

Article

Strategies Addressing the Challenges of the COVID-19 Pandemic in Long-Term, Palliative and Hospice Care: A Qualitative Study on the Perspectives of Patients' Family Members

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Abstract: Patients in long-term, palliative, and hospice care are at increased risk of a severe course of COVID-19. For purposes of infection control, different strategies have been implemented by the respective health care facilities, also comprising visitation and other forms of contact restrictions. The aim of the present study was to examine how these strategies are perceived by family members of patients in these settings. An exploratory, qualitative approach was used to examine perceptions of policies and strategies using partially standardized guided interviews analyzed by means of a thematic approach. Interviews were conducted with 10 family members of long-term, palliative, and hospice care patients. Interviewees were between 30 and 75 years old. Because of the pandemic-related measures, respondents felt that their basic rights were restricted. Results indicate that perceptions of strategies and interventions in long-term, palliative, and hospice care facilities are particularly influenced by the opportunity to visit and the number of visitors allowed. Strict bans on visits, particularly during end-of-life care, are associated with a strong emotional burden for patients and family members alike. Aside from sufficient opportunities for visits, virtual communication technologies need to be utilized to facilitate communication between patients, families, and caregivers.

Keywords: palliative; hospice; end-of-life; COVID-19; SARS-CoV-2



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1. Introduction

During the COVID-19 pandemic, long-term, palliative, and hospice care facilities have faced numerous challenges [1]. Patients in these health care settings are at an increased risk for a severe course of COVID-19 because of existing co-morbidity and often advanced age [2]. To address the pandemic, different infection control measures were implemented by facilities, including visitation bans and other forms of contact restrictions [3–6].

Visits by family and friends are critical emotional anchors for patients, particularly for those in palliative care. Visitation bans implemented as infection control measures may lead to loneliness and increase the emotional burden for both patients and their loved ones [1,7]. In light of visitation bans, patients in in-patient facilities were encouraged to maintain contact with family members using digital communication services. Patients who are not tech-savvy, however, required assistance, which could often not be provided by staff because of limited personnel resources [1]. In some facilities, this led to patients being isolated and often dying without their relatives being present [8]. Despite exceptions to restrictions occasionally granted, for example for patients at the end of their life, the impact on dying patients was considerable [8]. Additionally, patients' relatives and friends were exposed to additional burden by being confronted with social distancing measures and visitation restrictions in already emotionally tense situations [9]. The grief processes during

the COVID-19 pandemic were, thus, compounded by the experience of physical distancing and isolation, as well as feelings of insecurity, anxiety, and frustration affecting their own mental and physical wellbeing [6,10].

With these issues in perspective, the aim of this paper is to examine how family members of patients perceive the strategies and measures that have been used by long-term, palliative, and hospice facilities to address the challenges of the COVID-19 pandemic. The findings provide insight into family members’ perspectives and allow to formulate recommendations with respect to how expectations of patients and their families can be better met during the pandemic and can assist health care providers to adapt existing strategies for current and future public health crises.

2. Materials and Methods

2.1. Study Design

In the present study, a qualitative research approach was used given that the subjective perspectives were the focus of analysis [11]. Data collection was conducted by means of partially standardized guided interviews [12]. The interview guide was developed jointly by all authors based on existing research in the field. It consisted of four categories and covered, among others, changes due to the COVID-19 pandemic in medical and nursing care, strategies developed for addressing challenges of the COVID-19 pandemic, support measures implemented for patients and relatives, and ethical and social aspects of the strategies developed. Relatives were recruited through the authors with assistance from staff in the health care facilities. In addition, study participants were recruited via open online groups using social media. Eligible participants were 18 years of age or older and relatives of patients who were in long-term care or palliative/hospice care during the COVID-19 pandemic. As a measure of precaution and to prevent any additional infection risks for participants, interviews were carried out via telephone. Interviews were conducted by one of the authors (I.Ö.E.), who has extensive experience in qualitative research. Interviews took place between October 2020 and March 2021 with 10 family members of palliative care patients aged 30–75 years. Interviewees included eight women and two men. Four of the individuals interviewed had a relative in hospice care, three had a relative in palliative care. The other three interviewees had relatives who were first in a palliative care unit and then in a hospice or were first in a hospital and were later transferred to a palliative care unit, a hospice, or home care. Interviewees were related to the palliative/hospice care patients by being daughters ($n = 5$), wives ($n = 3$), a husband ($n = 1$), or a son-in-law ($n = 1$). Interviews were conducted until a sufficient level of information saturation was reached. The duration of the interviews varied between 40 and 80 minutes. Table 1 provides an overview of the sociodemographic characteristics of the interviewees.

Table 1. Sociodemographic data of the study participants.

Interview ID.	Sex	Age (Years)	Marital Status	Relationship between Study Participant and Patient in Long-Term/Palliative/Hospice Care	Facility/Duration of Stay
IP01	female	75	married	wife/palliative care husband	Hospice
IP02	female	53	married	daughter/deceased mother	Hospital, rehab facility, and most recently home care
IP03	female	47	married	daughter/deceased mother	Palliative care unit
IP04	female	33	married	daughter/deceased mother	Palliative care unit
IP05	male	43	married	son-in-law/ deceased father-in-law	Nursing facility/ palliative care unit
IP06	female	46	single	daughter/deceased mother	Hospital, palliative care, hospice facility
IP07	female	30	married	daughter/deceased mother	Hospital, hospice facility
IP08	female	68	widowed	wife/deceased husband	Hospice
IP09	female	42	widowed	wife/deceased husband	Hospice
IP10	male	66	widowed	husband / deceased wife	Hospital, palliative care unit

2.2. Data Analysis

The interviews were transcribed by a research assistant, with verbatim transcription including pauses in the conversation and expressions such as speech disfluency (“ehm”, “hmm”), sobs, crying, etc. During transcription, the interviews were anonymized. The data analysis was based on thematic analysis, which enables a mixture of inductive and

deductive coding procedures [13]. The deductive category system was created with the help of the main topics of the interview guide and expanded during the analysis with inductive categories based on the data material. The coding was carried out by two authors (I.Ö.E. and L.P.) independently from each other; during the analysis, the codes were compiled and discussed among all authors. The analysis was assisted by the software MAXQDA [14].

2.3. Ethical Aspects

The study was approved by the ethics committee of Witten/Herdecke University (No. 153/2020; 31 August 2020). The study participants were informed about the study objectives and about the voluntary nature and confidentiality of the study and gave verbal and written informed consent to participate in the study before the interviews were conducted. In addition, consent was obtained for the recording and transcription of the interviews. Study participants did not receive any reimbursement for their participation in the study.

3. Results

The analysis allowed to identify central themes with regard to how family members of patients perceive measures and strategies developed by long-term, hospice, and palliative care facilities, and what they expect from health care during the time of the pandemic. Overall, four main themes could be identified. They are presented in the following.

3.1. Contact and Visitation Restrictions

A significant factor contributing to family members' perceptions of measures and strategies implemented to address the COVID-19 pandemic were existing contact and visitation restrictions, which increased feelings of stress and added to already existing burdens. Contact and visitation restrictions varied by the type of facility. In hospice and palliative care facilities, restrictions included the number of visitors or the length of time relatives were allowed to stay in the room, while respondents reported to have encountered full visitation bans in long-term nursing facilities. In some facilities, exceptions were allowed so that two or more family members could visit patients simultaneously. Overnight stays were mainly provided by hospices, where relatives had the possibility to use an armchair or bed in the palliative care patient's room. The respondents also encountered the aforementioned regulations in situation involving dying patients. Some relatives were not allowed to enter the room of the dying person together with fellow family members, but had to say their goodbye separately, thus lacking emotional support from each other. According to the respondents, no time limits were set for the farewell, but hygiene regulations had to be observed.

"[...] you had to keep to it [...] yes we were asked eh, that we keep to it actually only separately to her in the room to go in, we have of course also done" IP07

"[...] from the time of the pandemic everything was shut down, so it was allowed eh there were no more visits allowed ehm even since he had a first floor room, we were not even allowed to go into the garden of the facility and make contact with him through the window, absolute ban on visits [...]" IP05

"[...] they would have, so if it had only been one night, an armchair, which is not so comfortable for the duration, but they would also have pushed me a whole bed in [...]" IP06

3.2. Impact of the COVID-19 Pandemic and Infection Control Measures

Some respondents described that visitation bans caused the physical condition of their loved ones to deteriorate, contributing to an earlier death. Furthermore, some respondents had the impression that nursing care was neglected during the pandemic, resulting in conflicts with doctors and nursing staff. It became evident from the interviews that infection control measures contributed to emotional strain and stress among family members. In addition, it was stated that due to the restrictions on the number of visitors and on the duration of visits, some family members were unable to visit or say goodbye to their loved

ones. Conflicts arose in facilities because of lack of exceptions with respect to protective measures or lack of responsiveness and limited possibilities for communication with health care staff. Some nursing homes also reduced home visits by supervising primary care physicians and scaled back care to basic services further reinforcing relatives' impression about a diminishing quality of health care. However, some respondents also reported being satisfied with the medical and nursing care their loved ones received. They also indicated that care was taken to address the subjective needs of patients as best as possible.

As a result of visitation restrictions, most relatives adopted digital communication tools in order to stay in touch with patients. It was uniformly stated that smartphones, tablets, or laptops were not provided by the facilities but were purchased by relatives themselves. Patients who had problems using such digital communication tools relied on help from nursing staff, who often did not have the time to provide adequate assistance. Relatives had different experiences in communicating with caregivers. Most respondents were positive about communicating with caregivers, stating that they received a lot of support from caregivers, such as being listened to and being offered uplifting words or prayers. In addition, they noted that they could approach the staff at any time and that staff took the time to exchange with relatives. Other participants complained about a lack of proactive communication on the part of the nursing staff.

"Yes, the problem was that many people were not able to say goodbye or were not allowed to see them again during that time [. . .]." IP04

"And that has ultimately certainly contributed to his early death, because ehm when he had visitors, he ate and drank and ehm as I said, it was very very close contact with his daughters and that was then suddenly no longer possible" IP05

"Mhm yes, exactly so by phone was possible, we were also used to that before the pandemic but as I said the handling of the iPad that was, that was already difficult for him because ehm it was also not possible to find a caregiver who could take the time and together with him, to make the iPad ready for use [. . .]" IP05

"[. . .] via WhatsApp we have then communicated with each other, we have seen each other and that was wonderful, my husband is even, has even in his old days still learned ehm that just could start video and has seen me then and we could talk twice a day and that was wonderful" IP08

3.3. Perception of COVID-19 Strategies in Long-Term, Palliative, and Hospice Facilities

According to some of the interviewees, the COVID-19 pandemic containment strategies were not perceived as a burden. For interviewee IP07, the measures did not play a significant role as long as visitation was possible—irrespective of other protective measures implemented in the facility. In addition, some interviewees stated that they had the feeling that the pandemic "does not exist" in the facility, despite various measures taken by the facility.

Nevertheless, many perceived an overwhelming burden as a result of the pandemic-related protective measures. Providing contact information as a protective strategy to allow contact tracing was perceived as "annoying" because the risk of infection was not considered to be high. Furthermore, waiting outside the hospital in cold temperatures was perceived as an "outrageous" requirement. It became clear from the interviews that particularly visiting bans resulted in a strong emotional burden for relatives and patients. By limiting the number of visitors, relatives felt a lack of emotional support, which resulted in emotional distress.

Respondents uniformly indicated that they felt their basic rights had been restricted due to pandemic-related policies and strategies. Passing away was regarded to be a special situation requiring exceptions to all measures that restrict visits. Respondents who were confronted with a strict ban on visitation perceived it as a strong restriction of their basic rights as well as those of their loved ones.

"[. . .] that ehm yes, the visitor regulations were now limited to one person, maximum 2 on palliative care, I would say yes, it is already very restricted [. . .] unfortunately my

husband had to go out whereby I, where I would have needed him just in the moment, [...] that was where I had to be strong for my sister, although I myself would have needed someone [...]” IP04

”[...] So he was mentally very unwell and as I said his daughters were very very sad and depressed as well, that was a huge burden that was actually dominating everyday life [...]” IP05

”[...] Freedom to make decisions and to move freely and to do what you want, that is of course restricted [...] what we already felt as very restrictive was just that we were not allowed to visit them, I would have wished that differently [...]” IP07

”[...] she was segregated in a single room and that was a condition that I don’t wish to happen to anyone, that has shaped me so much [...] my wife and I were married for 42 years and eh that has affected me, still hits me hard today, that is a condition that is simply inhumane [...]” IP10

3.4. Need and Expectations for Better Support

To improve care in long-term, palliative, and hospice facilities, interviewees considered higher staffing levels to enable nurses to also take the time during care to provide support to relatives. It was often mentioned that dying is an exceptional situation in which visitors should be allowed access without restriction and also that the number of visitors should not be pre-determined by the facility. Relatives stated that they felt left alone. They said they required more support and preparation, for example by being told what to expect and what dying will look like. In addition, it was stated that psycho-oncological care and other palliative services for patients and their relatives should be maintained, especially in times of pandemics, as the emotional state of relatives and patients can change greatly as a result of the measures implemented.

Furthermore, continuous staff education and the development of appropriate pandemic plans were mentioned as recommendations for care in long-term, palliative, and hospice facilities. In addition to maintaining visits as well as ensuring support from staff, it was recommended that no palliative care units be closed, as support by medical and nursing staff during the dying phase is necessary, especially during the pandemic.

”Maybe a little more staff and a little more ... Encouragement and a little more comfort and a nice word [at times] ... a smile” IP01

”[...] I would have liked it just that everyone who wants, no matter how many people there are, as long as the patient wants it and does not explicitly say, [...] to allow to receive visitors, just when the person is simply dying, yes he feels alone otherwise. There are so many people who would like to see my mom [...] a better concept in this respect simply ehm I mean clearly there are hygiene concepts everywhere, but this does not have to be done by only one person per day, so I don’t understand why it has to be throttled down so much [...]” IP04

”So I think, seriously ill and dying, in the palliative situations I think patients must have unrestricted access to relatives [...] I think it needs a lot of knowledge and education, constant education, I also don’t think that this was the last pandemic we had to deal with and ehm that is actually reason enough to fundamentally think about how we want to deal with our seriously ill people and that ehm, I hope that we learn the lessons from this current pandemic that we are smarter next time and ehm do justice to it and and ehm make sure that people can be adequately cared for in every respect” IP05

4. Discussion

This study used a qualitative research approach to examine how strategies implemented in long-term, palliative, and hospice care facilities during the COVID-19 pandemic are perceived by family members of patients who receive palliative care. The findings show that perceptions of strategies are particularly influenced by the extent to which visitation

restrictions are in place. They highlight that strict bans on visits are associated with a strong emotional burden for patients and family members. These findings are in line with the results of a study from the US, in which social workers in hospice facilities were interviewed about the pandemic situation [15]. The study found that isolation is an additional challenge and emotional burden for both hospice patients and their families, especially when a ban on visitation is maintained even during the patients' dying phase [15]. In another study from the US, in which the relatives of palliative patients were interviewed, it was shown that visitation restrictions or bans, poor communication with staff, and inadequate quality of care resulted in despair among relatives and feelings of anxiety about the patient dying alone [16]. In a study from the United Kingdom, more than half of the relatives surveyed stated that they were not allowed to visit their loved ones during the dying phase. The study also revealed that relatives who were allowed to visit were more likely to feel supported than those without possibilities for visits [17]. In the present study, it was shown that by limiting the number of visitors, relatives lack emotional support during their loved ones' dying process, corroborating findings from previous research in Germany [18].

High-quality communication with nursing staff during the pandemic is characterized by two components: (1) easy access to staff to address concerns and questions about the patient's care and (2) involvement of family members in decision-making processes about nursing care [16]. Various studies have highlighted the increased relevance of adequate communication during pandemic periods when visits are no longer possible or limited as a result of infection control measures. Staff that is difficult to reach or inaccessible, as well as lack of information about the health status of patients and the impression that family members are kept out of decision-making processes, led to fear and uncertainty among relatives, as well as the perception of inadequate end-of-life care [16,19]. These findings are consistent with the results of the present study, given that in cases where interviewees perceived poor communication, they also criticized the quality of nursing care and support. Pre-pandemic studies show that both family members and patients consider communication to be essential in palliative care [20–24].

Visitation bans and restricted in-person communication require alternative communication tools to meet needs of patients and their relatives. Video or at least telephone calls make it possible for relatives to see or talk to patients when visits are not possible. Furthermore, video or phone calls allow relatives to receive assurance that their loved ones are well [25]. Limited access to virtual communication technologies or communication tools that are difficult to use without assistance can lead to family members' perception of inferior care and result in frustration about lack of support and poor exchange [16].

Respondents' needs and expectations with respect to better support during a pandemic included more comfort and encouragement from caregivers and the removal of visitation restrictions and bans. The death of a family member is seen as a special situation in which family members and friends consider it essential to say goodbye to the patient not only in person but together with fellow relatives. Saying goodbye together provides resources of mutual emotional support, which in many cases was not available during the pandemic. The reported needs of the relatives are in line with results from other studies and are also reflected in recommendations in national and international guidelines [3,6,17,26,27].

Some limitations of the present study need to be considered. Only two of the ten interviewees were men and most of the participants were over 40 years old, potentially not sufficiently covering the perspective of male relatives and younger individuals, respectively. Insights gained by the present study therefore need to be complemented by investigations that can provide a contrasting perspective between men and women. Additionally, the sample was not diverse in terms of culture, ethnicity, and migration status. Considering that individuals from collectivistic cultures may be more affected by contact restrictions than individuals from individualistic cultures, and thus, preexisting health disparities could be further exacerbated, future studies need to examine how well strategies are able to take into account diversity in the society.

5. Conclusions

Open communication is an important factor in long-term, palliative, and hospice care. Since face-to-face interaction between patients, families, and health care staff may be limited as a result of infection control measures, alternative communication methods need to be used [19]. Different guidelines exist aiming to assist health care facilities with implementation [3,28,29]. Visits by relatives play an important role, particularly in end-of-life care, for both patients as well relatives themselves and should, therefore, be facilitated during pandemics and balanced with measures of infection control [30]. In addition, the potential for virtual communication must be utilized. Representatives of patients and relatives must be involved in the development of appropriate support strategies in order to ensure that measures implemented consider patients' and relatives' needs as best as possible.

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