and over 5 years. The groups were demarcated to ensure relatively similar sample sizes in each group, and to allow analysis of longer stay residents. Ten variables previously identified as associated with length of stay in the dataset were included in the analysis to control for resident, LTCF and country characteristics [39]. These were age, gender, marital status, place of admission, presence of cancer, presence and severity of dementia, physical functioning, LTCF type, LTCF funding status and country.

Age and gender were determined at the time of admission. Severity of dementia was calculated using a combined score from the Global Dementia Scale (GDS) [40] and the Cognitive Performance Scale (CPS) [41]. The Bedford Alzheimer Nursing-Severity Scale (BANS-S) [42] was used to measure physical functioning.

Each LTCF was categorised by the type of care offered, as type 1, 2 or 3 [9]. Type 1 facilities offer on-site care provided by physicians, nurses and care assistants (available in Italy, the Netherlands, and Poland). Type 2 facilities offer on-site care provided by nurses and care assistants with medical provision provided by local, external primary care services (available in all countries). Type 3 facilities offer on-site care provided by care assistants, with nursing and medical provision provided by local, external primary care services (available in England). Funding status of the LTCF was classed as either public (non-profit), private (non-profit) or private (for profit).

2.3. Statistical Analysis

Data were collected on 1707 deceased residents from 322 LTCFs. Residents were excluded from the sample if length of stay was less than one day or could not be calculated, if a resident was missing data on age or was younger than 65 years of age on admission, or no questionnaire was returned by LTCF staff (n = 470), resulting in a final sample of 1237 residents. Non-response analysis was conducted on residents for whom staff returned questionnaires and for those whom staff did not return questionnaires, based on the length of stay. Sample characteristics and frequencies for each of the outcomes are reported by length of stay.

For continuous outcomes, associations between length of stay and quality of care in the last month of life (QoD-LTC), comfort in the last week of life (EOLD-CAD) and their subscales were determined using generalised linear regression models. In each model, total scores of the QoD-LTC, EOLD-CAD and their subscales were added as the dependent variable, with length of stay added as a covariate. Resident, facility and country level characteristics previously identified as varying by length of stay were also added to each model as covariates; these were age, gender, marital status, place of admission, cancer, dementia, physical functioning, LTCF type, LTCF funding status and country. A variable identifying each LTCF was added as a random factor. Goodness of fit for each model was assessed using the Akaike information criterion.

For binary outcomes, associations between length of stay and the presence of advance directives, contact with health services and consensus on care and treatment were determined using logistic regression models. In each model, the outcome was added as a dependent variable, with length of stay added as a covariate along with resident, facility and country level characteristics. A variable identifying each LTCF was added as a random factor. The adequacy of the model was assessed using the Hosmer and Lemeshow's goodness-of-fit test. Interactions between age and gender were tested and added to the model where appropriate. Multi-collinearity was checked using variance inflation factors [43].

A positive coefficient indicates that an increase in the value of the dependant variable is associated with an increase in the value of the independent variable. A negative coefficient indicates that a decrease in the value of the dependant variable is associated with a decrease in the value of the independent variable. Statistical significance was set as $p < 0.05$. All analyses were performed using Stata (version 16) [44].

3. Results

The final sample included 1237 residents; 262 in Belgium, 252 in Finland, 192 in Italy, 193 in the Netherlands, 263 in Poland and 75 in England. No significant differences were identified in the lengths of stay of residents for whom a staff questionnaire was or was not completed and returned ($p = 0.356$). The median length of stay was 73.4 weeks (range 16–103.9 weeks) and average length of stay was 126 weeks (SD 157), ranging from 93 (SD 156) to 163 (SD 182) weeks. The mean age of residents at admission was 83.9 years (SD 7.2), ranging from 81.56 (SD 7.12) in residents with length of stay over 5 years to 85.45 (SD 7.2) in residents with a length of stay of 3 months to 1 year. The percentage of residents who were female was 67.6%, ranging from 55.8% in residents with length of stay of 1 to 3 months and 81.1% in residents with length of stay over 5 years. Characteristics of the sample and main outcomes are shown in Tables 1 and 2.

3.1. *Quality of End of Life Care in the Last Month of Life (QoD-LTC)*

Associations between end of life care and length of stay are shown in Table 3. Length of stay was associated with quality of care in the last month of life in the multivariate model. Total scores on the QoD-LTC were significantly higher in residents with a length of stay of 3 months to 1 year compared to under 1 month ($p = 0.002$); and increase significantly up to and over 5 years ($p < 0.001$). Scores on the personhood subscale were significantly higher in residents with a length of stay of 3 months to 1 year compared to under 1 month ($p = 0.010$); and increase significantly up to and over 5 years ($p = 0.001$). Scores on the closure subscale were also significantly higher in residents with a length of stay of 1 to 3 months compared to under 1 month ($p = 0.014$); and increase significantly up to and over 5 years ($p < 0.001$). Scores on the preparatory tasks subscale were significantly higher between 1 to 2 years ($p = 0.027$), 2 to 3 years ($p = 0.002$) and 3 to 5 years ($p < 0.001$), and approached statistical significance at over 5 years ($p = 0.052$).

3.2. *Comfort in the Last Week of Life (EOLD-CAD)*

Total scores on the EOLD-CAD were higher in residents with longer lengths of stay, however length of stay was significantly associated with comfort in the last week of life at only over 5 years compared to under 1 month ($p = 0.005$) in the multivariate model. Scores on the physical distress subscale were significantly higher in residents with a length of stay between 1 to 2 years ($p = 0.040$), 3 to 5 years ($p = 0.027$) and over 5 years ($p < 0.001$). Scores on the emotional distress subscale were significantly higher in residents with a length of stay of 3 to 5 years ($p = 0.007$) and over 5 years ($p = 0.001$) and on the wellbeing subscale at over 5 years ($p = 0.001$). Scores on the dying symptoms subscale were not significantly associated with length of stay.

Table 1. Characteristics of deceased long term care facility (LTCF) residents by length of stay in a LTCF until death.

	Under 1 month	**1 to 3 months**	**3 months to 1 year**	**1 year to 2 years**	**2 year to 3 years**	**3 year to 5 years**	**5 years +**	**Total**	***p* value**
	***n* = 163**	***n* = 135**	***n* = 223**	***n* = 208**	***n* = 162**	***n* = 160**	***n* = 186**	***n* = 1237**	
Age at admission—mean (SD)	83.8 (8.1)	83.7 (7.7)	85.5 (7.2)	84.56 (6.7)	84 (7.1)	83.67 (6)	81.6 (7.2)	83.9 (7.2)	**<0.001**
Gender—female (%)	91 (55.8)	87 (64.4)	142 (64.3)	132 (64.4)	110 (68.8)	119 (74.4)	150 (81.1)	831 (67.6)	**<0.001**
Marital status—married or in a civil partnership	47 (34.8)	37 (31.6)	47 (22.7)	47 (24.1)	35 (22.3)	27 (17.4)	13 (7.2)	253 (22.1)	**<0.001**
Place of admission (%)									
Community	54 (34.6)	49 (39.8)	87 (43.9)	82 (45.1)	68 (47.9)	80 (58.4)	112 (69.6)	532 (48.4)	**<0.001**
Hospital	78 (50)	52 (42.2)	75 (37.9)	59 (32.4)	39 (27.5)	30 (21.9)	32 (19.9)	365 (33.2)	**<0.001**
Other LTCF	24 (15.4)	22 (17.9)	36 (18.2)	41 (22.5)	35 (24.7)	27 (19.7)	17 (10.6)	202 (18.4)	**0.036**
BANS-S—total score—mean (SD) *	20.51 (5.4)	20.00 (4.9)	19.47 (4.8)	19.39 (4.7)	19.46 (4.5)	20.15 (4.3)	19.68 (4.9)	19.77 (4.8)	0.239
Cancer (%)	26 (16)	29 (21.5)	39 (17.5)	31 (14.9)	21 (13)	17 (10.6)	18 (9.7)	181 (14.6)	**0.046**
Dementia (%)									
Resident did not have dementia	63 (48.5)	39 (34.2)	56 (29)	57 (31.5)	33 (23.1)	38 (27.9)	52 (31.9)	338 (31.9)	**0.001**
Mild or moderate	11 (8.5)	24 (21.1)	31 (16.1)	25 (13.8)	17 (11.9)	11 (8.09)	15 (9.2)	134 (12.6)	**0.014**
Severe, very severe or advanced dementia	56 (43.1)	51 (44.8)	106 (54.9)	99 (54.7)	93 (65.1)	87 (64)	96 (58.9)	588 (55.5)	**0.001**
LTCF type (%)									
Type 1—onsite nursing/onsite physician	79 (48.8)	53 (39.6)	60 (27.7)	39 (19.2)	36 (22.4)	22 (13.9)	27 (14.6)	316 (25.9)	**<0.001**
Type 2—onsite nursing/offsite physician	81 (50)	79 (59)	153 (70.5)	158 (77.5)	123 (76.4)	129 (81.7)	146 (78.9)	869 (71.2)	**<0.001**
Type 3—offsite nursing/offsite physician	2 (1.2)	2 (1.5)	4 (1.8)	7 (3.4)	2 (1.2)	7 (4.4)	12 (6.5)	36 (3)	**0.023**
LTCF ownership (%)									
Public—non profit	91 (56.2)	88 (65.7)	129 (60)	120 (59.1)	95 (59.8)	101 (63.9)	121 (65.4)	745 (61.3)	0.497
Private—non profit	45 (27.8)	26 (19.4)	53 (24.7)	46 (22.7)	44 (27.7)	32 (20.3)	40 (21.6)	286 (23.5)	0.427
Private—profit	26 (16.1)	20 (14.9)	33 (15.4)	37 (18.2)	20 (12.6)	25 (15.8)	24 (13)	185 (15.2)	0.790
Country (%)									
Belgium	17 (10.4)	19 (14.1)	49 (22)	46 (22.1)	40 (24.7)	35 (21.9)	56 (30.1)	262 (21.2)	**<0.001**
Finland	25 (15.3)	27 (20)	41 (18.4)	53 (25.5)	35 (21.6)	43 (26.9)	28 (15.1)	252 (20.4)	**0.029**
Italy	29 (17.8)	19 (14.1)	39 (17.5)	37 (17.8)	26 (16.1)	25 (15.6)	17 (9.1)	192 (15.5)	0.228
Netherlands	14 (8.6)	16 (11.9)	34 (15.3)	35 (16.8)	30 (18.5)	25 (15.6)	39 (21)	193 (15.6)	**0.045**
Poland	71 (43.6)	47 (34.8)	47 (21.1)	25 (12)	22 (13.6)	20 (12.5)	31 (17)	263 (6.1)	**<0.001**
England	7 (4.3)	7 (5.2)	13 (5.8)	12 (5.8)	9 (5.6)	12 (7.5)	15 (8.1)	75 (6.1)	0.797

BANS-S: Bedford Alzheimer Nursing Severity Scale; LTCF: long term care facility; SD: standard deviation. * higher scores indicate poorer physical functioning. p values calculated using Pearson chi-square and one way ANOVAs. A p value of <0.05 indicated a statistically significant difference in values between lengths of stay. Missing data: gender $n = 8$, marital status $n = 90$, place of admission $n = 138$, BANS-S $n = 22$, dementia $n = 177$, LTCF type $n = 16$ and LTCF ownership $n = 21$.

Table 2. Indicators of end of life care of deceased LTCF residents by length of stay in a LTCF until death.

	Under 1 month	**1 to 3 months**	**3 months to 1 year**	**1 year to 2 years**	**2 year to 3 years**	**3 year to 5 years**	**5 years +**	**Total**	***p* value**
	***n* = 163**	***n* = 135**	***n* = 223**	***n* = 208**	***n* = 162**	***n* = 160**	***n* = 186**	***n* = 1237**	
Quality of care in the last month of life (QoD-LTC)									
Total score—mean (SD)	35.80 (6.96)	37.75 (6.97)	38.59 (7.56)	38.89 (7.73)	39.55 (7.32)	40.06 (8.08)	40.41 (7.65)	38.79 (7.62)	**<0.001**
Personhood subscale—mean (SD)	19.67 (3.35)	20.19 (3.52)	20.54 (3.55)	20.99 (2.94)	21.17 (3.56)	21.11 (3.61)	21.09 (3.39)	20.70 (3.44)	**<0.001**
Closure subscale—mean (SD)	8.01 (2.72)	9.03 (2.77)	9.21 (2.91)	9.29 (2.84)	9.14 (2.94)	9.47 (2.96)	9.72 (9.72)	9.15 (9.15)	**<0.001**
Preparatory tasks subscale—mean (SD)	6.92 (3.41)	7.70 (3.26)	8.02 (3.80)	8.07 (3.95)	8.32 (3.76)	8.47 (4.08)	8.58 (3.74)	8.03 (3.77)	**0.001**
Comfort in the last week of life (EOLD-CAD)									
Total score—mean (SD)	29.63 (5.50)	29.46 (5.78)	30.58 (5.33)	31.07 (5.07)	30.41 (5.42)	31.20 (5.21)	31.82 (5.06)	30.67 (5.36)	**0.001**
Physical distress subscale—mean (SD)	4.29 (1.70)	4.35 (1.80)	4.77 (1.77)	4.85 (1.66)	4.75 (1.64)	4.76 (1.81)	5.16 (1.57)	4.73 (1.72)	**<0.001**
Dying symptoms subscale—mean (SD)	6.86 (2.47)	6.97 (2.24)	7.07 (2.12)	7.15 (1.99)	7.04 (2.04)	7.05 (2.13)	7.17 (2.22)	7.05 (2.17)	0.874
Emotional distress subscale—mean (SD)	8.90 (2.69)	9.01 (2.47)	9.36 (2.27)	9.54 (2.17)	9.55 (2.08)	9.69 (2.13)	9.88 (1.85)	9.44 (2.25)	**0.001**
Wellbeing subscale—mean (SD)	5.02 (1.90)	5.23 (1.71)	5.64 (1.81)	5.83 (1.91)	5.68 (1.86)	5.82 (1.91)	6.09 (1.78)	5.65 (1.87)	**0.001**
Contact with health services in the last month of life									
Physician visits (%)									
0–5 visits	56 (51.38)	53 (54.64)	94 (58.75)	101 (70.63)	65 (61.90)	68 (55.74)	78 (60.47)	515 (59.54)	0.055
More than five visits	53 (48.62)	44 (45.36)	66 (41.25)	42 (29.37)	40 (38.10)	54 (44.26)	51 (39.53)	350 (40.46)	
Hospital admissions (%)									
None	98 (70.50)	98 (79.03)	164 (77.36)	159 (80.71)	125 (81.70)	126 (82.35)	157 (86.26)	927 (79.91)	**0.028**
One or more visits	41 (29.50)	26 (20.97)	48 (22.64)	38 (19.29)	28 (18.30)	27 (17.65)	25 (13.74)	233 (87.14)	
Emergency department visits (%)									
None	124 (88.57)	107 (86.29)	185 (86.85)	160 (82.47)	138 (90.20)	135 (87.10)	161 (89.44)	1010 (87.14)	0.396
One or more visits	16 (11.43)	17 (13.71)	28 (13.15)	34 (17.53)	15 (9.80)	20 (12.90)	19 (10.56)	149 (12.86)	
Place of death (%)									
LTCF	133 (84.7)	106 (82.8)	195 (88.6)	173 (84.8)	139 (86.9)	145 (90.6)	159 (84)	1050 (86.5)	0.460
Hospital	24 (15.3)	22 (17.2)	25 (11.4)	31 (15.2)	21 (13.1)	15 (9.4)	26 (14.1)	164 (13.5)	
Presence of advance directives									
Resident had any written advance directives in place (%)	33 (20.3)	46 (34.07)	81 (36.3)	81 (38.9)	60 (37)	74 (46.3)	88 (47.3)	463 (37.4)	**<0.001**
Resident had lasting power of attorney for personal welfare (%)	38 (28.2)	39 (36.5)	57 (32.4)	63 (37.8)	44 (35.8)	42 (32.1)	62 (43.4)	345 (35.1)	0.182
Staff spoke with the resident about end of life care (%)	20 (13.5)	28 (22.3)	50 (23.4)	51 (24.7)	39 (24.7)	39 (25.2)	60 (33.6)	287 (24.7)	**0.005**
Staff spoke with the relative about end of life care (%)	70 (44.9)	55 (43)	129 (60.6)	128 (61.9)	105 (66.9)	112 (71.4)	110 (60.8)	709 (59.2)	**<0.001**
Consensus in care and treatment									
Among staff (%)	152 (97.4)	125 (99.2)	203 (98.1)	193 (97.5)	152 (99.4)	146 (97.3)	172 (98.9)	1143 (98.2)	0.673
Among family (%) *	142 (98.6)	108 (97.3)	187 (96.9)	183 (97.7)	147 (99.3)	137 (97.2)	158 (100)	1062 (98.2)	0.299
Among all involved (%)	152 (98.7)	120 (97.6)	200 (98.1)	194 (97.5)	152 (99.4)	146 (98)	173 (98.9)	1137 (98.3)	0.836

QoD-LTC: Quality of Dying in Long-Term Care. EOLD-CAD: End of Life in Dementia Scale-Comfort Assessment while Dying. Theoretical range of QoD-LTC—total score: 11–55, personhood subscale: 5–25, closure subscale: 3–15, preparatory tasks: 3–15. Theoretical range of EOLD-CAD—total score: 14–42, physical distress subscale: 4–12, dying symptoms subscale: 4–12, dying symptoms subscale: 4–12, emotional distress: 4–12, wellbeing subscale: 3–9. Theoretical ranges based on no missing data. LTCF: long term care facility; SD: standard deviation. p values calculated using Pearson chi-square and one way ANOVAs. A p value of <0.05 indicated a statistically significant difference in values between lengths of stay. Missing data: QoD-LTC total score $n = 41$, personhood subscale $n = 13$, closure subscale $n = 18$, preparatory tasks subscale $n = 32$, EOLD-CAD total score $n = 76$, physical distress $n = 43$, dying symptoms $n = 42$, emotional distress $n = 50$, wellbeing subscale $n = 61$, physician visits $n = 372$, hospital admissions $n = 77$, emergency department visits $n = 78$, place of death $n = 23$, lasting power of attorney $n = 255$, staff member spoke with the resident about end of life care $n = 49$, staff member spoke with the relative about end of life care $n = 38$, consensus of care among staff $n = 73$, consensus of care among family $n = 89$, consensus of care among all involved $n = 80$. * family were not involved in residents care $n = 66$.

Table 3. Associations between indicators of end of life care of deceased LTCF and length of stay in a LTCF until death.

	Length of Stay—Coefficient (95% CI)						
	Under 1 month	**1 to 3 months**	**3 months to 1 year**	**1 year to 2 years**	**2 year to 3 years**	**3 year to 5 years**	**5 years +**
Quality of care in the last month of life (QoD-LTC)							
Total score	ref	1.14 (−0.77–3.05)	**2.71 (1.00–4.42)** **	**3.03 (1.23–4.84)** **	**4.03 (2.15–5.90)** **	**4.80 (2.87–6.72)** **	**4.16 (2.21–6.11)** **
Personhood subscale	ref	0.48 (−0.39–1.36)	**1.02 (0.24–1.80)** *	**1.34 (0.53–2.15)****	**1.31 (0.47–2.15)** **	**1.53 (0.68–2.38)** **	**1.41 (0.56–2.26)** **
Closure subscale	ref	0.91 (0.18–1.64)	**1.21 (0.56–1.86)** *	**1.32 (0.65–1.99)** **	**1.26 (0.57–1.96)** **	**1.64 (0.94–2.34)** **	**1.72 (1.02–2.41)** **
Preparatory tasks subscale	ref	0.20 (−0.73–1.14)	0.72 (−0.12–1.56)	**1.00 (0.11–1.88)** *	**1.45 (0.53–2.37)** **	**1.69 (0.75–2.63)** **	0.94 (−0.01–1.90)
Comfort in the last week of life (EOLD-CAD)							
Total score	ref	−0.36 (−1.75–1.04)	0.15 (−1.11–1.40)	0.66 (−0.62–1.93)	0.31 (−1.02–1.64)	1.14 (−0.21–2.49)	**1.88 (0.58–3.18)** **
Physical distress subscale	ref	0.16 (−0.25–0.58)	0.35 (−0.03–0.73)	**0.41 (0.02–0.79)** *	0.34 (−0.06–0.75)	**0.46 (0.05–0.87)** *	**0.86 (0.46–1.25)** **
Dying symptoms subscale	ref	0.05 (−0.48–0.59)	−0.10 (−0.58–0.38)	−0.15 (−0.63–0.33)	−0.07 (−0.58–0.44)	−0.01 (−0.53–0.50)	0.06 (−0.44–0.55)
Emotional distress subscale	ref	0.10 (−0.46–0.65)	0.31 (−0.19–0.81)	0.34 (−0.16–0.85)	0.49 (−0.05–1.02)	**0.74 (0.20–1.28)** **	**0.88 (0.36–1.39)** **
Wellbeing subscale	ref	0.03 (−0.42–0.48)	0.26 (−0.14–0.66)	0.40 (−0.01–0.82)	0.29 (−0.14–0.72)	0.41 (−0.02–0.85)	**0.73 (0.31–1.15)** **
Contact with health services in the last month of life							
Physician visits (0–5 visits vs. more than five visits)	ref	0.15 (−0.49–0.80)	0.02 (−0.57–0.62)	−0.47 (−1.12–0.18)	−0.09 (−0.76–0.58)	0.13 (−0.50–0.77)	−0.29 (−0.92–0.35)
Hospital visits (none vs. one or more visits)	ref	−0.58 (−1.33–0.16)	−0.31 (−0.96–0.34)	−0.53 (−1.22–0.17)	−0.51 (−1.23–0.21)	−0.67 (−1.40–0.07)	**−1.01 (−1.76–0.26)** **
Emergency department admissions (none vs. one or more visits)	ref	0.34 (−0.50–1.17)	0.11 (−0.66–0.88)	0.30 (−0.46–1.06)	−0.04 (−0.88–0.81)	0.07 (−0.76–0.90)	−0.12 (−0.94–0.71)
Place of death (LTCF vs. hospital)	ref	0.30 (−0.57–1.17)	−0.50 (−1.33–0.33)	−0.29 (−1.13–0.55)	−0.15 (−1.03–0.73)	**−1.03 (−2.04–0.03)***	−0.72 (−1.66–0.22)
Presence of advance directives							
Resident had any written advance directives in place	ref	0.58 (−0.17–1.33)	0.60 (−0.09–1.29)	0.67 (−0.02–1.37)	0.58 (−0.14–1.30)	**1.21 (0.46–1.96)** **	**0.91 (0.18–1.64)** *
Resident had lasting power of attorney for personal welfare	ref	0.60 (−0.01–1.21)	0.53 (−0.04–1.10)	**0.87 (0.28–1.46)** **	**0.72 (0.09–1.36)** *	**0.73 (0.10–1.36)** *	**1.10 (0.48–1.73)** **
Staff spoke with the resident about end of life care	ref	0.66 (−0.14–1.45)	0.49 (−0.25–1.23)	0.64 (−0.11–1.38)	0.54 (−0.23–1.31)	0.65 (−0.15–1.45)	**0.86 (0.08–1.64)** *
Staff spoke with the relative about end of life care	ref	−0.46 (−1.07–0.16)	0.25 (−0.30–0.81)	0.14 (−0.43–0.71)	0.51 (−0.10–1.11)	**0.72 (0.09–1.35)** *	0.19 (−0.44–0.81)
Consensus in care and treatment							
Among staff (no vs. yes)	ref	1.00 (−1.37–3.37)	0.82 (−0.83–2.47)	0.42 (−1.18–2.02)	2.16 (−0.24–4.55)	0.87 (−1.06–2.80)	1.06 (−0.90–3.01)
Among family (no vs. yes)	ref	−0.63 (−2.48–1.23)	−0.57 (−2.30–1.17)	−0.08 (−1.99–1.83)	0.75 (−1.75–3.26)	−0.52 (−2.47–1.44)	n/a
Among all involved (no vs. yes)	ref	−0.85 (−3.34–1.65)	−0.92 (−3.25–1.40)	−0.86 (−3.20–1.48)	0.30 (−2.62–3.21)	0.07 (−2.84–2.98)	−0.50 (−3.08–2.08)

QoD-LTC: Quality of Dying in Long-Term Care. EOLD-CAD: End of Life in Dementia Scale-Comfort Assessment while Dying. LTCF: long term care facility. CI: confidence interval. Generalised mixed models with each end of life care outcome as the dependant variables, length of stay as the independent variable, age, gender, marital status, place of admission, cancer, dementia, physical functioning, LTCF type, LTCF funding status and country as covariates and a variable identifying each LTCF was added as a random factor. *p* value < 0.05 *, *p* value < 0.01 **.

3.3. Contact with Health Services in the Last Month of Life and Place of Death

Residents with a length of stay of over 5 years had significantly fewer hospital admissions in the last month of life compared to under 1 month ($p = 0.008$). No significant associations were identified between physician visits and length of stay or emergency department visits and length of stay. Death in hospital was significantly less likely compared to death in a LTCF at a length of stay of 3 to 5 years ($p = 0.044$), however no trend was identified as length of stay increased.

3.4. Presence of Advance Directives

Residents were significantly more likely to have a written advance directive in place at 3 to 5 years and over 5 years, compared to under 1 month post admission ($p = 0.002$ and $p = 0.015$, respectively). Residents were also significantly more likely to have a lasting power of attorney for personal welfare in place between 1 to 2 years ($p = 0.004$), 2 to 3 years ($p = 0.025$), 3 to 5 years ($p = 0.024$) and over 5 years ($p = 0.001$), compared to under 1 month. The likelihood of a staff member having spoken with the resident about end of life preferences was significantly associated with length of stay over 5 years, compared to 1 month ($p = 0.031$). The likelihood of a staff member having spoken with a relative about end of life preferences was significantly associated with length of stay of 3 to 5 years, compared to under 1 month ($p = 0.025$).

3.5. Consensus on Care and Treatment in the Last Month of Life

No significant associations were identified between length of stay and consensus on care and treatment in the last month of life among LTCF staff, among family or among all those involved in the resident's care.

4. Discussion

4.1. Summary of Main Findings

Longer lengths of stay were associated with higher scores of quality of care in the last month of life and on the personhood, closure and preparatory tasks subscales. Longer lengths of stay were also associated with higher scores of comfort in the last week of life, on all subscales except the dying symptoms subscale. Associations between longer lengths of stay and quality of end of care occurred earlier than in comfort in the last week of life, with significantly higher scores identified from 3 months compared to 1 year.

A slight but statistically significant association was identified with fewer hospital admissions and resident deaths in hospital when length of stay was longer. In addition, longer stay residents were more likely to have written advance directives and lasting power of attorney in place, and have had a staff member discuss end of life care with either themselves or a relative. No significant associations were identified between length of stay and physician visits, emergency department visits or consensus on care and treatment. The analysis controlled for resident characteristics associated with variation in length of stay and country of residence.

4.2. Strengths and Limitations

This is the first study of which the research team is aware that focuses specifically on the relationship between length of stay in an LTCF and end of life care. A strength of the data used in this analysis is their representativeness of a large sample of LTCFs across six European countries. As the study was retrospective, the data were not limited by a follow up period, therefore data on length of stay is available for residents with especially long lengths of stay (no right censoring).

The main limitation of the study is that the data were collected by staff members up to 3 months after the resident's death. Such an approach has a number of implications for the validity of the data. Firstly, the risk of recall bias increases, however, data collected on length of stay cannot be biased as there is no loss to follow up. In addition, if such as bias exists in this dataset as opposed to non-systematic measurement error, it would be the same across all countries, although the direction of the bias is unclear [45].

Secondly, the relationship between the staff member providing the data and the resident may affect the findings. It is possible that staff members who did not feel they knew the resident well enough to answer the questionnaire, and could not access written records on the residents care, did not return the questionnaire, leading to a bias in the data towards staff members with closer relationships with the residents.

Further to this, one explanation for the findings could be that staff members may feel they know and understand residents with longer lengths of stay more than recently admitted residents, and are therefore more confident in their judgement of resident experience. As some of the indicators used in the EOLD-CAD are relatively subjective to judgement (fear, serenity, anxiety etc.) the findings may be influenced by greater confidence in the staff member to make these assessments, and therefore more likely to provide appropriate care, i.e., symptom management.

There are also specific limitations to each of the measures used to indicate quality of end of life care. For example, data were not collected on the time when written advance directives or lasting power of attorney were established, therefore it is unclear if these occurred prior to LTCF admission. Discussions with the resident and relative about end of life care may have occurred, however no data were collected on whether the decisions made in these conversations were recorded or acted upon, where possible. Data collected on advance directives are specific to the availability and legality of advance directives in each country. For example, the data from England does not necessarily indicate that a conversation has occurred between LTCF staff and the resident, it is possible that advanced care planning documentation collected as part of the Gold Standard Framework was used to obtain the answer, which were neither initiated or filled in by the residents themselves [46]. Future research could further contextualise these findings by including the approach to end of life care adopted at each facility, including staff mix and training.

Finally, the data used in this analysis is limited to consensus in care and treatment as judged only by one staff member and not family members. The analysis is limited by a lack of data collected from residents and relatives' perspectives on their perceptions of the quality of care at end of life.

4.3. Interpretation of Findings

The primary finding of this analysis is that residents who have resided in an LTCF for a longer length of time had better quality of care and comfort at end of life than recent LTCF admissions, after controlling for characteristics of short and long stay resident populations.

Differences in the findings for each of the QoD-LTC subscales require further discussion. The preparatory tasks subscale refers to activities which can be planned in advance (treatment preferences in writing, establishing a named decision-maker, funeral planning) indicating that lack of time for such activities to be enacted by LTCF staff may explain lower scores among newly admitted residents. Similarly, the personhood subscale focuses on the relationship between the resident and wider staff (a nurse or aide with whom the resident felt comfortable, affectionate touch daily, physician knew him or her as a whole person) which, again, develop over time.

However, the items on the dying symptoms subscale of the EOLD-CAD (choking, gurgling, difficulty swallowing, shortness of breath) are arguably more difficult for LTCF staff to modify without physician involvement. Additionally, data were not collected on whether the resident received treatment for such symptoms, therefore, in this study the presence of such symptoms does not necessarily indicate poorer quality of care.

In a review of preconditions for successful advance care planning in nursing homes, five domains were identified; sufficient knowledge and skills, willingness and ability to participate in advance care planning, a good relationship (between staff and family caregivers and residents), availability of an administrative system for documenting wishes and monitoring care and supportive contextual factors within the nursing home [47]. Applied to the findings of this paper, a longer length of residence before death could allow for the involvement of an appropriately skilled professional, for a record of resident wishes to be written and accessible or for sufficient time and resources to be allocated to establishing preferences at end of life care. However, as the association only becomes significant after 1 year of residence, a more plausible explanation could be that it takes this long for a relationship to be established between LTCF staff, residents and their families.

The few significant results identified for consensus in care and contact with health services shows that these experiences remain consistent regardless of subsequent length of stay. Although the analysis failed to show a difference across the groups, this could indicate that if consensus is not established in the first month after admission, it is unlikely to be subsequently achieved. Alternatively, admissions to either hospital or an emergency department for preventable reasons (pneumonia, urinary tract infections etc.) are common in this population, however, the likelihood may not differ based on length of stay.

4.4. Implications for Future Research, Policy and Practice

International epidemiological research on the health and health care needs of LTCF residents is gaining more attention [48–50], allowing for heterogeneity in the care residents' experience to be explored further. Despite the emphasis on ageing in place [51], and a common preference for older adults to remain living in the community until death [52], there is little evidence to suggest that cohorts on admission are in poorer health or have shorter lengths of stay than those in previous years [53]. Further research is needed to explore the underlying reasons for this trend, and its implications for providing good quality end of life care to all LTCF residents. The inclusion of LTCF residents in nationally representative epidemiological studies, allowing for longitudinal analysis of characteristics prior to admission [54] and better identification of LTCF residents in existing routinely collected datasets [55], would greatly support research in this area.

Although numerous interventions to improve end of life care have been developed and implemented in LTCFs, few have tailored their approach to residents depending on length of stay. In a recent scoping review of implementation strategies for such interventions, prioritising time for staff members to provide end of life care, and ensuring staff are available for residents to develop a relationship with, allowing discussions on end of life to occur, were highlighted as facilitators to successful implementation [56]. An approach which can be tailored to shorter and longer stay residents is needed, including how such an environment can be developed prior to resident admission. In particular, further research is needed to explore the experiences of residents with lengths of stay under 1 month and the underlying mechanisms that account for fewer indicators of end of life care.

5. Conclusions

Older adults residing in LTCFs often have multiple health needs, are likely to be approaching end of life and require good quality end of life care. This study explored associations between length of stay in LTCF residents with five measures of end of life care, using data on deceased residents in six European countries. In addition to the differences in population characteristics of shorter and longer stay residents, the findings of this analysis indicate that residents with longer lengths of stay experience better end of life care than those with shorter lengths of stay on some of the indicators explored. This trend is identified even after controlling for resident characteristics associated with variation in length of stay and country of residence. Further research is needed to explore why such an association is found, and how appropriate end of life care can be provided to all residents from admission to death.

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Article

Dry Eyes, Ocular Lubricants, and Use of Systemic Medications Known or Suspected to Cause Dry Eyes in Residents of Aged Care Services

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Abstract: Ocular issues are common, burdensome, and under-researched among residents of aged care services. This study aims to investigate the prevalence of dry eyes or use of ocular lubricants among residents, and the possible association with systemic medications known or suspected to cause dry eyes. A cross-sectional study of 383 residents of six aged care services in South Australia was conducted. Data were extracted from participants' medical histories, medication charts, and validated assessments. The main exposure was systemic medications known to cause, contribute to, or aggravate dry eyes. The primary outcome was documented dry eyes or regular administration of ocular lubricants. Logistic regression was used to estimate odds ratios (ORs) and 95% confidence intervals (CIs) for the association between systemic medications and dry eyes/use of ocular lubricants. Dry eyes were documented for 53 (13.8%) residents and 98 (25.6%) residents were administered ocular lubricants. Overall, 116 (30.3%) residents had documented dry eyes/used ocular lubricants. Of these, half (n = 58) were taking a medication known to cause, contribute to, or aggravate dry eyes. Taking one or more medications listed as known to cause dry eyes was associated with having dry eyes/use of ocular lubricants (OR 1.83, 95% CI 1.15–2.94). In sub-analyses, no individual medication was associated with dry eyes/use of ocular lubricants. Dry eyes and use of ocular lubricants are common in residential aged care. Our hypothesis generating findings suggest the need for further research into the clinical significance of systemic medications as a possible cause of dry eyes.

Keywords: dry eye syndromes; drug side effects; aged; dementia; frailty; long-term care

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1. Introduction

Ocular issues are common, burdensome, and under-researched among residents of aged care services (ACSs) [1,2]. Studies have reported that the prevalence of visual complications in residents of ACSs is generally higher than older adults living in the community [3,4]. While ocular complications can impact the life of all older adults, those with dementia and frailty are particularly vulnerable. Due to cognitive and functional impairment, visual dysfunction may further contribute to or exacerbate eye conditions [2,5]. One of the issues that may lead to ocular and visual complications is dry eyes [6].

Dry eye syndrome is a complex disease of the eye characterized by the lack of a stable tear film with symptoms that vary from a mild gritty sensation to severe discomfort that affects the daily living of the individual, and can be accompanied with abnormality of the ocular surface [7]. Dry eye syndrome can impact the quality of life of the individual as it causes dryness, grittiness, visual discomfort, and ocular complications. This increases both the health and economic burden on the individual, caregivers and society [8].

The prevalence of dry eyes is associated with age, with older people more likely to experience dry eye symptoms [9]. It is estimated worldwide prevalence of symptomatic dry eyes in people aged 40 years and older ranges from 20 to 50% [9]. Other risk factors include hazardous environments, inflammatory and other systemic conditions, ophthalmic surgery, and medication use [10]. Medication classes such as antihistamines, anticholinergics, antidepressants, and anxiolytics have been reported to be associated with dry eyes [10]. However, evidence for these associations is generally weak and there is a lack of data on the possible association among residents of ACSs. The Tear Film and Ocular Surface Society (TFOS) Dry Eye Workshop (DEWS) generated a list of medications that are "known or suspected to cause, contribute, or aggravate dry eyes" [10]. The possible mechanisms by which medications may contribute include decreasing tear production, altering tear stability leading to increased evaporation, and inducing inflammatory changes on secretory glands [10,11].

Residents of ACSs are generally older and experience higher rates of multimorbidity and polypharmacy than adults living in the community [12]. This may mean this population is susceptible to dry eyes. However, there is a lack of literature in this vulnerable population, including in those with dementia and frailty. Thus, the aim of this study was to investigate the prevalence of dry eyes in residents of ACSs and the possible association between systemic medication use, dementia, frailty, and dry eyes.

2. Materials and Methods

2.1. Sample and Data Source

This was a secondary analysis of cross-sectional data for 383 long-term residents of six ACSs in South Australia in 2014. The included participants were similar to all residents of the ACSs from which they were sampled in terms of age (87.5 years (standard deviation [SD] 6.2) vs. 87.3 years (SD 6.4), $p = 0.66$), sex (77.5% female vs. 78.5% female, $p = 0.90$), and dementia diagnosis (44.1% vs. 46.8%, $p = 0.72$). Collection of data was performed by three experienced and trained study nurses. A detailed description of the study design has been published previously [13]. In short, medical diagnoses were extracted from medical histories of all participants and information on medications were extracted from participants' medication charts. Other clinical data were obtained using validated scales suitable for use among people with and without dementia.

2.2. Medication Exposure

The main exposure was systemic medications listed as being suspected or known to cause, contribute to or aggravate dry eyes. This list was outlined in the TFOS DEWS II iatrogenic report. The report includes 118 suspected medications of which 40 were considered as being known to be associated with dry eyes. A detailed list is reported in Table S1. All medications charted as regular or as-required were included and were categorized using the Anatomical Therapeutic Chemical (ATC) classification system [14].

2.3. Outcome

The primary outcome was a diagnosis of dry eyes recorded in the medical record or the regular administration of lubricating eye drops/ointments (ATC codes: S01XA20 and S01KA02) at least daily within the previous week. Regular administration of lubricating eye drops/ointments was investigated in addition to documented dry eyes to account for possible under-documentation of dry eyes in the medical record. Eye drops/ointments could be either administered by ACS staff or self-administered by the resident. However, most residents of Australian ACSs do not self-administer medications and administration is typically performed by registered nurses, enrolled nurses, or personal care assistants.

2.4. Covariates

Covariates included age, sex, history of ophthalmic conditions, the Charlson comorbidity index (CCI), systemic conditions associated with dry eyes, dementia severity, and frailty. The Charlson comorbidity index was used as a measure of comorbidity and disease severity. It is a method of weighting comorbidities to give a single comorbidity score for each individual based on their relative risk of mortality [15]. Presence or history of an ophthalmic condition can influence the prevalence of dry eyes [16,17]. Ophthalmic conditions included presence or history of glaucoma, use of glaucoma eye drops, cataracts, macular degeneration, and other ophthalmic conditions, including surgery. Systemic conditions that are reported or suspected to cause or worsen dry eyes included Sjögren's syndrome, diabetes, arthritis, osteoporosis, asthma, Parkinson disease, and thyroid/hormonal dysfunction [9,18]. The Dementia Severity Rating Scale (DSRS) was used to measure dementia severity in all residents both with and without a documented dementia diagnosis. A DSRS score of >18 is considered moderate to severe severity [19]. The FRAIL-NH screening tool was used to assess frailty [20]. The scale was constructed using clinical data and includes seven items: fatigue, resistance, ambulation, incontinence, loss of weight, nutrition, and dressing.

2.5. Statistical Analysis

Descriptive statistics were used to compare participants' baseline characteristics according to documentation of dry eyes or administration of ocular lubricants. Binary logistic regression was used to estimate odd ratios (ORs) and 95% confidence intervals (CIs) for the association between systemic medications known or suspected to cause dry eyes, dementia and frailty with documented dry eyes or use of ocular lubricants. Model 1 was adjusted for age and sex, while Model 2 was additionally adjusted for history of ophthalmic conditions, CCI, number of systemic conditions, dementia severity, frailty, and medication exposure where appropriate. The use of glaucoma drops was excluded from the analysis to avoid potential multicollinearity with glaucoma diagnosis. Two sets of sub-analyses were also performed. Firstly, each of the main medication classes listed as being known to cause, contribute to, or aggravate dry eyes were investigated for their association with dry eyes or administration of ocular lubricants. Secondly, the main analyses were repeated when the primary outcome was limited to those residents who had a diagnosis of dry eyes documented in the medical record. All analyses were performed in SAS version 9.4 (SAS Institute, Inc., Cary, NC, USA).

2.6. Ethical Approval

Ethical approval was obtained by The Royal Australian College of General Practitioners National Research and Evaluation Ethics Committee and the Monash University Health Research Ethics Committee. Written informed consent was obtained from all participants prior to inclusion. Where residents were unable to provide informed consent, this was obtained from a guardian, next of kin, or significant other.

3. Results

A total of 383 participants were included in this study. Dry eyes was present in 30.3% (n = 116) of residents; this included 53 residents with a documented diagnosis of dry eyes in the medical record, and 98 residents regularly administered lubricating eye drops/ointments. Of those with dry eyes or using ocular lubricants, 78.5% (n = 91) were aged 85 years or older and the same proportion were female (Table 1). Those with dry eyes or using ocular lubricants had moderate frailty (mean (SD)

FRAIL-NH 5.10 [4.4]), and 43% (*n* = 49) had moderate-to-severe dementia severity. All residents with dry eyes or using ocular lubricants (*n* = 116) were taking one or more medications listed by the TFOS as being suspected to cause, contribute to, or aggravate dry eyes. The most commonly used of these medications were vitamins (78%), atenolol (16%) and mirtazapine (13%). Half (*n* = 58) of the residents with dry eyes or using ocular lubricants took one or more medications listed as being known to cause, contribute to, or aggravate dry eyes. The most commonly used of these medications were aspirin (34%), diazepam (4%), and propranolol (2%). There were no statistically significant associations between any individual class of medication and dry eyes or using ocular lubricants.

Table 1. Baseline characteristics of participants with and without dry eyes.

Characteristic	Dry Eyes	No Dry Eyes	Total
Total	116 (30.3 %)	267 (69.7 %)	383 (100 %)
Age, mean (SD)	88.32 (6.3)	87.19 (6.1)	87.53 (6.2)
84 or younger	25 (21.6 %)	83 (31.1 %)	108 (28.2 %)
85–90	44 (37.9 %)	105 (39.3 %)	149 (38.9 %)
Older than 90	47 (40.5 %)	79 (29.6 %)	126 (32.9 %)
Female	91 (78.5 %)	206 (77.2 %)	297 (77.6 %)
Ophthalmic conditions	72 (62.1 %)	152 (56.9 %)	224 (58.5 %)
Glaucoma	16 (13.8 %)	32 (12.0 %)	48 (12.5 %)
Glaucoma eye drops use	14 (12.1 %)	28 (10.5 %)	42 (11 %)
Macular degeneration	16 (13.8 %)	43 (16.1 %)	59 (15.4 %)
Cataracts	45 (38.8 %)	91 (34.1 %)	136 (35.5 %)
IOL	18 (15.5 %)	24 (9.0 %)	43 (11.0 %)
Impaired vision	24 (20.7 %)	45 (16.9 %)	69 (18.02 %)
Other conditions	15 (12.9 %)	20 (7.5 %)	35 (9.1 %)
Dry eye-related systemic diseases, mean (SD)	2.07 (0.91)	2.00 (0.99)	2.02 (0.97)
Diabetes	30 (25.9 %)	59 (22.1 %)	89 (23.2 %)
Arthritis	97 (83.6 %)	214 (80.2 %)	311 (81.2 %)
Parkinson's disease	4 (3.5 %)	15 (5.6 %)	19 (5.0 %)
Thyroid	18 (15.6 %)	52 (19.5 %)	70 (18.3 %)
Asthma	19 (16.4 %)	36 (13.5 %)	55 (14.4 %)
Osteoporosis / fracture	58 (50.00 %)	131 (49.1%)	189 (49.4 %)
Gout	14 (12.1 %)	27 (10.1 %)	41 (10.7 %)
CCI, mean (SD)	2.65 (1.62)	2.42 (1.84)	2.49 (1.78)
FRAIL-NH, mean (SD)	5.10 (4.4)	4.5 (3.9)	4.7 (4.05)
DSRS > 18	49 (43.0 %)	124 (46.6 %)	173 (45.5 %)
Dry Eye-Related Systemic Medications			
Suspected Medications [a]			
0–1	21 (18.1 %)	70 (26.2 %)	91 (23.8 %)
2–3	62 (55.9 %)	140 (55.3 %)	202 (55.5 %)
4 or more	33 (29.7 %)	57 (22.5 %)	90 (24.7 %)
Known Medications [b]			
0	58 (50.0 %)	170 (63.4 %)	228 (59.5 %)
1	51 (44.0 %)	86 (32.2 %)	137 (35.8 %)
2–3	7 (6.0 %)	11 (4.1 %)	18 (4.7 %)

SD, standard deviation; IOL, intraocular implant; CCI, Charlson comorbidity index; and DSRS, Dementia Severity Rating Scale; a. Suspected medications include those that have probable or possible relationship to dry eye symptoms; b. Known medications include those that have been determined to cause dry eye symptoms by withdrawal and rechallenge tests.

Table 2 shows the age and sex-adjusted and fully-adjusted odds ratios for having dry eyes or using ocular lubricants. In the second, fully adjusted model, compared to non-users, taking one or more medications listed as being known to cause, contribute to, or aggravate dry eyes was associated with having dry eyes or using ocular lubricants (OR = 1.83 (95%CI 1.15 to 2.94), $p = 0.01$). Similarly, frailty was associated with dry eyes or using ocular lubricants (OR = 1.11 (95 CI 1.02 to 1.19), $p = 0.01$). Dementia was inversely associated with dry eyes or ocular lubricants use (OR = 0.47 (95%CI 0.25 to 0.88), $p = 0.02$).

Table 2. Odds ratios and 95% confidence intervals for the association between systemic medications, dementia, and dry eyes.

Variable	**Model 1** [a]		**Model 2** [b]	
Suspected medications	OR (95% CI)	*p*-value	OR (95% CI)	*p*-value
Number of medications				
1 or more	1.28 (0.44, 3.67)	0.65	1.43 (0.47, 4.33)	0.53
0–1	1.00 (reference)		1.00 (reference)	
2–3	1.46 (0.82, 2.60)	0.20	1.45 (0.80, 2.62)	0.22
4 or more	1.97 (1.02, 3.81)	0.04	1.84 (0.93, 3.66)	0.08
Known medications	OR (95% CI)	*p*-value	OR (95% CI)	*p*-value
1 or more	1.78 (1.13, 2.80)	0.01	1.83 (1.15, 2.94)	0.01
0	1.00 (reference)		1.00 (reference)	
1	1.76 (1.11, 2.82)	0.02	1.90 (1.16, 3.08)	0.01
2–3	1.92 (0.70, 5.28)	0.21	1.43 (0.48, 4.25)	0.52
DSRS >18 [c]	0.85 (0.54, 1.36)	0.47	0.47 (0.25, 0.88)	0.02
FRAIL-NH score [c]	1.03 (0.98, 1.09)	0.25	1.11 (1.02, 1.19)	0.01

OR, odds ratio; CI, confidence interval; NSAIDs, non-steroidal anti-inflammatory drugs; and DSRS, Dementia Severity Rating Scale; [a]. Adjusted for age and sex; [b]. Adjusted for age, sex, ophthalmic conditions, dry eye-related systemic conditions, Charlson comorbidity index, DSRS, and FRAIL-NH; c. The DSRS and FRAIL-NH Model 2 was additionally adjusted for 1 or more known dry eye-related medications.

When the analyses was limited to having documented dry eyes only, taking one or more medications listed as being known to cause, contribute to, or aggravate dry eyes remained significantly associated with having documented dry eyes (OR = 2.51 (95%CI 1.33 to 4.73), $p < 0.01$) (Table S2). However, frailty and dementia severity were no longer associated with documented dry eyes.

4. Discussion

To our knowledge, this is the first study to specifically investigate the prevalence of dry eyes and use of ocular lubricants among residents of ACSs. Our study found that a third of residents had either dry eyes or use of ocular lubricants. The use of one or more medications listed as being known to cause, contribute to, or aggravate dry eyes was associated with higher odds of documented dry eyes or use of ocular lubricants. Residents with greater frailty had higher odds of dry eyes or use of ocular lubricants while those with greater dementia severity had lower odds.

Few studies have investigated the prevalence of dry eyes in the ACS setting. An earlier study by Handelman et al. investigated the association between hyposalivatory medications, dry mouth, and salivary flow [21]. Their study reported a 30% prevalence of perceived eye dryness in residents of ACSs who took medications known to cause hyposalivation [21]. Previous studies have investigated the prevalence of dry eyes in the general older population. A review of eight studies of people aged 60 years and older found the prevalence of dry eyes ranged from 10.7% to 73.5% [9]. In those 80 years and older, a study by Schaumberg et al. reported dry eye prevalence to be around 7.7% [22]. Another study conducted in France found 21.9% of older adults, with a mean age of 80 years, had definite dry eyes [23]. The prevalence of dry eyes in our study appears to be higher than the aforementioned two studies. This could be because of differences in the definition of dry eyes and our sample being of older age and having higher rates of multimorbidity. Environmental factors, such as being confined to an indoor artificial climate, and dehydration may have also contributed [9].

Our study found that residents who used one or more medications listed as being known to cause, contribute to, or aggravate dry eyes were at 83% higher odds of having documented dry eyes or use of ocular lubricants compared to non-users. This remained significant after performing sensitivity analyses to restrict our definition of dry eyes to a documented diagnosis in the medical records. While it is possible that underlying comorbidities were responsible for dry eyes, with systemic medications acting as a proxy, we adjusted for a range of specific dry-eye related systemic diseases and CCI in our analyses. Possible mechanisms by which systemic medications may exert dry eye symptoms are complex [10]. Plausible mechanisms include their effect on meibomian glands and conjunctival goblet cells [24]. These structures can be affected by medication via alteration of neurological innervation; additionally, since these areas are highly vascularized tissues, some medications can access them and hence exhibit a direct effect (24). Muscarinic receptors are found on the corneal and conjunctival cells and thought to have a proliferative effect [25], and cholinergic activation of the G-protein coupled muscarinic receptor leads to tear secretion by the lacrimal gland [10,26]. Medications with anticholinergic properties such as antidepressants, antihistamines, and anti-Parkinson's may thus affect tear production [10].

The most prevalent medication listed as being known to cause, contribute to, or aggravate dry eyes was aspirin. Previous research on the possible association between aspirin and dry eyes is inconsistent with some studies showing a link with dry eyes [27], and others showing users of aspirin were less likely to have dry eyes [28]. It has been suggested that aspirin and ibuprofen can be secreted in tears and therefore may play a role in tear instability [10]. This may lead to irritation or can increase tear evaporation [10]. While these medications rarely cause ocular problems at routinely prescribed doses, it is possible that ocular problems may become clinically significant at higher doses [29]. However, residents in our study predominately used low-dose aspirin for cardioprotection and sub-analyses identified no association between aspirin use and dry eyes or use of ocular lubricants. Other commonly used medications listed as being known to cause, contribute to, or aggravate dry eyes were propranolol and diazepam, possibly explained by decreased lacrimation [29].

While all residents with dry eyes were taking a medication suspected of causing dry eyes, this was largely driven by vitamin use. The association between vitamin use and dry eyes is inconsistent in the literature. Large epidemiological studies have found associations between multivitamin use and dry eyes [30,31], while others have found no significant effect. As vitamins have not been clearly defined in previous studies, we kept our definition of vitamins deliberately broad, encompassing all those listed under ATC code A11. This included not only multivitamin combinations, but also vitamin D preparations which accounted for the majority of vitamin use in our study population [32]. Vitamin D supplementation has been found to improve dry eye symptoms including tear quality and ocular surface conditions [33], particularly in those with low vitamin D levels and who have symptoms refractory to conventional treatment [34]. Further research should thus investigate the temporal association between vitamin use and dry eyes in longitudinal studies.

Increasing frailty levels were found to be associated with higher odds of having documented dry eyes or use of ocular lubricants. This likely reflects functional impairment and an increased risk for adverse health outcomes [35]. While the association between dry eyes and frailty has been understudied, a few previous studies have found an association between vision impairment and frailty [36,37]. For example, a longitudinal study of 2836 English community-dwellers aged ≥60 years found that non-frail older adults who experience poor vision had a two-fold increased risk of becoming prefrail or frail over four years of follow-up [37]. Dry eyes may be particularly important in frail older adults as, if left untreated, this may lead to visual complications in this vulnerable population [6,23].

In our study, residents with moderate to severe dementia severity were found to be less likely to have dry eyes or use ocular lubricants (OR = 0.47). This may be because people with dementia are less likely to report subjective symptoms of dry eye; hence, they are less likely to be diagnosed with dry eyes and in turn less likely to receive regular lubricating eye drops or ointments. A previous study reported that visual problems were underreported in residents with dementia, which could be attributed to under-recognition linked to residents with cognitive impairment not describing or expressing their symptoms in the same manner as residents without cognitive impairment [38]. This highlights the importance of ongoing ophthalmic and visual care by an appropriate eye care professional for this vulnerable population [2]. Despite these findings, frailty and dementia severity were not found to be significantly associated with dry eyes when limiting the definition to a recorded diagnosis in the medical record.

Our study has some limitations. Firstly, our definition of dry eyes was not based on whether or not residents actually experienced dry eyes on the day of assessment. Second, people with dry eyes may not have had this documented in the medical records. Conversely, residents charted lubricating eye drops/ointments may not have been currently experiencing dry eyes. We attempted to overcome this limitation by performing a sub-analysis in those with a documented diagnosis in the medical records. Third, we did not investigate the dose and duration of medications known or suspected to cause, contribute to, or aggravate dry eyes into account. This could influence the findings as those who are on higher doses or have taken exposure medications for a longer duration may have higher risk of dry eyes. Additionally, as we did not know the date of initiation of exposure medications, it was not possible to assess causality using an incident–user design. Fourth, this study did not use any subjective or objective clinical tests; rather, it relied on the documentation of a dry eye diagnosis or the regular administration of ocular lubricants. As a result, we could not determine if all participants with dry eyes were true cases of dry eye disease. Additionally, we were not able to assess severity of dry eyes, either through direct clinical assessment or through frequency of eye drop administration. Fifth, we did not consider other factors that can influence dry eyes such as environment and genetics in our analysis. Finally, given the cross-sectional study design, it is not possible to determine causality.

To the best of our knowledge this is the first study to specifically investigate the prevalence of dry eyes in residents of ACSs. Our findings are largely hypothesis generating but could positively impact current practice in several ways. First, our findings highlight the need for larger epidemiological studies to investigate the prevalence of dry eyes in ACSs and assess the possibility of a dose-response relationship between medication use and dry eyes. Second, our findings suggest the possible need to consider dry eyes when prescribing medications that are known to cause, contribute to, or aggravate this condition. In addition, a thorough eye examination of all residents in ACSs should be performed by general medical practitioners, optometrists, or ophthalmologists to identify and manage dry eyes in at-risk residents. Our findings suggest that this should include an assessment of medications that are known or suspected to cause dry eyes.

5. Conclusions

This study found that 30% of ACS residents have dry eyes or use ocular lubricants. While medications and frailty status may increase the risk of dry eyes, dementia severity was inversely associated. Larger studies are needed to confirm the possible association between specific medications and dry eyes in the residential aged care setting.

Supplementary Materials: The following are available online at http://www.mdpi.com/1660-4601/17/15/5349/s1, Table S1: Medications suspected or known to cause, contribute or aggravate dry eyes, Table S2: Odds ratios and 95% confidence intervals for the association between systemic medications, dementia and dry eye disease diagnosis documented in medical record.

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Article

Higher Prevalence of Dementia but No Change in Total Comfort While Dying among Nursing Home Residents with Dementia between 2010 and 2015: Results from Two Retrospective Epidemiological Studies

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Abstract: Important policy developments in dementia and palliative care in nursing homes between 2010 and 2015 in Flanders, Belgium might have influenced which people die in nursing homes and how they die. We aimed to examine differences between 2010 and 2015 in the prevalence and characteristics of residents with dementia in nursing homes in Flanders, and their palliative care service use and comfort in the last week of life. We used two retrospective epidemiological studies, including 198 residents in 2010 and 183 in 2015, who died with dementia in representative samples of nursing homes in Flanders. We found a 15%-point increase in dementia prevalence (p-value < 0.01), with a total of 11%-point decrease in severe to very severe cognitive impairment ($p = 0.04$). Controlling for residents' characteristics, in the last week of life, there was an increase in the use of pain assessment (+20%-point; $p < 0.03$) but no change in total comfort. The higher prevalence of dementia in nursing homes with no change in residents' total comfort while dying emphasizes an urgent need to better support nursing homes in improving their capacities to provide timely and high-quality palliative care services to more residents dying with dementia.

Keywords: long-term care; care homes; nursing homes; dementia; quality improvement; palliative care

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1. Introduction

Dementia is a progressive incurable condition, for which a palliative care approach is widely recommended [1]. Palliative care can improve the quality of life of people with dementia by addressing their multi-faceted physical, psychosocial and spiritual care needs for months or years until death [1–3]. In Europe, the prevalence of dementia is projected to almost double to about 18.8 million by 2050 [4]. Because people with dementia have prolonged and complex palliative care needs [2], half or more of them eventually live and receive care in nursing homes [5,6]. Yet, the quality of dying and end-of-life care in this setting in many countries, including those with high levels of palliative care development, such as in Belgium, is apparently sub-optimal [7,8]. Especially residents with dementia remain at risk of dying with great discomfort, potentially related to sub-optimal assessment and management of their complex care needs, which highlights an urgent need to identify ways on how to improve the quality of care in nursing homes for this population [2,9–12].

Over the past decade, there have been important policy developments related to dementia and palliative care in the nursing home sector in many countries, which might have influenced which people die in nursing homes and how they die, and can impact the provision of palliative care for nursing home residents with dementia [8,13]. Yet, there is a lack of high-quality data on the number of residents dying in nursing homes with varying stages of dementia; on the extent to which palliative care services are used; and on how these number of residents dying in nursing homes and their palliative care service use are changing over time. In this study, we will examine differences between 2010 and 2015 in the prevalence and characteristics of residents with dementia in nursing homes in Flanders, the Dutch-speaking part of Belgium where about 60% of the population live [14], as well as differences in their palliative care service use and comfort in the last week of life.

Between 2010 and 2015, new dementia policies in Flanders were oriented towards delaying the institutionalization of older people with dementia by enabling them to stay at home for as long as possible [15–19]. Several initiatives for people with dementia living in communities were also implemented regionwide, e.g., information campaigns and training of primary care professionals and family caregivers [20–23]. While these developments could potentially result in fewer admissions or shorter stays in nursing homes or more admissions of those with advanced conditions unmanageable at home [24,25], representative data showing these potential changes are lacking.

Particularly three developments related to palliative care in the nursing home sector in Flanders are historically important. First, supported by the 2002 Belgian Palliative Care Law that recognizes the legal right to palliative care of 'patients whose life-threatening illness no longer responds to curative treatments' [26], the Flemish government passed the Decree on Residential Care in 2009 [27]. This decree officially requires Flemish nursing homes to support, sensitize, and train all regular staff regarding palliative care. Second, in 2010, the Flanders' Federation of Palliative Care launched palliative care guidelines for professional caregivers in nursing homes in developing and implementing palliative care in their facility [28,29], including the comprehensive delivery of physical, psychosocial, and spiritual support [29]. Third, in 2013, the Flemish government introduced a strategy to evaluate the quality of care in nursing homes by having them report on 13 quality indicators [30]. Two of these quality indicators concern palliative care ('place of death' and 'advance care planning'). These indicators are used to systematically monitor the aggregate quality of care in this sector and to identify areas where improvements can be made. Despite these policy developments for nursing homes, no epidemiological study has yet examined the use of palliative care services of residents with dementia and their comfort while dying before and after these developments. Examining this will inform policymakers in Belgium on how to further improve the quality of care at the end of life of nursing home residents with dementia. Results can also be used to inform policies in many countries, especially in Western Europe with similar shifts in health care policies [8,13]. Hence, focusing on Flanders, we sought to answer the following research questions:

- Are there differences in the prevalence of dementia in nursing homes between 2010 and 2015?
- Are there differences in the socio-demographic and clinical characteristics of nursing home residents with dementia between 2010 and 2015?
- Are there differences in palliative care service use and comfort in the last week of the life of nursing home residents with dementia between 2010 and 2015?

2. Materials and Methods

2.1. Design

We used data from two retrospective epidemiological studies in regionwide representative samples of nursing homes in Flanders, Belgium, namely, the Dying Well with Dementia study focused on residents with dementia (2010) and the Palliative Care for Older People in care and nursing homes in Europe (PACE) study focused on all residents, of whom the presence of dementia was determined (2015) [31,32]. Both studies used similar research methods unless otherwise indicated.

2.2. Participating Nursing Homes

To obtain regionwide representative samples of nursing homes, proportional stratified random sampling methods were used. From a national list, the research team randomly sampled Flemish nursing homes, stratified by region (five provinces), bed capacity (up to or more than 90 beds, which is the median number of beds in nursing homes in Flanders), and ownership (public, private/non-profit, private/profit). Previous studies showed that region, bed capacity, and ownership are factors associated with end-of-life care quality in nursing homes [33,34]. If a nursing home refused to participate, another one was randomly selected from the same stratum until the targeted number per stratum was reached [31,32].

2.3. Data Collection and Study Population

The administrator/manager in each nursing home was asked to identify all residents who died in the previous three months. Because the 2010 study focused on dementia, the residents who did not have dementia were excluded immediately before data collection. This was done by asking the administrators/managers to further identify residents who met the Katz scale criteria used by the Belgian health insurance system to allocate financial resources: "category Cdementia", i.e., being completely care-dependent or needing help for bathing, dressing, eating, toileting, continence, and transferring plus being disoriented in time and space OR "disorientation in time and space" ($\geq$3 or "almost daily a problem with disorientation in time and space") [31,32,35].

In 2010, data were collected on residents who met any of the Katz scale criteria, while in 2015, data were collected on all identified residents. To collect data, both studies used after-death questionnaires distributed to nursing home staff most closely involved in care, general practitioner (GP), and nursing home administrator. Dementia was determined by asking the GP and the nursing home staff if the resident "had dementia" or "was diagnosed with dementia". We considered a resident to have dementia if the nursing home staff and/or the GP indicated it. A resident did not have dementia when both the nursing home staff and the GP indicated it, or when one of these respondents indicated it, but the other did not return the questionnaire or did not answer the question [31,32].

Response rates for staff, GPs, and administrators were, respectively, 88.4%, 52.9%, and 95.0% in 2010 and 85.1%, 68.3%, and 94.2% in 2015. We excluded residents for whom the nursing home staff did not return the questionnaire. Non-response analysis showed no difference in residents' characteristics between cases for whom the questionnaire was returned by nursing home staff or not [7,31].

2.4. Measurements and Outcome Measures

2.4.1. Residents' Characteristics

Using validated instruments, the nursing home staff reported residents' cognitive and functional impairment one month before death. Cognitive Performance Scale (CPS) uses five variables from the Minimum Data Set to group residents into six hierarchical cognitive performance categories, e.g., CPS scores 5–6 indicate severe and very severe impairment [36]. Global Deterioration Scale (GDS) is divided into seven stages, of which stage 7 indicates that a resident lost all verbal abilities, was incontinent/required assistance with eating and toileting, and lost basic psychomotor skills [37]. Hence, to determine whether a resident had GDS stage 7, the nursing home staff were asked whether the resident fit all the criteria of GDS stage 7 (yes/no). To compare with earlier studies [7,31], we determined the severity of dementia using CPS and GDS (CPS scores $\geq$ 5 and GDS stage = 7 had advanced dementia, while the rest had non-advanced dementia). The nursing home staff also reported the Bedford Alzheimer Nursing Severity scale (BANS-S), with total scores ranging from 7 (no impairment) to 28 (complete impairment) [38]. They also reported whether any clinical complication occurred in the last month of life, e.g., pneumonia or intake problems. The GPs reported co-existing conditions, e.g., cancer or cardiovascular disease. Nursing home administrators reported residents' age at time of death, gender, length of stay in nursing homes, place of death, and whether the residents stayed in an open or secured unit at the time of death and in a dementia care unit or not. These residents' characteristics could influence the palliative care service use and comfort at the of life of people with dementia [39–42].

2.4.2. Palliative Care Services Used

The nursing home staff reported data on palliative care service use, including (1) whether a palliative care record was initiated for residents and the days before death when this occurred; (2) whether a resident received palliative care at any time, including whether this palliative care was provided by a GP and whether the following persons/initiatives were involved in providing this care: coordinating and advisory physician, palliative care reference nurse, palliative care task group, specialist palliative home care team, or none of them. Since 2009, nursing homes in Flanders were officially required to establish a functional relationship with general practitioners (GPs) responsible for providing medical care and developing palliative care strategies for residents and coordinating and advisory physicians responsible for coordinating with GPs to review palliative care strategies and give advice and training to staff [27,43]. Further, the nursing homes must have a palliative care reference nurse responsible for establishing a supportive palliative care culture and awareness within the nursing home, training personnel regarding palliative care, and supporting and coordinating palliative care delivery, and a palliative care task group comprising of all palliative caregivers. For complex palliative situations, palliative home care teams can either call or visit nursing homes to provide advice or support [27,43]. The nursing home staff also reported whether the residents received services related to medical or nursing treatments/procedures in the last week of life, psychosocial interventions in the last month, and spiritual and/or pastoral care before death.

2.4.3. Comfort in the Last Week of Life

They also assessed comfort in the last week of life using the Comfort Assessment in Dying-End-of-Life in Dementia (CAD-EOLD) scale. CAD-EOLD is a validated 14-item scale comprising discomfort, pain, restlessness, shortness of breath, choking, gurgling, difficulty swallowing, fear, anxiety, crying, moaning, serenity, peace, and calm. Individual item scores range from 0–3, while total scores range from 14 to 42, with higher scores representing better comfort [44,45].

2.5. Data Analyses

The 2010 and 2015 databases were merged by R.M. and two palliative care researchers. The prevalence of dementia between 2010 and 2015 was compared using χ^2-test. Subsequent analyses were performed in IBM SPSS statistics version 26 (©IBM Corporation; Armonk, NY, USA) using generalized linear mixed model to account for clustering of data within nursing homes. We compared residents' characteristics and their palliative care service use and comfort scores between 2010 and 2015. We adjusted all analyses related to palliative care service use and comfort for resident characteristics while taking correlations between these resident characteristics into account. Using Benjamini-Hochberg procedure to decrease the false discovery rate, we adjusted the analyses related to comfort for multiple testing. Hypothesis testing was two-sided. Statistical significance was set at $p < 0.05$.

3. Results

3.1. Prevalence of Dementia

The prevalence of dementia significantly increased from 43% in 2010 (205 of 477 residents) to 58% in 2015 (199 of 342 residents) (+15%-point; p-value < 0.01; Figure 1). Of the residents with dementia, we excluded 7 residents in 2010 and 16 in 2015, as the nursing home staff did not return the questionnaires, leaving 198 and 183 residents for further analyses. In the large majority of nursing homes in both years, the number of residents in each nursing home ranged between 1 and 8. In 2010, two nursing homes had 11 and 14 residents, while in 2015, one nursing home had 9 residents.

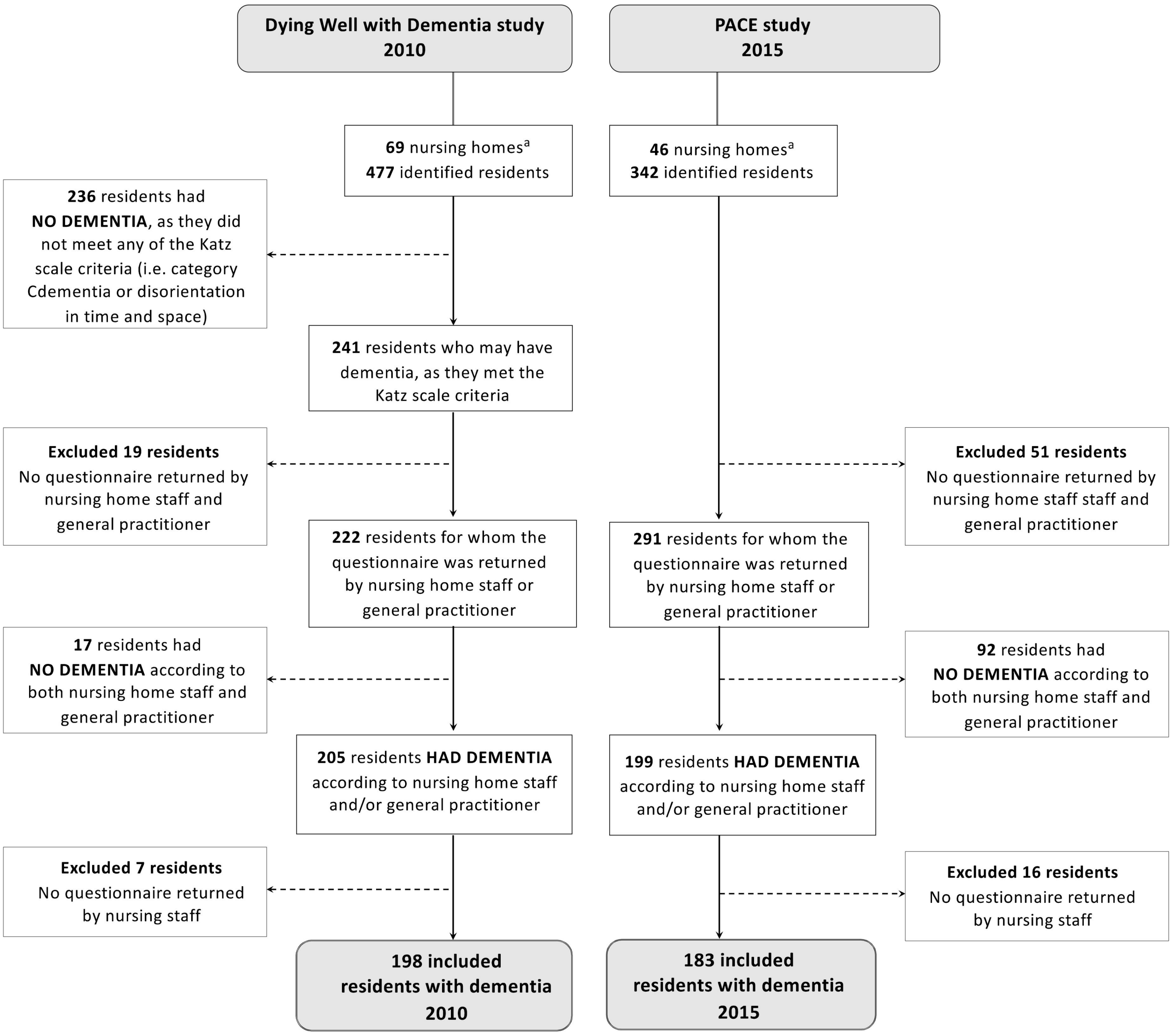

Figure 1. Overview of the identification of residents with dementia in 2010 and 2015. [a] Because we excluded a number of residents from the total sample, the final number of nursing homes were 64 in 2010 and 43 in 2015. In 2010, 205 residents had dementia (numerator) of the 477 identified residents. In 2015, 199 residents had dementia (numerator) of the 342 identified residents (denominator).

3.2. Characteristics of Residents with Dementia

Between 2010 and 2015, residents' characteristics did not change, except for scores on the Cognitive Performance Scale. One month before death, the proportion of residents with dementia with severe to very severe cognitive impairment (CPS scores 5-6) had a total of 11%-point decrease ($p = 0.04$; Table 1), while the proportion of residents with GDS stage 7 had a total of 14%-point increase ($p = 0.04$). The residents were about 86 years of age at the time of death, were predominantly women, and had BANS-S scores of 20.9 in 2010 and 20.3 in 2015. Of the residents in 2010 and 2015, respectively, 49% and 52% had advanced dementia, while 95% and 92% experienced any clinical complication a month before death. The most common co-existing conditions were cardiovascular diseases (29% in 2010 and 28% in 2015), followed by cancer and respiratory conditions. The median length of stay in nursing homes was 893 days in 2010 and 688 days in 2015. In 2010 and 2015, respectively, nursing home was the most common place of death (90% and 86%), while 9% and 14% died in hospitals.

Table 1. Comparing residents' characteristics between 2010 and 2015.

Residents' Characteristics	**2010 (N = 198)**	**2015 (N = 183)**	**Change**	**Difference between the Years *p*-Values †**
Socio-demographic characteristics				
Age at time of death, average in years (SD)	86.7 (7)	86.9 (7.3)	+0.2	0.73
Gender, female *n* (%)	115 (61)	114 (65)	+4	0.43
Clinical characteristics				
Cognitive performance scale (CPS), *n* (%)				0.04
- Intact, borderline intact, mild impairment (score 0-1-2)	8 (4)	21 (13)	+9	
- Moderate impairment (score 3)	27 (14)	20 (12)	−2	
- Moderately severe impairment (score 4)	9 (5)	15 (9)	+4	
- Severe impairment (score 5)	61 (33)	52 (31)	−2	
- Very severe impairment (score 6)	82 (44)	58 (35)	−9	
Global deterioration scale (GDS) stage 7, *n* (%)	105 (58)	123 (72)	+14	0.04
Bedford Alzheimer Nursing Severity scale (BANS-S) 1 month before death, mean (SD)	20.9 (3.9)	20.3 (4.3)	−0.6	0.19
Severity of dementia, *n* (%)				0.55
- Non-advanced dementia	95 (51)	75 (48)	−3	
- Advanced dementia	92 (49)	82 (52)	+3	
Occurrence of clinical complications in last month of life, *n* (%)	179 (95)	168 (92)	−3	0.31
Co-existing conditions				
- Cancer	12 (11)	19 (14)	+3	0.43
- Cardiovascular	32 (29)	37 (28)	−1	0.89
- Respiratory	15 (14)	14 (11)	−3	0.51
- Neurological (not dementia)	17 (15)	10 (8)	−7	0.08
- Urogenital	9 (8)	12 (9)	+1	0.82
- Other	18 (16)	22 (17)	+1	0.99
Length of stay in nursing home in days, median days (IQR)	893 (448–1694)	688 (283–1678)	−205	0.28
Place of death, *n* (%)				0.20
- Nursing homes	171 (90)	152 (86)	−4	
- Hospital	17 (9)	24 (14)	+5	
- Other ‡	2 (1)	0 (0)	−1	
Type of unit at time of death, *n* (%)				0.71
- Open unit	91 (48)	88 (50)	+2	
- Secured unit	98 (51)	88 (50)	−1	
Dementia care unit, yes, *n* (%)	99 (53)	93 (53)	0	0.95

SD = standard deviations; IQR = Interquartile range; GLMM = generalized linear mixed model analyses. † Calculated using GLMM to account for correlation of data within nursing homes; 'other' categories not included in calculation of *p*-values. Analyses showed correlation of CPS with GDS, BANS-S and severity of dementia, and this might be because they similarly cover residents' cognitive and functional status. The type of unit at the time of death was correlated with dementia care unit, and this might be because one nursing home can have both types of unit. Further analyses will be adjusted for CPS, dementia care unit, and the rest of the residents' characteristics. ‡ Examples of places of death other than nursing homes or hospitals include facility hospice/palliative care unit. Missing values, *n*: age, 2010 = 12; 2015 = 8 | gender, 2010 = 11; 2015 = 9 | severity of dementia, 2010 = 11; 2015 = 26 | CPS, 2010 = 11; 2015 = 17 | GDS, 2010 = 16; 2015 = 12 | BANS-S, 2010 = 4; 2015 = 2 | clinical complications, 2010 = 10; 2015 = 15 | all co-existing conditions except other, 2010 = 87; 2015 = 51 | other co-existing conditions, 2010 = 88; 2015 = 51 | length of stay in nursing homes, 2010 = 13; 2015 = 10 | place of death, 2010 = 10; 2015 = 7 | type of unit, 2010 = 9; 2015 = 7 | dementia care unit, 2010 = 10; 2015 = 8.

3.3. Palliative Care Service Use among Residents with Dementia

In the multivariable analyses controlled for residents' characteristics, in 2010 and 2015, respectively, a palliative care record was initiated for 62% and 72% of residents ($p = 0.17$), of which 51% and 60% occurred within 14 days before death ($p = 0.63$; Table 2). According to nursing home staff, 83% in 2010 and 82% in 2015 of residents received palliative care. For 17% (2010) and 20% (2015) of these people who received palliative care, no coordinating and advisory physician, palliative care reference nurse, palliative care task group, and palliative home care teams were involved ($p = 0.83$).

Table 2. Comparing palliative care service use between 2010 and 2015.

Palliative Care Service Use	**2010 (N = 198)**	**2015 (N = 183)**	**%-Point**	**Difference between Years (p-Values ‡)**	
	n (%)	*n* (%)	Change †	Crude	Adjusted
Residents who had a palliative care record	121 (62)	97 (72)	+10	0.10	0.17
Time before death when the palliative care record initiated					
- <14 days	51 (51)	38 (60)	+9	0.10	0.63
- 15 to 90 days	32 (32)	22 (35)	+3		
- >90 days	18 (18)	3 (5)	−13		
Residents who received palliative care at any time according to nursing home staff	162 (83)	145 (82)	−1	0.69	0.21
Palliative care was provided by GP	136 (84)	123 (86)	+2	0.84	0.89
Other person/initiatives involved in providing the palliative care					
- Coordinating and advisory physician	44 (27)	35 (23)	−4	0.44	0.11
- Palliative care reference nurse	110 (66)	94 (62)	−4	0.64	0.35
- Palliative care task group within the nursing home	81 (49)	64 (42)	−7	0.35	0.34
- Palliative home care teams (external)	16 (10)	8 (5)	−5	0.24	0.30
- No one from this list was involved	28 (17)	30 (20)	+3	0.55	0.83
Residents who received medical or nursing treatments/procedures during the last week of life					
Mouthcare	159 (80)	152 (88)	+8	0.055	0.54
Pain assessment	124 (63)	143 (83)	+20	0.001	0.03
Prevention of pressure ulcers	162 (82)	151 (87)	+5	0.15	0.72
Wound care	45 (23)	48 (28)	+5	0.27	0.97
Assistance with eating/drinking	142 (72)	141 (82)	+10	0.04	0.37
Residents who received psychosocial interventions in the last month of life					
Adjustments of environmental factors ¶	19 (10)	28 (16)	+6	0.10	0.18
Activity programmes	25 (13)	16 (9)	−4	0.33	0.85
Music therapy	48 (24)	28 (16)	−8	0.17	0.24
Behavioural therapy	0 (0)	1 (1)	+1	0.87	0.78
Experiential approaches #	52 (26)	47 (28)	+2	0.90	0.32
No psychosocial interventions received	74 (37)	81 (47)	+10	0.15	0.78
Residents who received spiritual and/or pastoral care shortly before death					
Spiritual care provider/Pastoral worker	98 (48)	72 (57)	+9	0.10	0.11

GLMM = generalized linear mixed model; GP = general practitioners; pp = percentage point. Crude model is the unadjusted model. Adjusted model is adjusted for all residents' characteristics, except for GDS, BANS-S, severity of dementia, and type of unit at the time of death to avoid multi-collinearity. † %-point = percentage point. %-point difference was calculated between 2010 and 2015. ‡ Calculated using GLMM analyses to account for correlation of data within nursing homes while accounting for differences in resident characteristics; 'other' categories not included in the calculation of p-values. ¶ Example of adjustments of environmental factors includes a modified environment for walking around safely. # Examples of experiential approaches include multisensory environment, validation therapy. Missing values, *n*: palliative care record, 2010 = 2; 2015 = 49 | receipt of palliative care, 2010 = 4; 2015 = 6 | palliative care provided by GP, 2010 = 5; 2015 = 9 | time before death when palliative care record was started, 2010 = 22; 2015 = 34 | all physical care, 2015 = 10 | all psychosocial care, 2015 = 12 | spiritual care, 2010 = 10; 2015 = 15.

In the last week of life, there was a significant increase in the percentages of residents for whom pain assessment was conducted (from 63% in 2010 to 83% in 2015; p = 0.03). In the last month of life, 37% (2010) and 47% (2015) of residents did not receive any psychosocial intervention (p = 0.78). In 2010 and 2015, respectively, shortly before death, 48% and 57% of residents received spiritual care, meaning that 52% and 43% did not receive it (p = 0.11).

3.4. Comfort in the Last Week of Life

In multivariable analyses controlled for residents' characteristics, a week before death, there was a 0.2-point increase in the comfort scores related to moaning (p = 0.03) (Table 3). However, this statistically significant increase in comfort scores disappeared after adjusting for multiple testing (p = 0.45). The estimated marginal means for the total comfort scores did not change between 2010 (30.0; 95% CI = 29.2–30.8) and 2015 (30.8; 29.2–30.9; p = 0.87).

Table 3. Comparing comfort in the last week of life between 2010 and 2015.

COMFORT IN THE LAST WEEK OF LIFE	**2010 (N = 198)**	**2015 (N = 183)**	**Score-Point**	**Difference between Years (p-Values ‡)**	
CAD-EOLD individual items	CAD-EOLD scores 0 (worst) to 3 (best)	CAD-EOLD scores 0 (worst) to 3 (best)	Change †	Crude	Adjusted
- Discomfort	2.1 (2.0–2.2)	2.1 (2.0–2.2)	–	0.46	0.88
- Pain	2.0 (1.9–2.1)	2.2 (2.1–2.3)	+0.2	0.03	0.62
- Restlessness	2.1 (2.0–2.2)	2.1 (2.0–2.2)	–	0.72	0.39
- Shortness of breath	2.2 (2.1–2.3)	2.4 (2.3–2.5)	+0.2	0.03	0.14
- Choking	2.1 (2.0–2.2)	2.1 (2.0–2.2)	–	0.77	0.75
- Gurgling	2.3 (2.2–2.4)	2.5 (2.3–2.6)	+0.2	0.13	0.83
- Difficulty swallowing	1.9 (1.8–2.0)	1.9 (1.8–2.0)	–	0.61	0.84
- Fear	2.0 (1.9–2.2)	2.2 (2.1–2.3)	+0.2	0.04	0.45
- Anxiety	2.1 (2.1–2.3)	2.2 (2.1–2.3)	+0.1	0.32	0.88
- Crying	2.7 (2.6–2.8)	2.7 (2.6–2.8)	–	0.49	0.89
- Moaning	2.3 (2.3–2.4)	2.5 (2.4–2.6)	+0.2	0.02	0.03
- Serenity	2.0 (1.9–2.2)	2.1 (2.0–2.2)	+0.1	0.69	0.07
- Peace	2.0 (1.9–2.1)	2.0 (1.9–2.2)	–	0.63	0.24
- Calm	2.0 (1.9–2.1)	2.0 (1.9–2.1)	–	0.33	0.31
Total score ¶, estimated marginal means (95% CI)	30.0 (29.2–30.8)	30.8 (29.2–30.9)	+0.8	0.22	0.87

CAD-EOLD = Comfort Assessment in Dying—End of Life in Dementia; CI = confidence intervals. Crude model is the unadjusted model. Adjusted model is adjusted for all residents' characteristics, except for GDS, BANS-S, severity of dementia and type of unit at the time of death to avoid multi-collinearity. † Score point change was calculated between 2010 and 2015. ‡ Calculated using GLMM analyses to account for correlation of data within NHs while accounting for differences in resident characteristics. ¶ Total scores are averages per whole scale multiplied by total number of items (i.e., 14). Cases with missing values on more than 25% of items per scale were excluded from total score calculation; scores range from 14 to 42; higher scores indicate better comfort when dying. Missing values, *n*: discomfort, 2010 = 19; 2015 = 12 | pain, 2010 = 9; 2015 = 10 | restlessness, 2010 = 15; 2015 = 10 | shortness of breath, 2010 = 12; 2015 = 10 | choking, 2010 = 16; 2015 = 9 | gurgling, 2010 = 18; 2015 = 11 | difficulty swallowing, 2010 = 11; 2015 = 11 | fear, 2010 = 13; 2015 = 10 | anxiety, 2010 = 14; 2015 = 10 | crying, 2010 = 17; 2015 = 10 | moaning, 2010 = 16; 2015 = 9 | serenity, 2010 = 16; 2015 = 12 | peace, 2010 = 18; 2015 = 12 | calm, 2010 = 19; 2015 = 12 | total score, 2010 = 16; 2015 = 10.

4. Discussion

Our study showed that between 2010 and 2015 in nursing homes in Flanders, Belgium, there was a 15%-point increase in the prevalence of dementia. Almost all residents' characteristics did not change, except for the level of cognitive impairment in the last month of life, with a total of 11%-point decrease in residents with severe and very severe cognitive impairment, and the level of cognitive and functional impairment, with a total of the 14%-point increase in residents who lost all verbal abilities, was incontinent/required assistance with eating and toileting and lost basic psychomotor skills. The percentages of residents with advanced dementia were 49% in 2010 and 52% in 2015. Pain assessment in the last week of life was performed proportionally more often for residents in 2015 than in 2010. However, in both years, between 37% and 52% of residents neither received psychosocial intervention in the last month of life nor spiritual care shortly before death. In the last week of life, we found no change in residents' total comfort in the last week of life.

This is the first time that two retrospective epidemiological studies are used to investigate changes over time for residents with dementia in the context of important developments in the landscape of dementia and palliative care policies and initiatives in nursing homes. Retrospective data collection is a feasible method for population-based epidemiological end-of-life studies, as it limits potential bias in prospective sampling, e.g., underrepresentation of people who live longer than the follow-up period [7]. Although these are separate studies, both utilized similar study designs, aiming to reach representative samples, and all variables of interest were measured in the same way. Finally, while the measurement of palliative care services is limited to services measured in both studies, these services comprise important components of palliative care in dementia, e.g., comprehensive delivery of physical, psychosocial, or spiritual support [1]. However, this study also has limitations. As these are two separate studies, and the study in 2010 primarily focused on dying nursing home residents with dementia, the variables that could be explored and compared between the years were limited, especially on nursing home characteristics, that might influence palliative care service use or comfort. While accounting for the clustering of data within nursing homes in the analyses could partly limit this limitation of our data, our inability to control for unmeasured variables that could influence palliative care service use or comfort remains a clear limitation of our study. Because data were collected after death, there might be some recall bias [7]. Further, only 2010 Dying Well with Dementia study used the Katz-scale criteria to exclude residents without dementia before data collection [35]. Nevertheless, such residents without dementia would have also been identified by the nursing home staff and/or the GPs in the PACE study, as they were involved closely in resident care [46,47]. For 19 residents in 2010 and 51 residents in 2015, we could not determine the presence or absence of dementia, which may influence the prevalence of dementia. In certain variables, such as the CAD-EOLD, we have a relatively large proportion of missing values (>5%), which we have reported in detail in the footnotes of Tables 1–3. Finally, given the cross-sectional nature of the study, it is not possible to identify explanations for the findings within our study. For instance, we could not explore whether the extent of residents' palliative care service use relates to the identified lack of change in their total comfort in the last week of life (i.e., temporal relationship).

Our study clearly showed that between 2010 and 2015, there is a substantially higher prevalence of nursing home residents with dementia with very minimal change in their clinical and socio-demographic characteristics. Over this relatively short period, almost an additional 15% of the residents die with dementia. Perhaps, this is because such increase in the prevalence of dementia also occurred in the home setting, as the 2016 estimates in Flanders suggest that there were 15,855 more people with dementia in 2015 than in 2010 [48], which is congruent with the current trends in dementia prevalence in other countries in Europe [4]. At the end of life, people with dementia also have complex care needs that could complicate primary care delivery and could thus become unmanageable at home [11,12]. Hence, more people with dementia living at home may have been transferred eventually to nursing homes [24,25]. Further, over the years, nursing home residents with dementia apparently remain to have almost similar clinical and demographic characteristics, which suggests that their complex and prolonged care needs at the end of life persist over the years [11,12]. We found that among residents in 2010 and 2015, about half had advanced dementia, more than 90% developed any clinical complication in the last month of life, and the majority stayed in nursing homes for about two years. While we found a somewhat lower percentage of residents who died with severe cognitive impairment (i.e., CPS scores 5-6) in 2015 than in 2010, the percentage of residents who lost all verbal abilities, was incontinent/required assistance with eating and toileting, and lost basic psychomotor skills (i.e., GDS stage 7) increased over the years. These findings might explain the slightly higher but non-statistically significant difference in the proportion of residents with advanced dementia in 2015 than in 2010. The identified lower proportion of residents with severe cognitive impairment based on CPS scores suggests that these residents died from other diseases that do not result in cognitive impairment. Comorbidities, which often occur alongside old age and dementia, present additional challenges for nursing home staff and healthcare service delivery to residents living and dying with dementia [49].

In addition, our study showed that in the last week of the life of residents with dementia between 2010 and 2015, there was an increase in their use of medical/nursing procedures, in particular pain assessment. This is encouraging, as pain is highly prevalent among older people with dementia [50]. However, the use of other medical/nursing procedures, psychosocial interventions, and spiritual care at the end-of-life seemed to lag behind. For instance, the residents' use of assistance with eating and drinking did not change over time, which needs urgent attention, as intake problems are common in advanced dementia [11,12]. Further, there was still a substantial proportion of residents with dementia, who neither received psychosocial interventions nor spiritual care at the end of life. These findings underscore the persistent lack of attention given to the comprehensive care encompassing physical, psychosocial, and spiritual support, which are paramount to improving residents' overall comfort at the end-of-life [1].

Promoting comfort for nursing home residents with dementia is a key policy goal of care in many countries and a palliative care approach has been widely advocated to improve comfort in this population [1,51–55]. However, providing high-quality and comprehensive palliative care to and improving comfort in nursing home residents with dementia is a highly demanding and complex work for care professionals [40,41]. Our identified increase in the prevalence of nursing home residents with dementia and the minimal change in the complexity of their care needs at the end-of-life highlight the increasing complexity of the challenges faced by the nursing home sector. This evolution is likely to continue in the future, as the prevalence of dementia in Flanders has been projected to almost double by 2060 [48]. Such evolution might also be comparable with evolution in other countries that implemented similar dementia and palliative care policies and initiatives and have similarly increasing dementia prevalence [4,8,13]. Further, we found that despite an encouraging improvement in the use of pain assessment of residents with dementia, there remains a lack of change in their total comfort in the last week of life. In order to better support nursing home staff to maintain the high quality of care in nursing homes and to improve comfort at the end-of-life of a growing number of residents with dementia [9,48], there is an urgent need for continued and stronger public health investments and a more comprehensive palliative care approach in this sector [1]. The timely and consistent implementation of comprehensive palliative care in dementia approach requires a strong national and regional policy commitment and the incorporation of this approach in the attitudes and skills of nursing home staff [56,57]. Because there is still no known effective palliative care program for nursing home residents with dementia [58], future research should continue developing and evaluating palliative care programs that could improve comfort at the end-of-life in this population. Strategies on how to develop, implement, and evaluate complex palliative care interventions in nursing homes and the factors that need to be addressed in doing so have been published [59–61].

5. Conclusions

Our study suggests that between 2010 and 2015, there was a higher prevalence of residents with dementia in nursing homes in Flanders, Belgium who persistently have complex care needs at the end-of-life. Further, despite an encouraging improvement in the use of pain assessment of residents with dementia, there remains a lack of change in their total comfort in the last week of life. These findings highlight the increasing complexity of challenges faced by the nursing home sector, which underscores an urgent need to better support nursing homes in improving their capacities to provide timely, high-quality, and comprehensive palliative care to a growing number of nursing home residents living and dying with dementia.

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Institutional Review Board Statement: Ethical approvals were obtained from the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels; Dying Well with Dementia=B.U.N. 14320108163; PACE=B.U.N. 143201422845). All respondents (nursing home staff, general practitioners, and nursing home managers) participated voluntarily in the study and remained anonymous. Returning a questionnaire was taken as consent to participate.

Informed Consent Statement: The respondents participated voluntarily, returning a questionnaire was taken as consent to participation, and their anonymity was guaranteed by using a unique anonymous identifier.

Data Availability Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Article

Root Cause Analysis to Identify Medication and Non-Medication Strategies to Prevent Infection-Related Hospitalizations from Australian Residential Aged Care Services

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Abstract: Infections are leading causes of hospitalizations from residential aged care services (RACS), which provide supported accommodation for people with care needs that can no longer be met at home. Preventing infections and early and effective management are important to avoid unnecessary hospital transfers, particularly in the Australian setting where new quality standards require RACS to minimize infection-related risks. The objective of this study was to examine root causes of infection-related hospitalizations from RACS and identify strategies to limit infections and avoid unnecessary hospitalizations. An aggregate root cause analysis (RCA) was undertaken using a structured local framework. A clinical nurse auditor and clinical pharmacist undertook a comprehensive review of 49 consecutive infection-related hospitalizations from 6 RACS. Data were collected from nursing progress notes, medical records, medication charts, hospital summaries, and incident reports using a purpose-built collection tool. The research team then utilized a structured classification system to guide the identification of root causes of hospital transfers. A multidisciplinary clinical panel assessed the root causes and formulated strategies to limit infections and hospitalizations. Overall, 59.2% of hospitalizations were for respiratory, 28.6% for urinary, and 10.2% for skin infections. Potential root causes of infections included medications that may increase infection risk and resident vaccination status. Potential contributors to hospital transfers included possible suboptimal selection of empirical antimicrobial therapy, inability of RACS staff to establish on-site intravenous access for antimicrobial administration, and the need to access subsidized medical services not provided in the RACS (e.g., radiology and pathology). Strategies identified by the panel included medication review, targeted bundles of care, additional antimicrobial stewardship initiatives, earlier identification

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of infection, and models of care that facilitate timely access to medical services. The RCA and clinical panel findings provide a roadmap to assist targeting services to prevent infection and limit unnecessary hospital transfers from RACS.

Keywords: infection; residential aged care; long-term care; hospitalization; root cause analysis; antimicrobial stewardship; medication review; Australia

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1. Introduction

Residents of aged care services often live in close proximity to one another, have comorbid conditions, and have unavoidable contact with health care workers. These conditions are conducive to rapid infection transmission and increase the risk of morbidity and mortality from infectious diseases [1]. Infections are one of the leading causes of hospitalization from residential aged care services (RACS) [1–5]. RACS are synonymous with "nursing homes" and "long-term care facilities" and provide supported accommodation for people with care needs that can no longer be met in their own homes [4,6]. Australian and European studies have found that up to 25% of all hospitalizations from RACS are for infection [3,4], most commonly for respiratory, urinary tract, gastrointestinal, and skin infections [2,5,7,8]. One study in the United States (US) found that potentially preventable hospitalizations accounted for 23% (USD 223.8 million) of the total cost of hospitalizations from RACS in 2004 [9]. Heterogeneity in RACS settings and different definitions of "preventable" means that the proportion of hospitalizations deemed potentially preventable varies [2]. However, previous research suggests that 13%–67% of infection-related hospitalizations are potentially preventable [2,5,10], and therefore preventing unnecessary hospitalizations is a priority for RACS providers.

Broad strategies for preventing infection-related hospitalization may aim to prevent an infection occurring (e.g., vaccinations) or to better manage an infection in the RACS to avoid hospitalization (e.g., early detection and administering appropriate antimicrobials). Prevention of infection in RACS is important as there is increasing concern regarding antimicrobial resistance [11]. Antimicrobial resistance is associated with increased hospital costs and length of stay and death [12]. Antimicrobial stewardship, outbreak control and initiatives to prevent urinary tract infections (UTIs) have strengthened in the US RACS from 2013 to 2018 [13]. A recent systematic review found high-quality evidence to suggest that vaccinating residents against influenza reduces hospitalizations from RACS [14]. Strategies to prevent infections include general infection control procedures, such as promoting hand hygiene [8,15]. Other strategies include ongoing staff education in infection control [8], effective communication between staff and with external healthcare providers [8], environmental cleaning, and use of personal protective equipment such as gloves and gowns [16]. These are the same key principles of infection prevention and control outlined by the Australian Government for RACS providers [17]. Hospitalizations for infectious diseases may be reduced if advance care directives are put in place on admission to RACS and reviewed when a resident's condition changes and/or deterioration in resident condition suggestive of infection is identified earlier [5]. Hospitalizations may also be reduced with effective communication among staff, and/or the management of infection at the RACS with the resources available, or with new models of care that facilitate provision of medical services that are not routinely available in Australian RACS [2,10,18].

Several strategies have been developed and trialed to prevent specific types of infection in RACS [16], although evidence regarding effectiveness of these strategies has been mixed [19]. These include protocols to reduce the number of catheter-associated UTIs [20], clinical care standards on infection [21], toolkits and protocols for preventing and managing gastroenteritis outbreaks [22], and protocols for effective monitoring and care of wounds including diabetic ulcers, pressure injuries, surgical wounds, and other injuries [16]. Adequate oral care for residents [23], identification of dysphagia and aspiration risk protocols [24], and pneumococcal [25] and influenza vaccination among residents [14,25] and RACS staff [26] have been recommended for prevention of respiratory infections.

A root cause analysis (RCA) is a process undertaken in healthcare settings to understand the underlying factors that led to a specific event of interest and develop strategies to help avoid similar occurrences in the future [27,28]. Previous research from the US has shown that an aggregate RCA process, which investigates a group of similar events, can be used to identify and develop strategies to prevent hospitalizations from skilled nursing facilities [18]. However, this strategy has yet to be applied in an Australian setting in the investigation of infection-related hospitalizations specifically.

In Australia, the formal, subsidized interdisciplinary antimicrobial stewardship programs that exist within the hospital setting are not routinely available in Australian RACS. However, new national Aged Care Quality Standards that apply from July 2019 outline the need for RACS provider organizations to implement antimicrobial stewardship policies and activities [29]. One quarter of all hospitalizations from South Australian RACS are for infections [4]. An improved understanding of strategies that could be applied to reduce infection risk and hospital transfers locally could assist stakeholders to enhance resident quality of care. The objective of this study was to examine root causes of infection-related hospitalizations from RACS and identify strategies to limit infections and avoid unnecessary hospitalizations among residents of aged care services.

2. Materials and Methods

2.1. Design and Setting

This study was an aggregate RCA that utilized the South Australia Health (SA Health) process for RCA as a framework [28]. SA Health is a government-funded entity that maintains public health services such as hospitals and ambulance services across country and metropolitan South Australia and contributes to research and policy development. The purpose of an RCA, as defined by SA Health, is to identify system issues that contribute to an incident and recommend strategies to prevent or minimize the risk of recurrence [28]. The approach focuses on learning from an incident to improve processes or systems used in care delivery. Using an interdisciplinary approach, we followed the first 4 steps of the SA Health RCA process: identification of events, data collection, root cause identification, and recommendation generation [28]. This process was similar to previous aggregate RCAs undertaken in the US, in which hospitalizations from RACS were reviewed, and a previous RCA that examined root causes of falls-related hospitalizations from RACS [30,31]. However, the current study focused specifically on infection-related hospitalizations from an Australian RACS setting.

2.2. Identification of Events

This RCA reviewed 49 infection-related hospitalizations among 41 residents of 6 RACS in South Australia. These infection-related hospitalizations were identified from a previous prospective cohort study that has been described elsewhere [4,32]. Briefly, the previous cohort study followed 383 residents aged ≥ 65 years over 12 months who were recruited from a group of 6 RACS in South Australia. The 383 residents who participated in the previous cohort study were representative of all residents of the 6 RACSs in terms of age, sex, and diagnosed dementia. For the 383 residents participating in the previous cohort study, details of all overnight hospitalizations (e.g., admission date, discharge date, and reason for hospitalization) during follow-up were extracted from RACS records. Hospital transfers that did not result in an overnight stay (e.g., emergency department visits, same day admissions, and outpatient appointments) were not captured. The reasons for all overnight hospitalizations were coded independently by two clinicians according to the World Health Organization International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10). Infection-related hospitalizations were identified by the following ICD-10 codes: A00-B99, N12, N13.6, N39.0, J09–J18, J22, J44.0, J69.0, L03, and T84.7 [4]. Of the 51 infection-related hospitalizations recorded during the 12 months follow-up, records were available for 49 hospitalizations for inclusion in the present RCA.

2.3. Data Collection

The RCA was conducted using a purpose-built tool, developed with input from a multidisciplinary expert panel. The panel consisted of a geriatrician, general medical practitioner (GP), infectious disease physician, 4 pharmacists (infectious diseases pharmacist, geriatrics specialist pharmacist, ambulance service pharmacist, and a community pharmacist who provided collaborative medication reviews in RACS), a consumer representative, and 4 registered nurses. A complete list of panel members appears in the acknowledgments section. The panel included staff from within the RACS provider as well as external experts. Development of this tool was also informed by a review of published literature and the INTERACT Quality Improvement Tool for Review of Acute Care Transfers [30]. The tool was tailored for use in an Australian RACS setting and focused specifically on infection-related hospitalizations. It was designed to capture information about resident characteristics, risk factors, medication use, vaccination status, details of the hospital transfer, actions taken prior to hospital transfer, infection-specific vital signs and symptoms, pathology and other test results, and discharge information provided post-hospitalization. The tool was reviewed for face and content validity by an infectious diseases physician, a pharmacist, and 3 registered nurses.

Using the purpose-built tool described above, a clinical audit nurse extracted data on resident risk factors for infection, changes in resident condition leading up to the hospitalization, and management of risk factors in the RACS. Data were extracted from RACS nursing progress notes, medical records, medication charts, hospital discharge notes, and incident reports for each resident. A pharmacist also reviewed each resident's medication administration chart to identify medications taken in the month prior to hospitalization that are associated with an increased risk of infection, including oral corticosteroids [33], oxybutynin [34,35], etanercept [36], methotrexate [37], and proton pump inhibitors [38]. Data were collected and managed using the Research Electronic Data Capture (REDCap) web-based tool hosted by Monash University [39].

2.4. Root Cause Identification

Data extracted for each resident by the clinical audit nurse and pharmacist using the purpose-built tool were reviewed by the research team and an infectious disease physician. The research team were cognizant that clinical staff at the RACS are trained to use a charting by exception approach when documenting information in resident case notes. Factor identification for each case was guided by the SA Health Contributing Factors classification tool, which provides 9 broad factor categories ranging from proximal factors, such as patient assessment, to distal factors, such as facility policies and procedures [28]. For each factor, the research team were asked to apply the 5 why's technique to ensure the factor represented a root cause rather than a symptom [40,41]. The 5 why's technique is common approach for conducting RCA in patient safety, and involves the investigator exploring incidents in increasing depth (through continually asking why) until the underlying root cause is identified [31,40–42]. An example of using the 5 why's technique is provided in Table 1. The research team considered events leading up to the hospital transfer and content in the hospital discharge letter, and repeatedly asked "why" when reviewing each key event until the root causes were identified [40–42]. The root cause findings were then collated into root cause statements that were grouped according the themes outlined in the SA Health Contributing Factors tool [28]. The root cause statements were tabulated for presentation to the multidisciplinary expert panel.

Table 1. Example of using the 5 why's technique.

- The resident showed signs of deterioration after a recent hospitalization for infection—why?
- Because the resident did not receive an antibiotic—why?
- Because the antibiotic was not commenced on return to the residential aged care service as recommended in the hospital discharge letter—why?
- Because the resident's usual general medical practitioner did not initiate the antibiotic on return to the residential aged care service—why?
- Because the actions to take post-discharge were not clearly outlined in the hospital discharge letter

2.5. Recommendation Generation

The same multidisciplinary expert panel that developed the purpose-built tool was reconvened to review all factors that may have contributed to each infection-related hospitalization. For each root cause, panel members were asked to brainstorm potential medication and non-medication interventions that may help to prevent future infection-related hospitalizations. Finally, panel members were asked to review interventions and discuss whether the interventions may be feasible and consider any potential unintended consequences of implementation.

2.6. Data Analysis

Descriptive statistics were used to describe the infection, the processes prior to hospitalization, and the resident characteristics at the time of the infection-related hospitalization. The root cause statements and final recommendations of the panel were tabulated according the themes outlined in the SA Health Contributing Factors tool [28].

2.7. Ethical Considerations

Ethical approval for this study was obtained from the Monash University Human Research Ethics Committee on November 9, 2017 (application ID 11418). Written informed consent for resident participation in the original cohort study was obtained previously. Panel members provided written informed consent to participate in the RCA. We confirm that the investigations were carried out following the rules of the Declaration of Helsinki of 1975, revised in 2013.

3. Results

Among the infection-related hospitalizations reviewed in this study, the median age for residents hospitalized for infection was 86 years (interquartile range 82–92) and 65.3% were female (Table 2). Heart failure (38.8%), chronic obstructive pulmonary disorders (COPD) (34.7%), and diabetes (32.7%) were the most common medical conditions among residents hospitalized for infection. Among residents hospitalized with infection, 12.2% had an indwelling urinary catheter and 20% were taking medications in the month prior to hospitalization that may increase infection risk.

Table 2. Resident characteristics at the time of the infection-related hospitalization ($n = 49$ hospitalizations).

Characteristic	*N* (%) or Median (Interquartile Range)
Age (Years)	86 (82–92)
Female	32 (65.3)
Medical conditions	
Dementia	10 (20.4)
Diabetes	16 (32.7)
Asthma	8 (16.3)
Chronic obstructive pulmonary disease	17 (34.7)
Ischemic heart disease	16 (32.7)
Heart failure	19 (38.8)
Prior stroke	7 (14.3)
Current smoker	2 (4.1)
Indwelling catheter	6 (12.2)
History of infection in the previous 6 months	15 (30.6)
Advance care directive in place prior to hospitalization	34 (69.4)

Table 2. *Cont.*

Characteristic	***N* (%) or Median (Interquartile Range)**
Medication use [a]	
Polypharmacy (≥9 regular medications) [b]	32 (71.1)
Charted regular medications that may increase infection risk [b]	9 (20.0)
Influenza vaccination prescribed by GP on the RACS medication chart and documented as administered [c]	11 (24.4)

Abbreviations: GP, general medical practitioner; RACS, residential aged care service. [a] Medication chart for the 2 weeks prior to hospitalization was not available on four occasions. [b] Assessed in the 2 weeks prior to the hospitalization. [c] Assessed in the 12 months prior to hospitalization. It is noted that influenza vaccinations may sometimes be recorded by GPs as administered in the progress notes only.

In total, 59.2% of infection-related hospitalizations were for respiratory infections, followed by urinary (28.6%), and skin infections (10.2%) (Table 3). Urinalysis or urinary dipstick testing was undertaken prior to 26.5% of hospital transfers for infection and 17% of residents had blood tests. At the time the infection was suspected and prior to hospital transfer, vital signs were monitored in 81.6% of residents and medications that may increase infection risk were charted in the previous fortnight in 20% of residents. Just over one-third of residents (37.8%) received antimicrobial therapy prior hospital transfer. In four out of five cases (81.6%), the resident's usual GP, a GP from same practice, or a locum GP had evaluated the resident prior to hospital transfer. Almost three-quarters of hospital transfers for infection occurred on a weekday. Figure 1 shows the time and day of week when each resident was transferred to hospital.

Table 3. Characteristics of the infection and resulting infection-related hospital transfer.

Characteristic	***N* (%) (*n* = 49)**
Infection type	
Respiratory infection	29 (59.2)
Pneumonia	12 (24.5)
Exacerbation of chronic obstructive pulmonary disease	5 (10.2)
Urinary infection	14 (28.6)
Urinary tract infection	7 (14.3)
Urosepsis	6 (12.2)
Hospitalizations for urinary infection where an indwelling catheter was present	2 (4.1)
Skin infection	5 (10.2)
Cellulitis	3 (6.1)
Other	4 (8.2)
New or worsening signs or symptoms in the 2 weeks prior to hospital transfer	
Feeling unwell	15 (30.6)
Altered mental status or changes in behavior	7 (14.3)
Malaise, lethargy, drowsiness, or refusal to get out of bed	13 (26.5)
Functional decline	9 (18.4)
Fall	7 (14.3)
New or worsening pain	17 (34.7)
Fever, chills, or rigors	7 (14.3)
Decreased oral intake	10 (20.4)
Nausea or vomiting	13 (26.5)
New/increasing abdominal pain or diarrhea	8 (17.0)
Testing undertaken within the RACS in the 2 weeks prior to hospital transfer [a]	
Blood test	8 (17.0)
Urinary dipstick or urinalysis	13 (26.5)
Other	3 (6.4)
Radiology	0 (0.0)
No testing undertaken	29 (61.7)

Table 3. *Cont.*

Characteristic	***N* (%)** **(*n* = 49)**
Interventions undertaken within the RACS from the time the condition was first suspected until hospital transfer	
Monitor vital signs	40 (81.6)
New or change in medication(s)	27 (55.1)
Oxygen	22 (44.9)
Physiotherapy review/treatment	3 (6.1)
Other	5 (10.2)
None required	3 (6.1)
External provider evaluation of the resident	
Usual GP or GP from same practice	27 (55.1)
Locum GP	13 (26.5)
Nurse Practitioner	1 (2.0)
Extended care paramedic	5 (10.2)
Resident's condition discussed with GP or locum via telephone	5 (10.2)
Nil documented	6 (12.2)
Antimicrobial use in the 2 weeks prior to hospital transfer [b]	17 (37.8)
Penicillin	9 (20.0)
Cephalosporin	5 (11.1)
Macrolide	5 (11.1)
Trimethoprim or nitrofurantoin	4 (8.9)
Oseltamivir	2 (4.4)
Person authorizing hospital transfer	
Usual GP or GP from same practice	13 (26.5)
Locum GP	8 (16.3)
Nurse practitioner	2 (4.1)
Registered nurse	19 (38.8)
Resident or family member	4 (8.2)
Extended care paramedic	3 (6.1)
Day of hospital transfer	
Weekday (Monday–Friday)	36 (73.5)
Weekend (Saturday–Sunday)	13 (26.5)
Time of hospital transfer	
Between 07:00 and 14:59	24 (49.0)
Between 15:00 and 22:59	13 (26.5)
Between 23:00 and 06:59	12 (24.5)

Abbreviations: GP, general medical practitioner; RACS, residential aged care service. [a] Information was available for *n* = 47 events. [b] Medication administration charts for the 2 weeks prior to hospitalization were available for *n* = 45 events.

Table 4 lists the factors contributing to infection-related hospitalizations identified in the aggregate RCA. Factors identified include administration of medications that increase the risk of infection. Possible suboptimal selection of empirical antimicrobial therapy and access to medical services including intravenous access, radiology, and pathology were also identified as potential contributors to infection-related hospitalizations. Table 4 also outlines potential strategies to mitigate risk of infection-related hospitalizations as identified by the expert panel. These include strategies such as targeted bundles of care, medication review, antimicrobial stewardship, earlier identification of infection, and models of care that facilitate timely access to medical services.

Table 4. Factors contributing to infection-related hospitalizations identified through the root cause analysis and potential strategies to mitigate the risk of hospitalization that were identified by panel members.

Domain	Factors Contributing to Infection-Related Hospitalizations Identified through the Root Cause Analysis	Potential Strategies to Mitigate Risk of Infection-Related Hospitalizations
Resident assessment	• Administration of medications that increase the risk of infection (e.g., corticosteroids) or contribute to urinary retention (e.g., medications with anticholinergic properties) • Possible suboptimal management of adrenal insufficiency during acute infection • Possible suboptimal selection of empirical antimicrobial therapy	• Consider implementation of a screening tool to identify residents who are at high risk of infection • Increase awareness and access to evidence-based resources and guidelines for management of common infections and increase on-site and electronic availability (e.g., Therapeutic Guidelines) • Embed flags and decision support tools relating to identification of medication use that may increase infection risk, identify residents at risk of adrenal insufficiency during acute infection, and support optimal empirical antimicrobial selection into electronic RACS medication management systems, where available in the RACS • Increase awareness and access to tools to facilitate regular review of skin care in residents at high risk of skin infections (e.g., those with diabetes or using topical corticosteroids for extended periods) • Increase awareness and access to tools to monitor fluid balance • Implement a subsidized RACS antimicrobial stewardship program that is adequately resourced to bring together GPs, facility staff, pharmacists, and external infectious disease physician expertise • Clinical pharmacist or nurse employed within the RACS as part of a subsidized program to undertake antimicrobial stewardship
Staff training and resident factors	• Earlier identification and response to signs and symptoms of confusion, delirium, infection, and sepsis • Earlier recognition and response to signs and symptoms of reduced oral intake and dehydration as early signs of infection • Possible deficits in knowledge and practices relating to specimen collection • Possible inconsistent documentation of observations where indicated (e.g., documented in the progress notes and/or observation chart) • Inhaler technique may not be regularly checked or corrected by a health professional	• Implement a structured checklist and training package to support clinical staff to identify signs and symptoms of dehydration, infection, and sepsis • Develop and implement a clinical pathway to assist staff to respond to suspected infections • Implement a subsidized "diagnostic stewardship" program that is adequately resourced to engage GPs and clinical RACS staff • Increase awareness and access to existing chronic obstructive pulmonary disease and asthma action plans • Involve pharmacists in the review of inhaler technique, training for staff/residents and provision of chronic obstructive pulmonary disease and asthma action plans • Increased access to "hospital in the home" or similar external service to support parenteral rehydration in residents with limited oral intake and dehydration

Table 4. *Cont.*

Domain	Factors Contributing to Infection-Related Hospitalizations Identified through the Root Cause Analysis	Potential Strategies to Mitigate Risk of Infection-Related Hospitalizations
Equipment and work environment	• Problems with timely access to subsidized medical, radiology, and pathology services • RACS clinical staff unable to establish intravenous access and administer parenteral antimicrobials at the RACS	• Increase access to mobile or on-site pathology and radiology services that are subsidized for residents • Utilize telehealth services to facilitate review and inform the decision to initiate a hospital transfer • Develop and implement subsidized models of care that support proactive on-site multidisciplinary care from GPs and geriatricians • Increased access to "hospital in the home" or external OPAT services to support parenteral antimicrobial administration in RACS to support hospital avoidance or early discharge • Models that support input from infectious diseases physicians during infectious disease outbreaks that may occur within RACS
Information, policies, and procedures	• The resident and/or family member's wishes regarding hospital transfers may be unknown • Influenza vaccinations were not always prescribed and/or there may be difficulty in determining current vaccination status. Pneumococcal vaccination status was difficult to determine as residents may have been immunized many years prior to admission to the RACS but documentation regarding administration may not have been received from the previous GP and/or the resident or family may not be able to provide vaccination history when the resident first enters the RACS	• A specific procedure to support documentation of resident's wishes (e.g., advance care directives) in a clear and consistent manner to inform decision-making regarding a hospital transfer for infection • Nurse practitioners or advance care directive "champions" within a RACS could assist with documentation of advanced care directives (implemented since completion of study) • Support health professionals to reference existing and emerging tools (e.g., electronic health records such as Australia's My Health Record or immunization registers such as the Australian Immunization Register) to record vaccines given to residents • Embed flags to highlight future immunization dates into electronic RACS medication management systems where available and in use • Robust procedures in place to ensure immunizations are administered and this is documented for RACS staff to view
Communication and coordination	• Challenges with timely communication between health professionals and staff at RACS when changes occur in resident behavior, cognition, physical status, and medications • Delays in reviewing pathology test results received post-initiation of empirical antimicrobial therapy • Suboptimal communication of results of pathology tests undertaken in hospital and ongoing antimicrobial therapy plan after hospital discharge	• Facilitate timely communication of changes in resident behavior, cognition, and medication use to all persons involved in the resident's care • Implement a standardized format for transfer of information, e.g., ISBAR • Facilitate timely access to review of empirical therapy through mechanisms such as antimicrobial stewardship programs

Abbreviations: GP, general medical practitioner; ISBAR, Introduction, Situation, Background, Assessment, Recommendation; OPAT, outpatient antimicrobial therapy; RACS, residential aged care service.

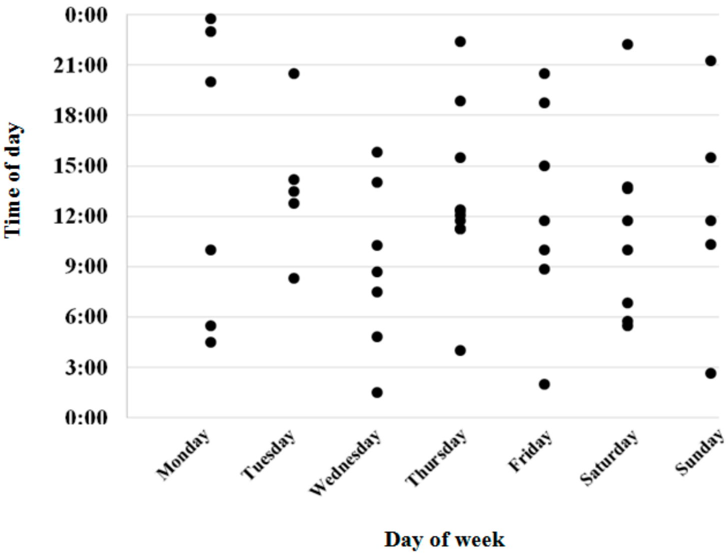

Figure 1. Time and day of hospital transfer among residents hospitalized for infection (*n* = 49).

4. Discussion

This was the first Australian aggregate RCA to investigate hospitalizations for infectious diseases from RACS. Factors identified that potentially contributed to infection-related hospitalizations include the use of medications that may increase the risk of infection, selection of empirical antimicrobial therapy, and timely access to subsidized medical, radiology, and pathology services.

Medications that may increase the risk of infection were administered to one in five residents who were hospitalized for infection. It may not be possible to avoid administration of some of these medications, and therefore, prevention and careful monitoring for infection, and early intervention when an infection is present in these "higher risk" residents is important. Potential strategies suggested by the expert panel included medication reviews, implementation of screening tools to identify residents at high risk of infection, embedding flags and decision support tools for high-risk medication use, and education/support for staff.

Respiratory infections and UTIs were identified as the two most common reasons for hospitalization due to infection in our RCA. This is consistent with other studies in the RACS setting [2,5,7,8]. Prevention of respiratory tract infections, in particular pneumonia, is a priority among RACS providers due to associated high rates of morbidity and mortality including hospitalization [43,44]. Prevention strategies include influenza and pneumococcal vaccinations [25]. An infection quality indicator program that includes four indicators pertaining to resident and staff vaccination was recently implemented in public-sector RACS in Victoria, Australia [45]. A recent Cochrane review noted that further research is required to determine whether professional oral care reduces the incidence of pneumonia in comparison to usual oral care [44]. Similarly, prevention of UTIs is important to minimize hospital transfer. A recent systematic review provided a comprehensive list of interventions for prevention of UTIs among residents with and without a urinary catheter [20]. In the present study, only two of the six hospitalizations where an indwelling catheter was present were for UTIs. This may be because the organization involved in this project has implemented a range of strategies to manage residents with urinary catheters including organizational protocols, incontinence nurse reviews, staff training programs, and skills assessments.

An Australian RACS study found that one-third of residents were colonized with at least one antimicrobial-resistant pathogen, including either methicillin-resistant *Staphylococcus aureus*, vancomycin-resistant enterococci, or multidrug-resistant Gram-negative bacilli [12]. The prevalence of multidrug-resistant organisms (MDROs) in RACS is increasing worldwide, with evidence suggesting that some MDROs are more prevalent in RACSs than in acute hospitalized patients [46,47].

A German study reported an average annual cost of €50,306 (USD $56,349) per resident due to antimicrobial-resistant pathogens [48]. Strategies for preventing antimicrobial resistance include monitoring antimicrobial use with a focus on appropriateness [8,49], hand hygiene [13,49], and avoiding unnecessary hospitalization [49]. Infection quality indicators to monitor for three significant organisms (methicillin-resistant *Staphylococcus aureus* and vancomycin-resistant *Enterococcus* and *Clostridium difficile*) have recently been implemented in Victorian public-sector RACS [45].

Selection of suboptimal empirical antimicrobial therapy was identified as a potential factor contributing to infection-related hospitalization. Inappropriate antimicrobial use increases the risk of treatment failure, drug interactions, adverse events, and treatment-related problems such as *Clostridium difficile* infection and contributes to antimicrobial resistance [50]. One of the potential strategies suggested by the expert panel was to optimize antimicrobial use by implementing an interdisciplinary antimicrobial stewardship program. Australian antimicrobial stewardship programs have predominantly focused on the hospital setting, although new Aged Care Quality Standards that apply from July 2019 outline the need for RACS to show evidence of policies and activities to minimize infection-related risks [29]. Since November 2017, multidisciplinary antimicrobial stewardship programs are mandated in all RACS in the US [51]. These programs were introduced to minimize inappropriate antimicrobial use and antimicrobial resistance. An Australian national survey [52] showed that 55.2% of the antimicrobial prescriptions were for residents with no signs and/or symptoms of infection in the week prior to the start date and, of these, only 18.4% met the internationally recognized McGeer et al. [53] infection definitions. Peron et al. found that in the US, 43% of all days of antimicrobial therapy in RACS were unnecessary based on guideline-recommendations [54]. Increased awareness and access to evidence-based resources and guidelines for the management of common infections for health professionals at the RACS was identified by the expert panel as another potential strategy to mitigate risk of hospitalizations due to suboptimal antimicrobial choice. This includes increased on-site and electronic availability to infectious diseases clinical practice guidelines for GPs, locums, other prescribers, and health professionals.

Necessary equipment, appropriately trained staff, and access to external healthcare provider support are required to treat infection within the RACS. These were identified by the expert panel as factors that may contribute to infection-related hospitalizations. Australian RACS provide nursing support rather than acute medical services. Therefore, there is limited capacity for RACS nursing staff to establish intravenous access and administer parenteral antimicrobials [6]. Increasing access to "hospital in the home" or outpatient antimicrobial therapy (OPAT) services to support parenteral antimicrobial administration in RACSs would likely improve resident satisfaction and comfort, minimize length of hospital stay, or avoid the need for hospitalization entirely. Two studies in Australia showed that a "hospital in the home" program could be effective in reducing hospital admissions from RACS residents [55,56]. As part of the RCA, data on the day and time of hospital transfer were recorded because there may be different access to staff and medical services at different times of the day. The availability of staff, equipment, clinical governance, and external clinical support, particularly after hours, have been identified in previous research as barriers to treatment within RACSs [2,18]. This indicates an opportunity that exists to reduce hospital transfers from RACSs by ensuring equipment and expertise are available. One potential solution is presented in a recent evaluation of a "Geriatric Flying Squad" (GFS) model [57]. The team of healthcare providers (the GFS) included a geriatrician, nurse practitioners/nurse practitioner candidates, and clinical nurse consultant who provided a 7-day service. This model involves RACSs referring acutely deteriorating residents to the GP or directly to the GFS if the GP is not contactable. The GFS visit the RACS and provide additional diagnostic and management support not available within the facility. The evaluation indicated that the GFS were able to manage 90.3% of cases within the facility, preventing 578 hospitalizations from RACSs over 18 months. Similarly, a collaborative approach, led by an advanced practice nurse with aged care skills, found that residents receiving this intervention were 41% less likely to be admitted to hospital [58]. Another potential solution may be to better equip primary care practitioners to better manage residents to minimize hospital transfer. This may include providing professional support and education for RACS staff on quality indicators, functional decline, and hospital transfers of residents [59]. Rolland et al. found that this intervention had a significant positive effect on the prevalence of assessment of pressure injury risk, depression, pain, and prevalence of hospital transfers [59].

Another factor identified as potentially contributing to hospitalization with infectious diseases was that the resident and/or family member's wishes regarding hospital transfers may be unknown. Additionally, some advanced care directives may be difficult to interpret and may lack specific information about specific treatments or hospitalizations. In Canada, 21.7% (n = 80,413) of residents had "do-not-hospitalize" directives documented between 2009–2010 and 2011–2012, and of these, 7.2% were hospitalized [60]. Among residents who were hospitalized and had a do-not-hospitalize directive, almost half (46.3%) of the hospitalizations were deemed potentially preventable [60]. A potential strategy suggested by the expert panel to mitigate the risk of hospitalization was employing nurse practitioners or training advance care directive "champions" in RACS. This could assist with documentation and interpretation of advanced care directives. A standardized approach to documentation of advanced care directives and specific examples may be important in preventing hospitalizations for infection.

Strengths and Limitations

This aggregate RCA recruited residents from six facilities in both metropolitan and rural areas of South Australia. However, the data for the RCA were retrospectively collected from a modest sample of residents, and the residents were recruited from six RACS maintained by one aged care provider organization, and therefore, generalizability may be limited. However, the 383 residents included in the original cohort study from which this aggregate RCA was derived were representative of all residents of the 6 RACS in terms of age, sex, and diagnosed dementia. Although the sample size is small compared to epidemiological studies, our study is based on a comprehensive and in-depth review of nursing progress notes, medical records, medication charts, hospital summaries, and incident reports for each of the participating residents. These data were reviewed independently by the research nurse, an infectious diseases physician, and an infectious diseases pharmacist. Additionally, the expert panel was composed of members internal and external to the RACS provider ensuring that reviews were well informed and independent. A lack of independence has previously been a criticism of RCA [61]. The purpose-specific data collection tool was based on the SA Health RCA tool. The tool was developed by the expert panel ensuring that all relevant information was captured to inform the RCA. While single incident analysis may lead to prioritizing actions and resources to a rare event, an aggregate RCA identifies recurring events allowing for consideration of system and human factors contributing to hospitalizations [61]. A limitation of our approach is that by only assessing infection-related hospitalizations, we were unable to ascertain whether factors perceived to contribute to infection-related hospitalizations were different to those which may contribute to hospitalizations for other health conditions. However, this is an important issue to examine because 25% of hospitalizations from RACS are for infection [4].

5. Conclusions

This aggregate RCA identified medication and non-medication opportunities that exist to prevent infection-related hospitalizations through targeted medication review, antimicrobial stewardship, earlier identification of infection, and models of care that facilitate timely and extended access to medical services. RACS provider organizations, clinicians, policy makers, and other stakeholders can use these findings to review current strategies in place and inform next steps to limit infections and associated hospital transfers from RACS. Future studies could explore factors associated with successful implementation and associated outcomes for residents and other stakeholders.

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Review

Mapping Research Conducted on Long-Term Care Facilities for Older People in Brazil: A Scoping Review

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Abstract: This scoping review aimed to explore the characteristics, strengths, and gaps in research conducted in Brazilian long-term care facilities (LTCFs) for older adults. Electronic searches investigating the residents ($\geq$60 years old), their families, and the LTCF workforce in Brazil were conducted in Medline, EMBASE, LILACS, and Google Scholar, within the timescale of 1999 to 2018, limited to English, Portuguese, or Spanish. The reference lists were hand searched for additional papers. The Mixed Methods Appraisal Tool (MMAT) was used for critical appraisal of evidence. Data were reported descriptively considering the study design, using content analysis: 327 studies were included (n = 159 quantitative non-randomized, n = 82 quantitative descriptive, n = 67 qualitative, n = 11 mixed methods, n = 6 randomized controlled trials, and n = 2 translation of assessment tools). Regardless of the study design, most were conducted in a single LTCF (45.8%), in urban locations (84.3%), and in non-profit settings (38.7%). The randomized trials and descriptive studies presented the lowest methodological quality based on the MMAT. This is the first review to provide an overview of research on LTCFs for older people in Brazil. It illustrates an excess of small-scale, predominantly qualitative papers, many of which are reported in ways that do not allow the quality of the work to be assured.

Keywords: older adults; care homes; nursing homes; long-term care; older people; scoping review

1. Introduction

The fast growth of the older population in low- and middle-income countries [1] has allowed little time for social and health care systems to adapt. Long-term care facilities (LTCFs) are an integral part of how such systems care for older people with frailty, particularly as health conditions become more complex over time and they are no longer able to be cared for at home.

The sustainability of the LTCF sector depends upon policy and economic decisions [2]. In Brazil, where aggregate levels of wealth are lower and welfare systems are underdeveloped, the financial burden of aging is predominantly borne by families or older individuals themselves, leading to precarity of funding and lack of investment to enable development of the sector [3–6].

In 2010, there were around 3500 registered LTCFs in Brazil, and around 100,000 older people (aged 60 years and older) were living in such facilities, making the sector much smaller than in many middle- and higher-income countries [6,7]. However, estimations of the size of the sector are impaired by a lack of systems for collecting and sharing national data on LTCFs [8]. This lack of information is, in turn, a hindrance to the development of the Brazilian LTCF sector.

Research on LTCFs is an emerging field in low- and middle-income countries [9,10]. In Brazil, it has not been supported or funded in a strategic way [7,11]. This lack of coordination means that we are, as yet, unclear about the extent, quality, and impact of research in the sector or how it impacts on older adults' care [7,11]. Taking stock of research carried out to date in Brazilian LTCFs will provide an understanding of the current state of the art of research in this area and highlight where work is needed.

This scoping review (SR) set out to provide an overview of the nature and extent of the scientific research conducted in Brazilian LTCFs in order to provide a summary for care providers and policymakers to inform the future endeavors in the field. The purpose of this is to give researchers, policymakers, and those commissioning research in Brazil a "big picture" overview of long-term care research conducted in Brazil over the past two decades. This overview can be used to design a coordinated plan of action for future research as well as linking to international expertise where appropriate.

We asked the following question: "What are the general features of, and gaps in, empirical research conducted across Brazilian LTCFs for those aged over 60 years?"

Our objectives were to:

1. Describe the type and quality of empirical research conducted in Brazilian LTCFs for those aged over 60 years;
2. Identify the topic areas of published research;
3. Map the regions in Brazil where this research was conducted;
4. Identify current knowledge gaps.

2. Methods

An international consortium established in 2019 with Brazilian, UK, and European partners (LOTUS—Improving Care in Long-Term Care Institutions in Brazil and Europe through Collaboration and Research) identified the need for this scoping review. A review protocol was previously published [11]. This paper is reported following the PRISMA Extension for Scoping Reviews (PRISMA-ScR) [12] and adheres to the theoretical framework published by the Joanna Briggs Institute to guide scoping reviews (JBI) [13].

Eligibility Criteria

The "population–concept–context (PCC)" framework recommended by the JBI [13] was used to define the eligibility criteria for this review. Studies wholly or partly conducted in LTCFs for older people in Brazil were included if they [11]:

- Were empirical original research published in scientific journals;
- Investigated LTCF residents (older people aged 60 years and above as per/in line with the Brazilian definition of older people), their families, the LTCF workforce (e.g., healthcare professionals, care staff, and management-level staff), or LTCF organizations.

Studies involving psychiatric LTCFs, a specific category of LTCF in Brazil, were excluded (even if these included older people), as the care organization and pathways differ from non-specialist LTCFs for older people in Brazil [14].

Searches to identify relevant papers were conducted in Medline (PubMed), EMBASE (Ovid), LILACS (*Literatura Latino-americana e do Caribe em Ciências da Saúde*), and Google Scholar, from inception up to November 2018. Articles published in English, Portuguese, or Spanish were considered. No restrictions to study designs or methods were applied. The reference lists of all relevant studies were manually checked for additional eligible manuscripts.

The search strategy was developed iteratively with the input of an information scientist [11]. Significant keywords and index terms were included: "homes for the aged" (MeSH); "long-term care institutions"; "LTCF"; "geriatric long-term care facilities"; "nursing homes"; "residential facilities"; "long-term care institutions"; "long term care institutions"; "assisted living"; "old age homes"; and "Brazil" or "Brazilian". In each block, the words were combined with the Boolean operator OR and, between the blocks, the operator AND.

After removing duplicates, two authors independently screened each article by title and abstracts against the eligibility criteria. Reference lists of included studies were also screened to identify additional relevant studies. Full-text eligible articles were each reviewed by two reviewers from a team of ten academics experienced in healthcare of older people from Brazil and the UK. When there was disagreement between them, a third reviewer reviewed the article, sighted on the area of disagreement, to achieve consensus. When the same study was reported in more than one publication, we reported the overall findings and treated them as one study.

The quality of included studies was critically appraised using the Mixed Methods Appraisal Tool (MMAT) [15]. The MMAT has different evaluation questions that enable it to be used to accommodate multiple study designs (qualitative, randomized controlled trials, non-randomized, quantitative descriptive, and mixed methods) [16]. As recommended by Hong et al. [17], the overall quality score was not calculated, and instead a more detailed presentation of the ratings of each criterion is provided.

Data were extracted by the ten authors (P.A.W., D.C.D.O., K.H.S., R.D., P.J.F.V.B., V.S., A.F.J., H.A.W.W., A.L.G., N.A.R.) independently and double-checked by three authors (P.A.W., D.C.D.O., N.A.R.) using a modified JBI data extraction tool. The following key information of each source was extracted: formal citation (author(s), title, year, institutional affiliation of the first author); region of Brazil where the study was conducted; study design by the MMAT classification; population; type of LTCF; main topics; and ethical issues. The extraction form was created and piloted by the team before the data extraction. Reasons for exclusions at each stage were registered. Study authors were contacted to request additional data if required.

Results were reported descriptively using tables, graphs, and narrative accounts using elements of content analysis in order to provide an overview of the features for the research conducted to date [13,18].

3. Results

3.1. Study Inclusion

A total of 512 publications were retrieved. A further 12 articles were identified during the secondary screening of the references. After deleting duplicates, 438 studies were assessed for eligibility. Ninety-nine papers were excluded, yielding 327 studies that were included. Figure 1 shows a PRISMA diagram summarizing the study selection process.

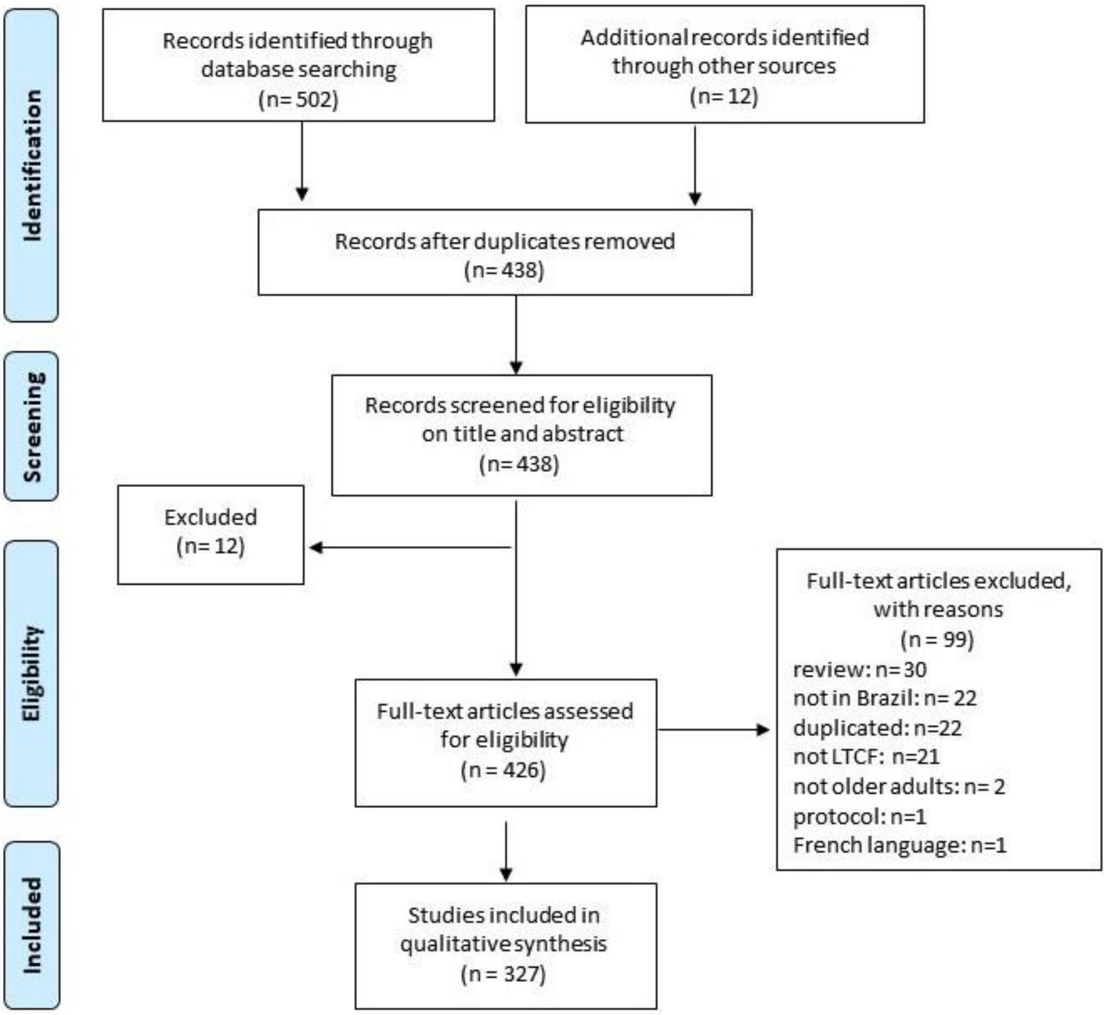

Figure 1. Flow chart with scoping review selection process.

3.2. Features of Included Studies

Table 1 presents an overview of the included studies. Two studies are not included in the tables as they did not fit any of the designs listed on the MMAT (translation/cultural adaptation of assessment tools). Quantitative non-randomized research (QNR) (for example, non-randomized controlled trials, cohort and case–control studies, and cross-sectional analytic studies) comprised almost half of the included papers (n = 159; 48.9%), followed by quantitative descriptive (QD) (n = 82; 25.2%), qualitative (n = 67; 20.6%), mixed methods (n = 11; 3.4%), and randomized controlled trials (RCT) (n = 6; 1.9%).

Most papers (n = 265; 81.5%) were published in the last ten years. The full text was available only in Portuguese in 180 publications (55.4%). Most articles had acceptable statements about ethical review; however, we could not locate any information on ethics procedures for 57 papers (17.5%). Figure 2 maps the Brazilian regions in which the studies were undertaken (according to first author institutional affiliation), illustrating the concentration of scientific research in the South and Southeast regions of Brazil.

Table 1. Characteristics of included studies regarding primary research conducted in Brazilian long-term care facilities (LTCFs) published in scientific journals by methodology.

	Qualitative (*n* = 67)	**Descriptive (*n* = 82)**	**Non-Randomized (*n* = 159)**	**RCT (*n* = 6)**	**Mixed Methods (*n* = 11)**
Publication Date					
1999–2009	11 (16.4%)	19 (23.1%)	24 (15.1%)	1 (16.6%)	5 (45.5%)
2010–2015	42 (62.6%)	45 (54.9%)	83 (52.2%)	1 (16.6%)	5 (45.5%)
≥2016	14 (20.9%)	18 (21.9%)	52 (32.7%)	4 (66.8%)	1 (9.0%)
Language					
English	6 (8.9%)	15 (18.3%)	47 (29.5%)	1 (16.6%)	2 (18.2%)
Portuguese	46 (68.7%)	51 (62.2%)	73 (45.9%)	3 (50.0%)	7 (63.6%)
At least Portuguese/English	15 (22.4%)	16 (19.5%)	39 (24.6%)	2 (33.4%)	2 (18.2%)
Geographic area *					
North	1 (1.5%)	0	4 (2.5%)	0	0
Northeast	13 (19.4%)	21 (25.6%)	32 (20.1%)	1 (16.6%)	0
South	29 (43.2%)	17 (20.7%)	35 (22.0%)	3 (50.0%)	7 (63.6%)
Southeast	14 (20.9%)	34 (41.5%)	65 (40.9%)	0	4 (36.4%)
Midwest	4 (5.9%)	6 (7.3%)	16 (10.0%)	1 (16.6%)	0
≥2 geographic area	3 (4.5%)	2 (2.4%)	3 (1.9%)	0	0
NR	3 (4.5%)	2 (2.4%)	4 (2.5%)	1 (16.6%)	0
1st Author Institution					
Public University	44 (65.7%)	59 (71.9%)	106 (66.7%)	4 (66.8%)	6 (54.5%)
Private University	19 (28.3%)	17 (20.7%)	33 (20.7%)	2 (33.2%)	5 (45.5%)
Health Service	2 (3.0%)	2 (2.4%)	6 (3.8%)	0	0
Governmental Agency	0	1 (1.2%)	1 (0.6%)	0	0
Others	2 (3.0%)	2 (2.4%)	1 (0.6%)	0	0
NR	0	1 (1.2%)	2 (1.2%)	0	0
Ethical approval †					
Yes	59 (88.0%)	64 (78.0%)	132 (83.0%)	5 (83.4%)	8 (72.7%)
NR	8 (12.0%)	18 (22.0%)	27 (17.0%)	1 (16.6%)	3 (27.3%)

RCT: randomized controlled trial; NR: not reported; * the Federal Constitution of 1988 divides Brazil into five regions: North, Northeast, Midwest, Southeast, and South; † ethical approval was clearly informed by the authors.

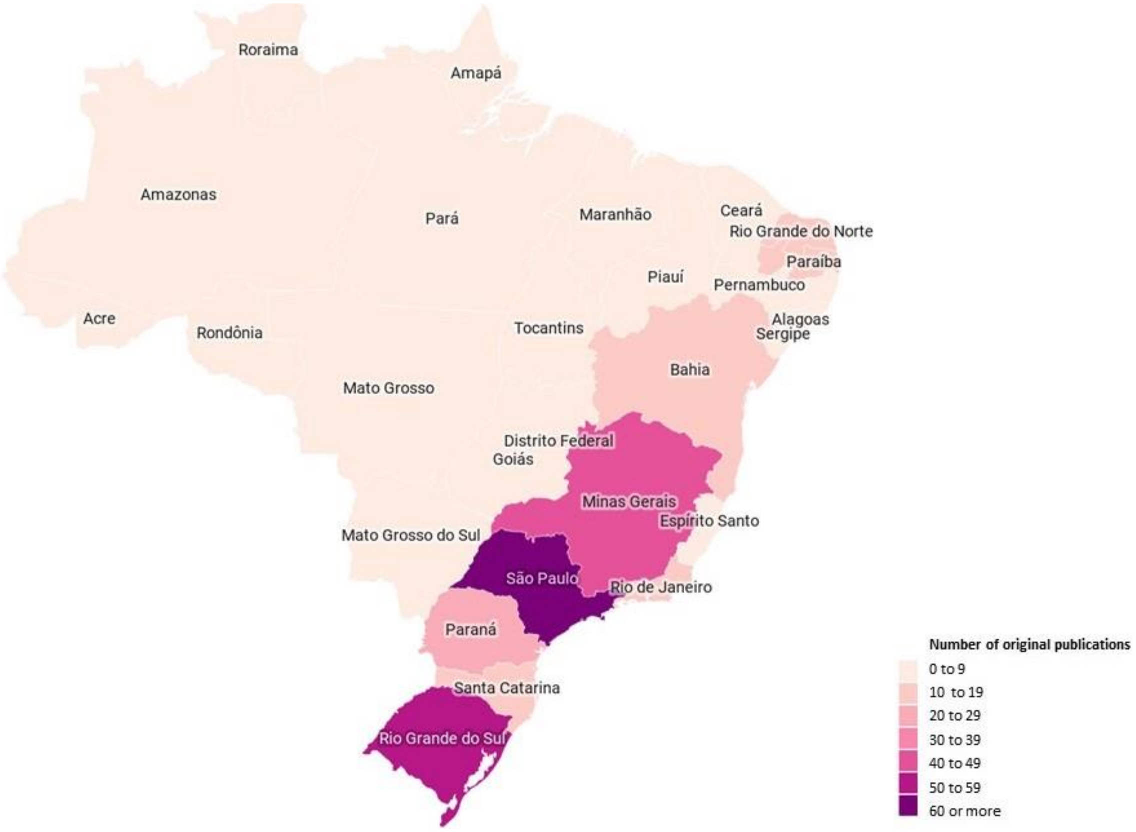

Figure 2. Characterization of the number of original publications included according to the Brazilian state of the institutional affiliation of the first author.

3.3. *Characteristics of Included LTCFs*

Regardless of the study design, most were conducted in a single LTCF (*n* = 149; 45.8%), in urban locations (*n* = 274; 84.3%), and in non-profit settings (*n* = 126; 38.7%) (Table 2). A high proportion of studies failed to sufficiently report the type of setting and its location (37.0% and 38.5%, respectively). The main sample composition involved LTCF residents (*n* = 241; 74.1%) with an average of 13 older adults (2 to 59) in qualitative studies and 178 older adults (1 to 2184) in descriptive quantitative papers.

3.4. *Research Topic Areas*

The main research topics were grouped into three categories: resident outcomes (*n* = 266; 81.8%), staff and family support (*n* = 41; 12.6%), and LTCF characteristics (*n* = 18; 5.6%). Within the resident outcomes topic, the most frequent subtopics were functional capacity (*n* = 36; 13.5%), mental health (*n* = 30; 11.3%), and nutrition (*n* = 26; 9.8%). Within "staff and family support", the main subtopics were experiences of care (*n* = 18; 43.9%) and work conditions (*n* = 4; 9.7%). Within "LTCF", organizational context (*n* = 12; 66.6%) and policies (*n* = 6; 33.4%) were the only two subtopics. A table covering the main topic areas of research conducted in Brazilian long-term care facilities is available in the Supplementary Materials (Table S1).

3.5. *Methodological Appraisal*

Table 3 summarizes the methodological appraisal of the included articles using the MMAT. RCT and descriptive studies had a higher proportion of MMAT classified as "no" or "cannot determine" than the other designs. Therefore, the quality of the evidence based on the MMAT was lower for these designs. Studies with a qualitative design scored higher.

Table 2. Characteristics of the long-term care facilities (LTCFs) studied in the included papers from primary research conducted in Brazilian LTCFs published in scientific journals by the type of methodology.

	Qualitative (*n* = 67)	**Descriptive (*n* = 82)**	**Non-Randomized (*n* = 159)**	**RCT (*n* = 6)**	**Mixed Methods (*n* = 11)**
Type of setting					
Profit	2 (3.0%)	0	1 (0.6%)	0	0
Non-profit	**32 (47.7%)**	**31 (37.8%)**	59 (37.1%)	**3 (50.0%)**	1 (9.0%)
Both	12 (17.9%)	17 (20.7%)	36 (22.6%)	0	**5 (45.5%)**
NR	21 (31.4%)	**34 (41.5%)**	**63 (39.6%)**	**3 (50.0%)**	**5 (45.5%)**
Setting Location					
Rural	1 (1.5%)	0	1 (0.6%)	0	0
Urban	**43 (64.2%)**	**42 (51.2%)**	**94 (59.1%)**	2 (33.2%)	**8 (72.7%)**
Both	0	5 (6.1%)	8 (5.0%)	0	0
NR	23 (34.3%)	35 (42.7%)	56 (35.3%)	**4 (66.8%)**	3 (27.2%)
Number of LTCF					
1	**46 (68.7%)**	**35 (42.1%)**	**60 (37.7%)**	**3 (50.0%)**	**5 (45.5%)**
2–5	9 (13.4%)	19 (22.9%)	37 (23.2%)	**3 (50.0%)**	1 (9.0%)
6–10	8 (11.9%)	12 (15.6%)	25 (15.7%)	0	0
≥11	3 (4.5%)	08 (9.7%)	22 (13.8%)	0	4 (36.5%)
NR/NA	1 (1.5%)	08 (9.7%)	15 (9.4%)	0	1 (9.0%)
(Min–Max, mean, median)	(0–52, 3.7, 1)	(1–156, 10.1, 2)	(1–125,6.4, 2)	(1–5, 2.0, 1.5)	(1–52, 14.4, 1)
Sample composition					
Older adults	**33 (49.2%)**	**64 (78.0%)**	**133 (83.6%)**	**6 (100%)**	**5 (45.5%)**
Total (Min–Max, mean, median)	Total = 428 (2–59, 12.9, 10)	Total = 11,358 (1–2184, 177.4, 76)	Total = 22.747 (4–3903, 171.0, 81.0)	Total = 164 (13–37, 27.3, 30)	Total = 204 (8–55, 40.8, 43)
Family	1 (1.5%)	0	0	0	0
Total (Min–Max, mean, median)	Total = 6				
Staff	19 (28.3%)	7 (8.5%)	7 (4.4%)	0	3 (27.2%)
Total (Min–Max, mean, median)	Total = 337 (7–40, 17.7, 16)	Total = 411 (12–181, 58.7, 38.5)	Total = 459 (22–181, 65.5, 45)		Total = 281 (38–181, 93.6, 62)
LTCF characteristics	3 (4.4%)	7 (8.5%)	2 (1.3%)	0	0
Total (Min–Max, mean, median)	Total = 59 (1–52, 19.6, 6)	199 (4–156, 28.4, 7.5)	Total = 80 (29–51, 40.0, 40)		
Managers and stakeholders	3 (4.4%)	1 (1.2%)	0	0	
Total (Min–Max, mean, median)	Total = 18 (5–7, 6.0, 6)	Total = 67			
Older adults × Non-institutionalized older adults	0	2 (2.4%)	15 (9.4%)	0	1 (9.0%)

Table 2. *Cont.*

	Qualitative (*n* = 67)	**Descriptive (*n* = 82)**	**Non-Randomized (*n* = 159)**	**RCT (*n* = 6)**	**Mixed Methods (*n* = 11)**
Total (Min–Max, mean, median)		Total = 192 (15–177, 96.0, 96) × Total = 273 (30–243, 136.5, 136.5)	Total = 1180 (14–393, 78.7, 42) × Total = 16,839 (14–598, 112.6, 76)		Total = 30 × Total = 30
Older adults × Staff	2 (3.0%)	1 (1.2%)	2 (1.3%)	0	2 (18.3%)
Total (Min–Max, mean, median)	Total = 13 (3–10, 6.5, 6.5) × Total = 25 (9–16, 12.5, 12.5)	Total = 62 × Total = 33	Total = 57 (11–46, 28.5,28.5) × Total = 40 (15–25, 20.0, 20)		Total = 314 (6–308,157.0, 157) × Total = 50 (7–43, 25.0, 25.0)
Older adults × Family	1 (1.5%)				
Total (Min–Max, mean, median)	Total = 3 × Total = 3				
Older adults × Managers	3 (4.4%)				
Total (Min–Max, mean, median)	Total = 27 (8–11, 13.5, 8) × Total = 17 (3–7, 8.5, 7)				
Family × Staff	1 (1.5%)				
Total (Min–Max, mean, median)	Total = 13 × Total = 19				
Managers × Staff	1 (1.5%)				
Total (Min–Max, mean, median)	Total = 20 × Total = 36				

NR: not reported; NA: not applicable; LTCFs: long-term care facilities. The numbers in bold represents the most frequent values.

Table 3. Critical appraisal of included sources of evidence through the Mixed Methods Appraisal Tool (MMAT), n = 325.

Screening Questions (for All Types)						**Qualitative (n = 67)**														
Are there clear research questions?			Do the collected data allow to address the research questions?			Is the qualitative approach appropriate to answer the research question?			Are the qualitative data collection methods adequate to address the research question?			Are the findings adequately derived from the data?			Is the interpretation of results sufficiently substantiated by data?			Is there coherence between qualitative data sources, collection, analysis, and interpretation?		
Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C
62	5	-	53	9	5	56	6	5	38	7	22	40	3	24	37	6	24	37	11	19
						Quantitative randomized controlled trials (n = 6)														
						Is randomization appropriately performed?			Are the groups comparable at baseline?			Are there complete outcome data?			Are outcome assessors blinded to the intervention provided?			Did the participants adhere to the assigned intervention?		
Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C
6	-	-	5	-	1	1	1	4	4	-	2	3	2	1	2	3	1	2	1	3
						Quantitative non- randomized (n = 159)														
						Are the participants representative of the target population?			Are measurements appropriate regarding both the outcome and intervention (or exposure)?			Are there complete outcome data?			Are the confounders accounted for in the design and analysis?			During the study period, is the intervention administered (or exposure occurred) as intended?		
Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C
156	3	-	140	6	13	57	47	55	120	19	20	126	7	26	56	58	45	120	15	24
						Quantitative descriptive (n = 82)														
						Is the sampling strategy relevant to address the research question?			Is the sample representative of the target population?			Are the measurements appropriate?			Is the risk of nonresponse bias low?			Is the statistical analysis appropriate to answer the research question?		
Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C
78	3	1	64	11	7	37	21	24	32	31	19	61	9	12	29	12	41	58	8	16
						Mixed methods (n = 11)														
						Is there an adequate rationale for using a mixed methods design to address the research question?			Are the different components of the study effectively integrated to answer the research question?			Are the outputs of the integration of qualitative and quantitative components adequately interpreted?			Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?			Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?		

Table 3. *Cont.*

Screening Questions (for All Types)						Qualitative (n = 67)														
Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C	Y	N	C
11	-	-	7	1	3	7	1	3	6	4	1	6	4	1	3	2	6	6	4	1

🟩 Category with most of the studies with YES

🟥 Category with most of the studies with NO

▨ Category with most of the studies with CANNOT DETERMINE

4. Discussion

This scoping review mapped the empirical scientific research undertaken in Brazilian LTCFs published in scientific journals from 1999 to 2018. We found that research in Brazilian LTCFs is in an early stage of development. From 1999—when the first study was published—until 2009, only 60 papers were reported, mostly descriptive and non-randomized quantitative manuscripts.

A recent review on global LTCF research found an increased rate of publications and citations in this field in the past 27 years, representing nearly an eightfold increase [19]. Most contributions (63%) were from the United States, Canada, and England. Brazil did not appear among the top 15 countries [19] which demonstrates that Brazil is behind the curve in terms of understanding the LTCF sector. That review [19] did not include databases beyond English ones (which may have restricted its global approach). Most publications found in our review were not published in English, so the language mismatch might have meant they were not included in prior reviews. Until such methodologies can adapt to a more international approach, the onus is therefore upon Brazilian researchers to publish in English to ensure that their data contribute to the larger debate.

The literature shows that global LTCF research has been defined by three stages: an early stage (2000–2005), where studies were primarily focused on care demand, functional, cognitive, and health status; a second stage (2006–2010), where the focus shifted to caregiving-related workforce factors; and a third stage (2011–2015), where attention moved to improving quality of care and to implementing clinical practice guidelines into LTCF homes [19]. In our review, Brazilian studies we found were mostly focused on resident outcomes and deficit-based approaches, mainly related to functional capacity, nutrition, mental health, assessment and profile, oral health, and another health status. These topics are largely related to the "early stage" focus. Research on the workforce and caregiving-related factors, person-centered care, quality of care, and quality improvements, although starting to emerge, seems relatively underdeveloped.

A large proportion of research was focused on small samples which may relate to over 20% of the papers being qualitative in design. These studies were predominantly ethnographic in nature, with limited evidence of ambition to develop middle-range or higher theory that might contribute to our understanding of Brazilian or international LTCFs, in a generalizable way. Many of the papers were outputs of research conducted towards undergraduate or postgraduate theses.

Leaving the academics to follow their muse is probably not wise. A previous review found that Italian nursing researchers, left to their own devices, tended to investigate technical and educational topics, rather than focusing on research priorities identified by the LTCF sector and care recipients [20]. One way to avoid this is to encourage and promote stakeholder participation in decisions regarding prioritization of topics for future research [10]. In such an initiative in the UK, eighty-three participants responded to a survey and ranked the five research priorities to be: questions on person-centered care, dignity, appropriate staffing, levels, and training and support requirements for LTCF staff [10].

The geographical concentration of research in the South and Southeast regions is likely to be a factor of available research funding (these regions make up 70% of the Brazilian Gross Domestic Product) [6] and also that these regions host the largest public and private universities. Based upon available data, these regions also seem to be home to the majority of LTCF homes (81.9% by one estimate) [6]. This represents a bias evident in all Brazilian research and, even more widely, reflects the concentration of public expenditure in these regions [21]. However, older people with frailty exist across Brazil and so a more disseminated approach to research is required [5]. When the United Kingdom faced similar challenges, with research concentrated in the South East around London, it overcame these challenges by developing the National Institute of Health Research (NIHR), embedded in the geographically distributed National Health Service (NHS), rather than in geographically concentrated academic institutions. This now includes a network for Enabling Research in

Care Homes (EnRICH) across the country [22]. Perhaps there is something for Brazil to emulate here.

There are some limitations to our review. Despite the broad scope and a substantial number of identified publications, the searches mainly identified scientific research papers. Reports and non-peer-reviewed literature were not included. These may have included important insights into the LTCF sector more broadly. We think that it is unlikely, however, that important academic research will have been overlooked, since the pressure to publish in peer-reviewed journals is so high amongst Brazilian academics that work undertaken for government or third-sector reports is usually replicated, in some form, in the scientific literature.

5. Conclusions and Implications

This is the first review to provide an overview of research on LTCFs for older people in Brazil. It has drawn together almost 20 years of Brazilian-based research and illustrated an excess of small-scale, predominantly quantitative non-randomized research, many of which are reported in ways that do not allow the quality of the work to be assured. The type of research and topics researched suggest that Brazilian LTCF research is in an embryonic state—it mostly focused on resident outcomes and deficit-based approaches and was predominantly concentrated around academic institutions.

The LTCF sector in Brazil is still poorly structured and underdeveloped [5]. Recently, however, significant non-governmental initiatives such as the "Frente Nacional de Fortalecimento à ILPI (FN—ILPI)" (National Front for Strengthening the LTCF) have been developed to gather and stimulate actions to support LTCFs. These serve as democratic spaces for debates, research, planning, articulation, and promotion [23]. This paper demonstrates that even modest structured research can highlight important inequities and deficiencies in current provision in a way that can help target policy. Research on the quality of care/quality improvement, workforce, and person-centered care, for instance, seems relatively underdeveloped. There is much to be learned from initiatives undertaken to develop disseminated research networks, focusing on stakeholder priorities in a coordinated way. We contend that, as the Federal Government looks to standardize long-term care provision, it should focus on a parallel effort to establish proportionate and sustainable approaches to LTCF research.

We recommend the following actions for researchers and policymakers. The immediate priority for LTCF research in Brazil should be stakeholder consultation to define research priorities. A research agenda that reflects the priorities of stakeholders will ensure topics addressed are meaningful to the people the research is intended to serve. Stakeholder consultation needs to include a wide range of stakeholders, including older people who live in LTCFs, their relatives, care workers, practitioners, management staff, and professional organizations relevant to the Brazilian LTCF context (FN—ILPI; Brazilian Society of Geriatrics and Gerontology). Due to the diversity across Brazilian states, it will be important to consult in a geographically inclusive way, recruiting stakeholders across different states. Setting research priorities will enable researchers and decision-makers in funding organizations to make informed choices around where research efforts should be placed. The focus then should be on developing a small number of sufficiently funded, high-quality research projects to investigate these. Lessons can be learned from how other countries have structured long-term care research. International knowledge exchange and sharing and collaboration will therefore be valuable. There is evidence of international knowledge exchange and sharing currently taking place. Jacinto et al. [7] outlined topics for research into Brazilian LTCFs which were identified during an international workshop which took place in Brazil in 2019. The workshop was supported by academics from across Brazil, the UK, the Netherlands, and Austria. An important metric will be the number of Brazilian LTCF publications accepted to international journals and thus contributing to the broader debate of what good LTCFs look like.

Supplementary Materials: The following are available online at https://www.mdpi.com/1660-4601/18/4/1522/s1, Table S1: Main topic areas of scientific peer-reviewed research conducted in Brazilian long-term care facilities, grouped into three categories.

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