



Article

The Caregiving Journey: Arts-Based Methods as Tools for Participatory Co-Design of Health Technologies

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Abstract: Being an informal caregiver to a loved one with an illness, disease, or chronic disability is a rewarding but frequently stressful experience. In this design research project, caregivers participated in a half-day workshop to (1) share their caregiving experience, (2) reflect on the potential of a mobile smartphone ‘app’ for carers and (3) co-design this app, as well as participate in in-depth interviews. Our design research process used multiple arts-based methods, including visual experience mapping tools, storytelling, photo-elicitation, documentary photography, cartoons, drawing, and research poetry, to provide rich and empathic insight into daily life as a caregiver and illuminate the potential of technology. Workshop activities included creating a visual collage of lived experience, annotated visual maps illustrating the reality and misconceptions of caregiving, pathways of care, and mapping a day in their life using the visual metaphor of a clock. Carers then trialled and provided feedback on a prototype app, creating a collective map of desired features. This co-design feedback informed the final app design, which was formally launched at a public exhibition showcasing stories collected from our arts and design-led processes. This paper outlines the value of arts and design methods in the design of future health technologies, which provide a critical space for an informed, reflexive, and empathic dialogue about illness and caregiving, resulting in designs that truly met consumer’s needs.

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1. Introduction

An estimated 63 million people are informal caregivers, providing unpaid care to family and friends with chronic health issues, mental illness, disabilities, advanced old age, or an end-of-life health condition. The type, duration and level of informal care tasks varies, but typically includes providing support with daily activities of living—from physical and personal care tasks (dressing, showering, toileting, feeding, lifting, transport), to managing medications, organising and attending appointments, dealing with health emergencies, and providing emotional and social support. Caregiving is rewarding, often providing a sense of meaning and accomplishment, but also frequently stressful, as everyday people become “care coordinators, medical record keepers, medical decision makers, insurance navigators, medication administrators and deliverers of complex medical care” (Sterling 2017, p. 78).

As technology has the potential to support patients and caregivers in the tasks of monitoring, coordinating, and communicating care activities and needs, this paper documents the participatory co-design process of developing a mobile smartphone ‘app’ (application) for, and with, informal caregivers. Alongside co-design methods, this project also deployed multiple arts-based research (documentary photography, photovoice, cartoons, drawing and research poetry) to better understand, document and share the unique

lived experience of being a caregiver. The combination of co-design with arts-based approaches, which resulted in a large interactive digital exhibition in Brisbane, Australia during Carers Week in 2018¹, provides rare and intimate insight into the psychosocial and emotional impact, practices, and experiences of caregiving. This paper explores how co-design and arts-based methods help provide meaningful space for self-exploration, awareness, and dialogue that creates critical new understandings about the lived experience of caregiving and informs the design of new health technologies.

1.1. Opportunities for Transformative Learning through Participatory Co-Design and Arts-Based Methods

While design and arts-based research methods have not often been fully integrated into research practice, such approaches provide promising and powerful methods for understanding and amplifying participants' unique lived experience—their practices, decisions, memories, feelings, fears, dreams, and hopes—and for translating these insights into design innovations that improve participants' daily lives.

Digital technologies, such as apps, can enable and empower consumers to proactively manage their health. Over 2 billion people use inexpensive mobile smartphone apps to measure, track, display and share their personal health data, with these digital tracking tools monitoring medications, food and water intake, glucose, oxygen saturation, body temperature, weight, pain levels, sleep patterns and many other activities (Miller and Polson 2019). Too often, however, apps are designed by developers, with limited engagement with research, theory, or end-users—which results in poorly designed apps and a “chaotic mix of apps of varying degrees of usefulness, quality, effectiveness and danger” (Hilty et al. 2017, p. 14; Joshi et al. 2019; West et al. 2013). Education, income, health, and age also influence engagement with digital health technologies, which are rarely designed with and for caregivers or with the specific needs of our ageing population in mind (Göransson et al. 2020; Wilson et al. 2021). Yet, as Sterling (2017) explains, caregivers are “the perfect team of experts to help develop the health information technology tools that would support our caregiving needs” (p. 77).

The lived experience of end-users is not commonly integrated into app creation and development, negatively impacting their useability, usefulness, and uptake. There is, however, a rich literature on the value of participatory co-design in healthcare. Nearly two decades ago, Bate and Robert (2006) argued that instead of redesigning health systems *around* the patient, services should be co-designed *with* the patient—advocating for the philosophy and method of experience-based *co-design* in health.

Emphasising the value of lived experience, alongside authentic and equitable collaboration between patients and clinicians, the participatory methods of experience-based *co-design* (variously termed participatory co-design, co-creation, co-production, co-innovation, human-centred design, and technology codesign) have become the new Zeitgeist, the approach and spirit of our times in healthcare quality improvement (Palmer 2020). By actively and deeply engaging with users, co-design works because it ensures “all aspects of subjectively experiencing a product or service—physical, sensual, cognitive, emotional, kinetic and aesthetic” (Bate and Robert 2006, p. 308) are identified, understood, and addressed, thus improving the service experience.

Narrative, storytelling, and visual methods (photography, film) were key components of Bate and Robert's (2006, 2007) participatory experience-based co-design approach for healthcare improvement. However, to date, academic writing has typically not prioritised the sharing of such stories—in part because the dominant Western culture values rational-cognitive ways of knowing above the emotional and embodied ways of knowing offered by arts-based approaches). By engaging our emotions and senses, through visual imagery, narrative, imagination, and metaphor, arts-based approaches facilitate compassion, empathy, authentic dialogue, and sense-making, which often results in critical reflection, transformational learning experiences and change (Tyler and Swartz 2012).

As Lawrence (2012) explains, “we encounter the arts through our full *presence*” (p. 472), with this “emphatic experience” (Eisner 2008, p. 7) having the potential to transform individual worldviews and communities, by challenging taken for granted assumptions and allowing us to envision different experiences and alternative realities. For psychosocial research, which highlights the complicated interconnections between self, subjectivities, and societies, emphasising that the individual can never be fully separated from their social context (Taylor 2017), arts-based approaches offer a powerful and unique tool for accessing and understanding lived experiences (Bennett et al. 2019).

1.2. Arts-Based Methods: Photo-Elicitation, Photography, Cartoons, Drawings, and Poetry

To evoke reflective and embodied engagement with the lived experience of caregiving, and transformative learning experiences, alongside the co-design activities, we engaged with five arts-based methods: four visual methods (photo-elicitation with participants, while professional creatives produced documentary photography, cartoons, and drawings) and one story-telling approach (research poetry). Via their uniquely intimate focus on the nuances and subtleties, arts-based visual methods, intentionally and memorably reveal truth through art and beauty, enabling us to access insight and knowledge that might otherwise remain hidden. “The arts, as Patricia Leavy explains, have a unique capacity to “educate, inspire, illuminate, resist, heal and persuade ... [connecting] us with these who are similar and dissimilar, open up new ways of seeing and experiencing, and illuminate that which often remains in darkness” (Leavy 2020, p. ix).

Although visual methods are increasingly used in research—as they foster participatory approaches to knowledge creation while generating rich, engaging and sensory insight into often ‘taken-for-granted’ experiences (Rose 2014)—it is rare to see multiple visual methods, created by both community members and professionals, in the one research project. Complimenting these visual methods, the unique approach of research poetry—alternatively termed transcript poems, poetic inquiry, or poetic transcription—turns interview transcripts into poems, or poem-like prose. Through the deceptively simple steps of a non-linear search through transcripts for key phrases, which are then re-arranged into poem-like prose, research poetry presents qualitative interview data in an unusual and captivating fashion (see Faulkner 2019). Research poems compress experience and emotion, and using poetic techniques such as rhythm, rhyme, repetition, metaphor, humour, imagery, sound, synthesis, and alliteration, have a memorable and refreshing authenticity, and often confronting, vulnerable vibrancy which uniquely reaches and resonates with audiences—listeners and readers tend to be moved by their simple power (see Gerber et al. 2022; Miller 2021).

As digital health researchers have long called for more “in-depth analysis of individuals’ subjectivities and embodiment in the world of m [mobile]- health” (Lupton 2012, p. 241), this paper explores the value of design and arts-based methods in exploring the caregiving experience and co-designing an app, with and for end-users. Two key research questions underpinned this co-design project: (1) to explore how design and arts-based methods might provide deeper understanding of the embodied, lived experience of caregiving; and (2) to identify the benefits and desired features of an app for caregivers.

2. Materials and Methods

A range of mixed research methods were used within the arts and design research process, including visual experience mapping tools, photo-elicitation and storytelling in the co-design workshop, as well as drawing and poetry. There were three key participant groups: the caregivers (co-design workshop, photo-elicitation, interviews and portraits), the professional creatives (the cartoonist, artist, and documentary photographer), and researchers (who ran the co-design workshop, conducted interviews, and created the research poetry).

2.1. Participants

Participants were nine female caregivers (seven informal caregivers, two paid), residing in Brisbane, Australia. The use of smaller sample size in the context of participatory co-design workshops can be highly informative and meaningful as demonstrated in other similar contexts. Sanders et al. (2010) states that participatory methods can involve between two people and “a larger group” (2010, p. 197), based on the needs of the project. With the exception of a young woman caring for her grandmother who lived in their own home in the community, the majority were older informal family carers looking after an ageing spouse or parent in their own home. After the workshop, four of these female carers agreed to be interviewed and photographed in their own homes, further reflecting on their care experience and posing for professional documentary portraits for an exhibition on care.

2.2. Procedure

After obtaining formal ethical clearance from the university Human Research Ethics Committee (1800000143), participants were recruited through a non-probability snowball sampling approach via personal contacts, word of mouth and industry contacts (seniors and carers networks), as well as social media. Interested carers received instructions for a pre-workshop photo-elicitation task, and to bring these photographs to a four-hour co-design workshop, held in a seminar room at a local university (see Figure 1). During the workshop, a professional cartoonist observed and generated cartoons of the conversations, while a professional photographer visually documented the event and another artist later sketched drawings illustrating key themes from the workshop and interview transcripts.



Figure 1. Image maps, using visual symbols to describe reality and myths of being a carer.

After the workshop, participants had the option to be interviewed and professionally photographed by a documentary photographer at a location of their choice (homes or workplace; see (Holm 2014) for photography as a research method) to share more about their caregiving experience. The documentary photographer was accompanied by a researcher, who asked one question: in your own words, please, tell us about your caring experiences—the highs and the lows. This interview and photographic process took between 60–90 min. While it is beyond the scope of this article to discuss in detail, the final app was formally launched² and these findings publicly disseminated via a large digital exhibition during Carers Week in 2018, with over 100 people attending the opening and a connected research symposium to reflect on and discuss the experience of caregiving, value of co-design and arts-based approaches, and the potential of technology to help.

2.3. Data Collection

Photo-Elicitation: Photo-elicitation is a research method that uses participant or researcher generated photographs during interviews or workshops (Harper 2002). Prior to participating in the co-design design workshop, carer participants received instructions for a pre-workshop photo-elicitation task: to take five photographs capturing highlights, low points, and challenges of being a carer. These were to be shared and discussed at the

workshop. Due to the workload associated with caring, only three participants completed the task and emailed pictures to the researchers before the workshop—although all later sent images in, for the public exhibition.

The Co-Design Workshop: Participatory workshop activities used visual tools to explore and understand the carer experience, encouraging participants to take a creative approach in sharing their caregiving experience, exploring symbolism and metaphors that held personal significance and meaning. Researchers developed the co-design toolkit following principles of generative design, with these activities of making, telling and enacting originating from psychological theory about memory and creativity. The deliberate, facilitated co-design process of participation and reflection uses evocative visual techniques to make thoughts, feelings and beliefs about the past—and ideas for the future—explicit (Brandt et al. 2012). Each activity outlined below was developed to enable participants to use a range of modalities—visual and text-based—to communicate their experiences, needs and requirements during crisis, transitional and maintenance phases, as appropriate based on their lived experience. Sterling's (2017) *Caregiving Information Cycle* which argues a caregiver is actively in one of three possible phases at any one time: responding to a crisis, in a care transition (e.g., moving from home to hospital) or maintenance mode, managing day-to-day care activities and responsibilities. As each phase has distinct information needs, in terms of what a caregiver might need to access, record, coordinate or connect, the design activities below purposely stepped participants through typical 'day-to-day' and 'crisis days' to ensure feasibility, useability and acceptability of app features. Figure 1 shows workshop resources, which included white A4 and A3 sheets of paper, participant-generated and pre-selected and photos, stickie notes, pens, and colour stickers.

Design Activity 1: What does it feel like to be a carer? Participants commenced by grounding themselves in the reality of their experience as a carer by creating and sharing a visual collage ('caregiver self-portrait') of their personal lived experience. Photographs were selected from copyright free collections for the visual toolkit, guided by prior research in the field identifying key areas of concern (e.g., social isolation, loss of mobility, healthcare costs, loss of independence, fear of deteriorating physical health, valuing family and social connectedness, continuity of normal life). As well as serving as an icebreaker, this grounded the workshop within the participant's own complex lived experience, capturing key images and terms. Participants then used stickers to mark their top three most concerning issues or top priorities—a typical phase of co-design, this co-analysis process isolated key experiences, information invaluable to the design of an app.

Design Activity 2: "A day in the life". The second activity captured a visual snapshot in the life of a caregiver using the visual metaphor of a clock as the basis for a visual experience map. In co-design the format of 'a day in the life' is a useful design mapping tool to map a good/bad day. The researchers considered using a "week wheel"—same principle but extended to capture a full week—however, it was deemed a day would generate more useful data given a carer's day can suddenly and unexpectedly change. Participants then used stickers to identify which times of day were most and least energy demanding.

Design Activity 3: Myth vs. Reality—Exploring perceptions of caregiving. In the third activity, participants juxtaposed image maps of drawing on outcomes of Design Activity 1 alongside what they've perceived to be the myths (or broader societal misconceptions) about carrying significant caring responsibility. Figure 1 illustrates this activity: one participant drew a heart, to represent that all she had to offer was love, while another selected images of a road and bars to convey her journey (feeling 'trapped' in this caregiving role until the inevitable end—the death of both her husband and best friend from cancer).

Design Activity 4: Crisis Day vs. Typical Day—mapping pathways of care. In accordance with co-design process, participants' iterative reflections and annotations established a rich context and backdrop to the generative app design phase. Participants first mapped their typical day, followed by a map of events on a crisis day. Participants asked 'how does information flow?' through each of these days, who was involved, how many people, what

information did they need/could share, etc. Lastly, they created another layer over the top to annotate communication pathways, using coloured stickers to map information needs against items: where they thought technology would be most helpful and why; and where technology may have no use or may be potentially harmful, and why. This process ensured participants retained agency over the process of positioning current and future role of technology within their daily caregiving activities, and creatively illuminates what app features would be most or least helpful.

Design Activity 5: Test existing app prototype. Participants had an opportunity to download and test an existing prototype for a carer's app. It was critical that an existing (basic) solution was introduced *after* participants reflected on, represented and iteratively explored their own experience, thus establishing an experiential benchmark for evaluating relevance of existing solutions to their needs. Each participant provided feedback on app design, features and navigation, with group discussion unpacking the pros and cons of existing solutions, strengths of the current design, and where it could be extended given preceding activities, creating a collective map of desired features—graphically represented by the cartoonist in Figure 2 alongside the main message from the workshop: all carers had in their toolkit was love, and they desired health technologies that could support them.

Design Activity 6: Ideation of the ultimate app for carers. Finally, drawing on all previously completed activities, participants engaged in a lively whole group ideation activity, collectively generating app design priorities in response to previously identified gaps, needs, and priorities.



Figure 2. Visual representation of the app, carer's toolkit, and discussing technology.

2.4. Data Analysis and Analytical Approach

Workshop data comprised annotated visual artefacts (experience maps, examples of symbolic communication, visual metaphors), researcher fieldnotes and workshop audio recordings, as well as the cartoons and sketches produced by the artists and participant-generated photo-elicitation. Interview data was audio-recorded and transcribed, and included professional documentary photographs. In this analysis, verbal interview and workshop data was combined and, with the photo-elicitation photographs, analysed together.

Analysis was inductive and data-driven, following the six phases of Braun and Clarke's reflexive thematic analysis (RTA) approach: familiarization with the data; coding; generating initial themes; reviewing themes; defining and naming themes; and, finally, writing up and weaving together the analytic narrative (Braun and Clarke 2019). RTA acknowledges the importance of reflexivity (critical thinking about our thinking), emphasizing the active role of the researcher in the situated and interactive research processes and practices that produce knowledge. We did not use a specific or predetermined theoretical framework—however, our analysis was informed by awareness of the Technology Acceptance Model (TAM) from information systems that outlines how users

come to use and accept technology and Sterling's (2017) *Caregiving Information Cycle* model.

This analysis was conducted from reading and listening to transcripts and recordings from the interview and workshop, as well as the workshop co-design artifacts, with the arts-based methods used to illustrate each theme. Analysis was an iterative process, led by the first author, with the project team immersing themselves in the narrative, design and arts-based data to create an initial categorization and interpretation for a public exhibition. After the broader project team discussed first impressions, potential themes and initial inductive codes to capture units of meaning and meaningful patterns, the first author collated the data extracts for each theme and developed this analysis.

As a strategy to engage deeply with the data, research poems were also created from transcripts and workshop notes, via a non-linear search for key words and then arranging these words into poetic form—thinkingly deeply about language use and alliteration, metaphor and image, rhythm, line, and form. Research poems are a form of data collection, interpretation, analysis, and representation, sharing stories of actual experiences (narrative poetry) and condensing emotions (lyric poetry) into a poem that enables a visceral experience for the reader/listener.

2.5. Reflexivity, Rigor and Dissemination

Reflexivity is the process of intentionally considering how researchers' disciplinary background, theoretical lens, and personal experiences expectations and assumptions shape data analysis. As qualitative arts and design researchers, our ontological position (our view of the world) is one of social constructivism. We acknowledge the subjectivity of human experience and believe that the multimodal, experiential, and visually engaging nature of arts and design tends to be a more accessible, empathetic, and impactful method of engagement and communication than the traditional written scientific form. To ensure our analysis was sufficiently rigorous and minimized the potential for bias, the broader project research team had frequent discussions regarding the activities and coding of data, reflecting on potential assumptions, and possible omissions. Two members of the research team also created poems, as a strategy to engage deeply with the data and express it emotively to the public. The use of multiple methods and participant-produced photographs helps strengthen authenticity, trustworthiness, and credibility, with purposeful thick description from participants (quotes, visual artefacts from the co-design workshop and photo-elicitation) in the results. While not thematically analysed, the professionally produced creative outputs (cartoons, sketches, documentary photography) and researcher-authored poems were used to disseminate project findings (the exhibition) and are presented here to support and illuminate the themes.

3. Results

Four themes were developed, supported by quotations from the co-design workshops and interviews, the photographs, as well as illustrative researcher-created poems and professional creative outputs. The first theme, *Crisis to Crisis—the Caregiving Stress Rollercoaster*, depicted in Figure 3, shares the challenging day to day experience of being an informal caregiver. The second theme, *Adapting and Adjusting, with Love* illustrates how carers pragmatically approach their care role but endeavour to show love and care in their actions. The third theme, *The invisible, unsupported carer—alone, tired and grieving*, emphasises how alone carers feel. The fourth and final theme, *Could Technology Help Me?*, reflects carers hope that technology might make the task of caring easier.



Figure 3. The care rollercoaster—lurching from crisis to crisis, carrying a heavy load.

3.1. Theme 1: Crisis to Crisis—The Caregiving Stress Rollercoaster

The images in Figure 3 illustrate carers experience of caregiving: being on a care rollercoaster, from lurching crisis to crisis, feeling like the weight of the world is on their shoulders. Carers explained that while others perceived them as “superhuman”, having “a special set of qualities” they were “just a human doing the best” to respond to what “life has thrown”—and they were “lurching from one crisis to the next”, “with no idea what I am doing, every day is different. You have no clue. You just have got to get on with it”. Maree—who is primary informal carer of both her mother and mother-in-law—vividly recalled the challenge of dealing with a crisis day: *My mother had a fall under family member’s watch, had to lift her getting her off the floor, tend to bruising, consoling, reassuring, calling doctor, addressing mother’s anxiety, getting a call to say mother-in-law is throwing up and so going over to assist”*.

Participant’s photographs captured the highs and lows of caring, as shown in Figure 4—from playing scrabble to the “never-tidy” laundry. Sally photographed her messy laundry, with the label “NEVER TIDY”, explaining: *“it’s just a never ending cycle of laundry and cleaning. It gets too much sometimes. It’s the drudgery of keeping the home all nice, working and trying to look after Mum at the same time. It’s so hard. I am so tired, ALL THE TIME”*. Similarly, Libby (who cared for her mother-in-law) took a photograph of a pile of sized and shaped pieces of timber, explaining that: *“each of these pieces of timber represents something that I have to attend to. At times the pile can feel so large that it becomes overwhelming, and it’s not clear how to prioritise which timber I need to pick up first. And often, in order to get to the piece of timber that I do need to attend to, I have to move a few others out of the way first”*. The stress and frustration of caregiving is emotively captured in the poems below, as Eli shares the experience of caring for her husband who has a terminal illness.



Figure 4. Participants’ photographs of caregiving, and a self-drawing showing little time for them.

Stress

he is so stubborn
 he can't do anything
 can't use cutlery
 can't make a cup of tea
 can't carry it
 he sits there
 he has bowel accidents
 he drools—

I lean over
 wipe his chin
 Other people look at him
 that doesn't bother me.

But I get frustrated.
 I have been getting
 cranky with him
 snap at him,
 sworn at him.
*what's going to happen
 if I die from stress?*
 Eli.

Frustration

I get frustrated
 we had planned
 to do a lot
 we can't do.

So, I kick things

I went out
 punched the palings
 out of the fence.

I have osteoporosis—
 So I broke all my knuckles.
 Eli.

3.2. Theme 2: Adapting, Adjusting and Caring, with Love

In this theme, carers described how they were continually “adapting and adjusting” in their quest to provide the best care possible, with two sub-themes: love, and adapting and adjusting, as reflected in the photographs and images in Figure 4. The first sub-theme emphasises the love underpinning carers’ actions. Libby’s photograph, for example, shows how, every week, she prepares meals for her frail 82-year-old mother-in-law who lives on their property in a granny flat. Each meal is presented beautifully, in a specially labelled container. Andrea who was of four family carers supporting her grandmother, tried to make the “care” part invisible, to show her respect. She explained how 80% of the time together was spent on functional care activities, with the real ‘treasure’ the 20% of quality conversation—represented in her photograph, showing family pictures over a scrabble board.

The second sub-theme of adapting and adjusting highlights how our world is not set up for disability, with the built environment often a barrier to independence. Andrea photographed a step outside a community support agency: a physical barrier to accessing support for her 92-year-old grandmother who uses a walking frame. Libby’s photographs focussed on the built environment at home—her mother-in-law Anna lives in a granny flat on their property. Anna uses a cane and can no longer climb the several steps of stairs to access the laundry in the main house. To maintain her independence, her granny flat has just been renovated to add a laundry and door handles she could open with arthritic hands, as well as place to hang her walking sticks. Adjusting to change was not easy, with Nell photographing a walker to show how: “*going from independent and capable to being a ‘falls risk’ and relying on others is tough. I found it hard to witness such a transition in someone I love, and yet, they have to live it*”.

3.3. Theme 3: The Invisible, Unsupported Carer—Alone, Tired, and Grieving

This theme highlights how carers felt invisible, not valued, and not supported in their role, as depicted in the creative professional’s cartoon, sketch and photograph in Figure 5. In the co-design workshop, one carer described how she had to “wear a mask—keeping

a capable and ‘happy face’, whereas underneath she was “so, so, so, tired” (the carer mask drawing, in Figure 5). Carers also lamented that there were very few services “out there” to support them and finding and accessing them was typically very challenging. Jennifer explained she stopped talking about being a carer: “most times I said nothing, because I got sick of being told by those that don’t understand to “stay strong”. Caring changed relationships. In the workshop, 81 year old Cathy (a carer for her 86 year old husband) chose a picture of wine and a candle with the simple yet poignant description “missed experience”—Cathy was grieving how her husband’s illness had changed their relationship, so she was no longer a wife doing fun things together (from the simple, dining together, to the more exotic, such as holiday cruises), and her new role was simply to provide care. As well as feeling alone while doing performing a caring role that society did not value, carers felt even more alone if and when the person they were caring for die.



Figure 5. The face of carers, who often felt alone and unsupported.

Carers explained that “*grief is messy.. there is a lot of snot and tears*”. The poems and creative images very emotively convey the pain of caring for, losing, and missing a loved one. As well as caring for her husband before he died, Dianne relocated cities for several months, to care for her best friend when she was dying from cancer. She held her hand and slept beside her during these last few weeks, as we see in the professional pictures in Figure 6. The deaths of two loved ones in 12 months had broken Dianne, who explained that “I will never, ever—I don’t ever want to love anyone again. Because to lose them is so heartbreaking. All I remember is the sadness. It was just 12 months of absolute sadness and misery”. Figure 7 illustrates a particularly challenging transition for carers: when home became a hospital, and the bed is no longer a place of rest and refuge, but a site of medical intervention. The sketch on the left shows a normal bedroom; the right side, the same bed with hospital equipment. The other sketch is of a memory; one carer explained how she could still sense her love husband in his beloved chair at home, with this sketch showing his ghostly form in his seat.

Cry Forever

Until he died
I didn’t even realise -
how deeply I loved him.

I did two years
of grief counselling—
I don’t think it’s
ever going to help me.

I still sit here,
cry every day.
I look at photos—and I cry
I think—I am going to

Friendship

Sick with—
agony, pain, vomit.
Vomiting, every single day
and night
Vomiting up to 20, 25 times.
Couldn’t eat anything
But I sat with her,
slept with her,
holding her hand—
with my friend.

Dianne

cry forever.

Diane

As the poems in this section illustrate, many of our participants had nursed their loved ones (partners, parents, and friends) at the end-of-life. Dianne's poems above reflect the pain of caring for, losing, and missing a loved one—her best friend Libby and husband Claus. As she explained, *"I will never, ever—I don't ever want to love anyone again. Because to lose them is so heartbreaking. All I remember is the sadness. It was just 12 months of absolute sadness and misery"*. As well as caring for his husband before he died, Dianne relocated cities for several months, to care for her friend when she was dying from cancer. Dianne held her hand and slept beside her during these last few weeks, pictures captured in Figure 6, taken by the professional photographer.



Figure 6. Professional photographs of carers, with their memoirs.

What carers found especially challenging was the transition—when home became a hospital. The bed was no longer a place of rest and refuge, but a site of medical intervention, as shown in Figure 7 below. The left-side sketch shows a normal bedroom on the left, and then the bed with hospital equipment on the other side, reflecting how daily life changes when caring for someone ill at home. The other sketch is of a memory; one carer explained how she could still sense her love husband in his beloved chair at home, and this sketch shows his ghostly form in his seat.

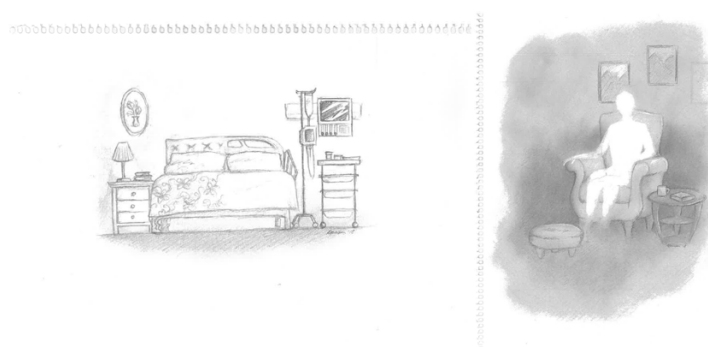


Figure 7. Sketches—when home became a hospital, and the memory of loss.

As we see below in her poem *Loss*, Dianne was struggling with the death and loss of her best friend and husband. Dianne especially struggled with being at home alone at night, sitting in her chair *"TV on, bored shitless, playing Solitaire until I get tired and I go to bed"*. *Loss* shares how Dianne misses the daily intimacies of physical contact from her husband, and his practical help in running their household—she missed his emotional and practical support much more than she had anticipated and was unfortunately finding that *"Life after is shit (laughs). For me, it's shit"*.

LOSS

I miss
his touch.
He would walk past me
in the kitchen
He would put
his hands, on my shoulders—you know.

And I took him for granted.
I knew I had a great husband—
he always did everything for me.
But I didn't know—how great he was, you know.

Since he's died,
the stuff I have had to learn—
to put a light bulb in.
I have never done that.
I dwell on—stuff like that.
Dianne

3.4. Theme 4: Could Technology Help Me?

This final theme reflects the hope carers had that technological systems, such as an app, could make the task of caring logistically easier. Typically, mobile phones (especially group texts) were used to communicate, with some also relying on 'pen and paper' by the bed or couch to record daily routines and important hand-over information (e.g., medicines, appointments, mood, priorities). There was a strong desire for a simple, visually based communication and connection tool that would record critical information and share tips, activities, plans or just simply describe how the night had been and the physical pain or emotional mood of their loved one. An ideal app would feature: icons to replace text; a place to record and track changes in health; a diary function to record happy memories; an easy place to list worries/concerns (for example, a fast way of communicating the care-receiver only ate half of their breakfast); future plans (a way of listing activities the care-receiver might enjoy); a 'Daily Diary', capturing the last 24 h and key updates; emergency contacts, a place for all emergency/fast contacts, including doctors, family members and a crisis plan; a 'Coffee' icon, linked to networking and support with a local community of carers; and a 'Help Me' function—for carers to use when exhausted, linking them to fellow carers for support

4. Discussion

In this paper, we have explored the process and findings of using art-based participatory design methods to actively engage carers directly in the co-design of a digital app intended to support them and people they care for. While there are existing apps in this space available, none were specifically for older carers, evidence-based or co-designed with end users—making this the first caregiving app to be co-designed with the older carers themselves. The specific details of the co-design tools deployed in the project (for example, the visual mapping of a crisis and typical day), care experience findings and insight about where and how technology could better support carers provide rare insight of value to may help inform the design of both future workshops and technological innovations.

Engaging in a process of participatory co-design is one way to help ensure novel technology solutions are designed in ways that enable carers to represent their needs and speak on their own behalf about what empowers them and what eases their burden. The clock mapping activity, ("a day in your life") revealed a visual and visceral dimension (often invisible, and therefore *under-represented*) understanding of the everyday, "around

the clock”, challenges and pressures that a carer faces from moment to moment. The images carers selected, including clock maps, uniquely illustrated the relentless time-bounded responsibilities of care, often leaving little or no time to for own wellbeing. In this, analysis provided an insight into the problematic nature of “some me time” for carers to focus on own needs, and the constant search for personal—and rare—moments of self-care.

The “crisis vs. typical day” task delineated the mental, emotional, and physical dexterity required of carers, who fluctuated from chaos and crisis management to a state of limbo, where events in the post-crisis moment created circumstances of ongoing uncertainty. Implicitly, participants’ accounts demonstrated the implications that caregiving has on their own identity, mental health and the management of their own lives. The tool mapping of “reality vs. misconceptions” enabled carers to unpack in-depth and discuss the social perceptions around what it means to be a carer, as well as the highly personal and subjective experience of caring, all of which provided deep insight.

Involving users at every stage of the development of digital tools, concept and prototype testing is essential if health technologies are to meet their needs, with this paper documenting some specific co-design activities and outcomes to help inform the development of health technologies with carers in mind. Carers are active and agentic participants in the caring process, which involves both their own wellbeing and the management of care they provide. They felt an app could help significantly improve the quality of life for the person they were caring for (for example, enabling communication about care preferences and also serving as a memory aid regarding recent activities), but could also assist them in their caregiving role (for example, by enabling them to track and communicate changes in a specific health condition, and share information across a care team).

The arts-based methods provided novel, immersive and memorable insight into the lived experience of being a carer, functioning in an almost therapeutic manner in validating the challenging experience of being a carer. Critically, the graphic storytelling and humour offered by cartoons and drawings can be seen as “both opinion-molding and opinion-reflecting” (Caswell 2004, p. 14), with these compelling visuals in these images reflecting, changing, and challenging the dominant discourse. Whether it is the evocative sketch of the memory of a loved one in a chair, the carers load—carrying everything on their back, the bed being transformed into a medical site or cartoons depicting the care rollercoaster, these images—drawings and cartoons, created by creative professionals—uniquely and memorably capture emotion to share experience and dispel stereotypes.

The photographs, both professional and photo-elicitation, provide further visual insight into the experience of caring and grieving, highlighting the importance of the design of the built environment (both home and the broader community) in facilitating access to support services and overall quality of life (see also Miller 2021). Leavy (2020) has noted that participatory arts-based research raises the question of aesthetics; the art made by amateurs, potentially without artistic ability or training, does not have the aesthetic impact of that made by professionals—although it often powerfully conveys experience and emotion. We can see that in the artistic quality and composition of the photographs taken by the documentary photographer compared to those taken by the participants; thus, while it is rare to have both participant-generated and professional photographs in the one research project, this study has shown the strength of such an approach.

Significantly, this study is also among the first to create research poems on caregiving, bereavement, and grief (see also Gerber et al. 2022; Miller 2021). These research poems powerfully and memorably convey the visceral psychological and physical experience of caregiving and grieving, in a creative and viscerally emotive way that resonates. The special language that is poetry resonates, offering unique insight into the essence of the caregiving experience “). Whether it is Ell’s description of her husband decline and her frustrations, or the depth of Dianne’s grief, the condensing of raw emotion in research poetry brings to life the highs, lows, losses, and tolls of being an informal caregiver.

There are, of course, several study limitations. Although there is research showing that the composition of informal carers is overwhelmingly female, there are male caregivers whose information and communication needs were not captured within the co-design process reported on here, with a larger, more culturally diverse sample needed. Recruitment attracted only female participants, with the sample comprised of primarily older (50–70s), predominantly white Australian women residing in or near urban Brisbane.

5. Conclusions

In closing, we have described the methods of the visual co-design process in significant detail as it offers a unique way to capture the unique lived experience of being a carer. Critically, the clock activity added a temporal layer, while the selection and sharing of visual metaphors prompted deep reflection and discussion about both the experience of being a carer and the potential of an app to help. Visual and co-design methods remain relatively rare in social science research, with this paper purposely documenting the method in detail to inspire other researchers to experiment with this approach. The outcomes of this project open critical questions about how carers' voices might be integrated into and inform conceptualisations of support infrastructure for carers. The work of care coordination, communication and record keeping, alongside the ability to mobilize appropriate people and resources, are supported by technology. This project, reporting on the tools, processes and learnings involved in the first step of the co-design, contributes to the growing body of co-design literature and highlights the potential utility of an app to improve the care experience—for both caregivers and care-receivers.

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Data Availability Statement: More findings, data, videos and exhibition information is publicly accessible from the project website: <https://ourcarejourney.wordpress> (accessed on use 22 June 2022).

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Notes

- ^{1.} See details on the project and exhibition here: <https://ourcarejourney.wordpress.com> (accessed on use 22 June 2022).
- ^{2.} Unfortunately, commercial reasons means the app is currently not on the market.

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