Palliative care culture in nursing homes: the relatives' perspective

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Abstract

Background: Nursing homes are confronted with a significant change in their client structure. Palliative care gains importance in caring for residents until the end of their life. Relatives play a crucial role in caring for older people in nursing homes, especially in palliative care. As the perspective of relatives on palliative care culture in nursing homes has not yet been studied extensively, research in this field still has an exploratory character.

Aim: The aim of the paper is to highlight some of the most important insights into themes and issues that relatives of persons having died in a nursing home find essential, with a view to fostering a well-established palliative care culture.

Methods: Within a qualitative approach, four focus group interviews were conducted.

Findings: Findings indicate that good communication is a core element of a well-established palliative care culture. Direct contact with relatives, talking about death and dying and the opportunity to be involved in decision-making all support a good palliative care culture. The fact that residents have a diverse range of social backgrounds, for example, regarding ethnicity, gender and living with dementia, influences palliative care in nursing homes and has to be taken into account.

Conclusions: To create a good palliative care culture, management has to support this approach, continuously develop appropriate structures and act in a competent way.

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Introduction

With an increasing ageing population across Europe, the importance of care provision for older people is widely recognised (e.g. Froggatt and Heimerl, 2008; Gott and Ingleton, 2011; Hall et al., 2011). A high percentage of caregiving is still performed by relatives in informal care settings, with older people staying at home as long as possible. Nursing homes are therefore challenged by an increasingly dependent clientele. Dementia, higher incidence of multimorbidity, chronic illness and frailty characterise older people's multiple complex health conditions. As a consequence, nursing homes are confronted with both a greater diversity of and an overall increase in the care needs of their residents (Brazil et al., 2017; Heller et al., 2007; Hockley and Froggatt, 2006; Kojer and Schmidl, 2011). At the same time, expectations and financial pressures on high quality care in nursing homes are increasing.

There have been initiatives to develop palliative care practice in nursing homes in countries across Europe and also in German speaking countries for over 15 years now. These have included education, service developments, clinical interventions, organisational development and political frameworks (Froggatt and Reitinger, 2013; Froggatt et al., 2012; Hall et al., 2011; Heimerl, 2008; Hockley and Kinley, 2016; Hockley et al., 2005; Parker and Hughes, 2010; Van den Block et al., 2015). Current nursing home research at a European level has developed a typology of the implementation of various palliative care initiatives in nursing homes, and an intervention study to develop high quality palliative and end-of-life care in nursing homes across six different countries (Froggatt et al., 2017; Van den Block et al., 2016).

What has not been addressed sufficiently is the perspective of relatives in relation to palliative care in nursing homes. Although relatives are acknowledged as relevant partners alongside being receivers of support in palliative care contexts, only a few research projects have been undertaken that focus on their perspective. Less than 50% of people rate the overall quality of end-of-life care in institutions as 'excellent' (Teno et al., 2004). Communication with families about end-of-life care is felt to be essential (Johnson and Bott, 2016) and family members experience a need to advocate for their dying relatives (Shield et al., 2010). Core aspects of relatives' perception presented in this paper have been explored with the concept of a palliative care culture: collective values, beliefs and principles of organisational members with respect to delivering palliative care in nursing homes that encompass patterns of behaviour in relation to communication, but also structural aspects, such as management and decision-making, are coming into sight (Bruera, 2004; Heimerl, 2008; Schein, 1992).

Aims and questions

As research into the perspective of relatives and a palliative care culture in nursing homes is still exploratory, the aim of this paper is to highlight some of the most important insights into themes and issues that relatives of persons having died in a

nursing home find essential when considering a well-established palliative care culture. The research question was:

What are relevant themes and issues concerning a palliative care culture in nursing homes from the relatives' perspective?

Methodology

Approach and design

A qualitative approach was chosen. This paper presents part of a larger project in which recommendations for sustainable integration of palliative care in nursing homes were formulated (Schuchter et al., 2015; Hockley et al., 2013).

In this paper we present findings from collaboration in four nursing homes in Germany. In nursing homes in Germany in which 24 hour care is provided, residents and their relatives have to contribute financially for living there. Theoretical sampling of the nursing homes included different sizes and locations of homes across three cities in Germany, as well as different providers working on diverse legal and structural formations and having different organisational cultures. For the purpose of the research, we chose nursing homes that already had experience in providing palliative care. Conducting research in nursing homes where a palliative care culture has grown over years enhanced the chance of innovative findings, especially concerning the relatives' perspective.

Sample and data collection

Four focus group interviews (see Table 1) in four nursing homes from three providers of welfare institutions were conducted (Flick, 2010; Fosse et al., 2017; Pastrana et al., 2010). Relatives received invitations from the managers (as 'door openers') of each nursing home. A total of 17 relatives (10 women and 7 men) participated in the focus groups.

The focus group interviews were facilitated, documented and recorded by two researchers. All focus group interviews took place in the respective nursing homes. After each focus group meeting, the researchers wrote brief notes of the main issues discussed that captured the intuitive character and insights of the focus groups. In each nursing home a

Table 1. Participants of focus groups.

Focus group	Women	Men	All
FG1	2	2	**4**
FG2	3	2	**5**
FG3	2	3	**5**
FG4	3	0	**3**
Total	**10**	**7**	**17**

Bold numbers (horizontal) show total numbers of female and male participants and bold numbers (vertical) of participants in each focus group (FG1-FG4).

feedback interview with management was organised based on these notes. Conducting feedback interviews with managers allowed researchers to identify additional aspects of the issues discussed during the focus group interviews. These feedback interviews with the managers were then written up (memos). During the whole time, researchers also took field notes. In summary, our data consisted of:

(a) recorded and transcribed focus group interviews;
(b) field notes; and
(c) memos from feedback interviews with management.

Research ethics

The process of considering ethical standards for research was based on the 'Helsinki declaration' (World Medical Association (WMA), 2013). Prior to undertaking the research, the research team gave thorough consideration to the risks and burdens of the project. The strongest risk was seen in the fact that talking about death and dying with bereaved relatives could possibly increase emotional stress (Toyama and Honda, 2016). We therefore decided to give participants enough time after each focus group to express and integrate adverse feelings where necessary. Although confronted with overwhelming situations, they were not considered to be vulnerable according to the precise understanding of the term in the context of health research standards (Pleschberger et al., 2011). The study was undertaken with the informed consent of each participant according to the principles of voluntary participation. All participants had the option to withdraw consent during/after the focus group. In order to obtain informed consent, detailed information about the project was given to each participant. All names quoted in the results have been changed and are either anonymous or pseudonymous so as to ensure privacy and confidentiality (Beauchamp and Childress, 2009; Zomorodi and Foley, 2009; Burns, 2007).

Interview guide

Our interview guide consisted of two opening questions to generate narratives of experiences related to death and dying in the nursing home. Initial questions were for example, 'You have experienced a family member dying in the nursing home. How was this situation dealt with?' or 'How does the nursing home deal with death, dying and bereavement?' We emphasised phrases like 'in the home', 'the organisation' and 'the nursing home' to focus attention on the palliative care culture of the nursing home.

Throughout the focus group consultation, questions relating to a deeper level of inquiry were asked. These questions were based on a consensus paper elaborated by the German 'National Hospice Working Group' (DHP and DGP, 2012) for measuring and assessing the quality of palliative care in nursing homes. This ensured that relatives' perceptions could be linked with the main categories ('indicators') of palliative care culture as defined by the (national) consensus of experts in this field, and included, for example, potential questions concerning inter-professional collaboration or the responsibilities of the management with regard to palliative care culture.

Altogether, a good balance between personal involvement and a view on more general issues concerning the organisation was achieved in our focus group interviews.

Data analysis

Data analysis followed a three-step process – rather similar to the approach for researching lived experience as developed by Lindseth and Norberg (2004). These steps included first, reading the interview transcripts and deriving an holistic representation of themes complemented by field notes and memos from feedback interviews with managers; second, the performance of sequential analysis of transcribed focus group dialogues implying a deconstruction and enrichment of the first step; and finally, the reconstruction of an integrative picture of the findings as presented in this paper.

The sequential analysis was achieved using a coding process, including investigator triangulation. The coding process comprised (a) reading, (b) highlighting relevant passages and (c) assigning codes. A first reduction to code families was done individually. Second, in two data analysis workshops, interdisciplinary perspectives were exchanged, emerging key themes were retained and a map of coherent themes was developed.

Our research focuses on the lived experiences of bereaved relatives through an analysis of the focus group interviews. Data from other sources (field notes and memos from feedback interviews with managers) allowed us to broaden the perspectives and to contextualise statements from relatives (data triangulation; Denzin, 2006).

Findings

The full range of narratives describes what bereaved relatives felt a well-developed palliative care culture should look like. It is summarised under three thematic headings, including 'communication', 'diversity' and 'palliative care culture of the management', with different issues composing each theme.

Communication

Communication between relatives and members of staff. Communication between relatives and members of staff was a decisive factor that highlighted a well-developed palliative care culture. Communication in this context reflects the complex relationship between relatives and staff as well as the complex social role of being a relative of a resident in a nursing home. A rich palliative care culture seemed to integrate potentially conflicting needs of relatives wishing to 'be seen' as bereaved persons and, at the same time, wanting to be involved as co-carers.

Relatives felt that small gestures of staff conveyed the impression of 'being seen' – in their grief, with all their concerns and sorrows as family members:

> Someone looked at you (…) and this is a good feeling (…) there are not many words, there is just this glance, when someone really looks at you and does not look down upon you or so (…). (FG1, 1049–1063)

According to the relatives, these small gestures, for example a few words or a cup of coffee, create a feeling of being appreciated. One relative even suggested that a culture of such small gestures could replace formal bereavement services:

> What really helped me when I arrived – my mother already had faded away – was that a nurse approached me in the ward and hugged me. That helped me a lot – it was really kind of her. (FG2, 716–719)

Furthermore, relatives felt they were 'being seen' when staff members informed them by telephone not only when there was a problem, but also when 'something positive occurred'. A relative told us that she really felt respected when a nurse from the home had called her to tell her that her mother had managed to go to the garden and the nurse wanted to inform the relatives so they could share this moment of happiness. Finally, relatives felt that they were 'being seen' when bad news was communicated in a sensitive manner.

Another important aspect of a good palliative care culture is involvement of relatives in decision-making. This involvement showed *respect for relatives as co-carers* and even as experts regarding the needs of their mother or father. Relatives noted a higher quality of care when their opinions were heard. Again, the relevance of a telephone call was emphasised as a key aspect of contact:

> Then a call comes from the nursing home, 'Your mother – what shall we do?' We collaborate of course . . . (FG3, 1127–1128)

Nevertheless, the role of a relative as a person in need (to be cared for) and the role as a co-carer (caring with) merge in certain situations. When relatives described the care for the deceased person, it seemed that the difference between being the bereaved and being a carer was transcended from both sides; that is, by relatives as well as by the nursing staff. Relatives reported how much it meant to them being informed about what had happened when their mother or father died and being given the opportunity to care for the deceased person, to wash and to dress him or her, together with a nurse.

> If my mother shows any signs of leaving then I would be called. And when my mother dies she will be washed and I would be able to be there and help with washing and dressing her and other residents will be able to say goodbye. I really appreciate this a lot. (FG1, 608–615)

On the other hand, relatives were aware of the emotional burden for staff members when residents die. Relatives clearly perceived how staff had to cope with a high number of people dying in the nursing home. From the perspective of the relatives, professional carers are affected by grief and bereavement.

Talking about. . . . Traditionally, the opportunity for residents and relatives to talk about death and dying is considered an important aspect of palliative care culture in care institutions. This can be confirmed from data in our sample, as our interview partners addressed this issue on many occasions. The statements of relatives revolve around the questions *when*, *with whom* and *how* end-of-life issues should be raised.

Relatives raised the question of *when* to consider talking about dying. They told us that it was often staff at the nursing home who initiated the conversations about death and dying.

> We really feel that we are in good hands here in the nursing home. We had a conversation about what will happen when my mother dies, and about my wishes and those of my sister. We hadn't talked about this before but we thought this was very good; very, very good, because it opened up things for us and we were able to make some preparations for my mother when she dies and what will happen after her death and we found this very good. After all, you brush those themes away. (FG1, 44–52)

Sometimes residents and relatives had reflected upon their wishes concerning end-of-life care prior to moving to the nursing home and already had their choices set out in advance directives. Nevertheless, our interview partners stated that it was a mistake to reduce communication about dying to the question of whether there was an advance directive or not.

In summary, with or without previous thoughts on death and dying, with or without advance directives, relatives perceived it as a sign of a good palliative care culture when members of the nursing home facilitated a dialogue on end-of-life care issues. In their perspective nursing homes need to provide time and space to talk about death, bereavement, last wishes and choices to be respected. One interview partner suggested that talking about death should be avoided during the vulnerable process of moving into the nursing home and should rather be addressed later and in a sensitive and stepwise manner.

Concerning the question of *with whom* to talk about death and dying, likewise, different experiences were reported. Relatives reported positive as well as negative experiences.

> I don't tell my friends about my mother's situation. When they ask, I just say 'good, thank you'. These women are 90 or 91, and are in care stage 3 – what shall I tell my friends? In five or ten years may be we will also be in this phase. (FG 4, 875–879)
> It's a taboo, it's not cool, there are more beautiful things in the world (...) (FG4, 937–940)

Finally, concerning the question of *how* to talk about death and dying, our interviews revealed a certain order of relatives' thoughts. Both the narrations of the relatives and the process of the focus group interviews followed the same order: the attempt to talk about death and dying often started with the inability to articulate thoughts, followed by the discussion of practical solutions. It then continued with the sharing of existential issues such as grief, suffering, happiness or experiences of 'beautiful moments' and ended with reflecting ethical issues such as euthanasia.

Communication about the nursing home and its image. Our focus group participants not only reported about experiences *in* the nursing home, they also reported their experience *of* the nursing home – as a whole and as an institution in society. This experience was coined by the difference between 'inside' and 'outside' the nursing home, which raises questions about the image of nursing homes and elderly care in society in general.

For all our participants, the transition to the nursing home was a crucial event in the process of caring. Between 'before' and 'after' the transition to a nursing home, relatives experienced a learning process and developed a new perspective about care in nursing homes, not least because of the presence of an active palliative care culture. The initial contact with the nursing home had been a shock for some of them:

> Throughout the final years, my mother didn't recognise me, and was just lifeless in her bed, I was never in this room, (...) and for me this corridor, to be honest, represented horror. (FG2, 177–181)

But he also continued in the same sentence to say that, when he had established relationships with many residents, the initial impression faded and moments of life and connectedness appeared:

> ... because I just went in and – all the rooms were open, it was summer – I knew the people by their names and some of them knew me already and wanted to talk to me. (FG2, 181–185)

In many stories, relatives reported similar 'beautiful moments' in the midst of suffering: the 'waking-up' of people with dementia when 'someone really takes care', or the farewell for a deceased resident, being 'sad but beautiful'.

Such key experiences allowed relatives to move on: they started with negative perceptions of nursing homes and later developed the view that nursing homes are just new 'homes', even

like 'big families'. As a result, relatives criticised the negative image of elderly care and nursing homes in society.

Diversity

A palliative care culture in nursing homes is linked to the diversity of people at the end of their life. Relatives describe the relevance of social categories such as 'intercultural dialogue', 'living with dementia' and 'gender' within a palliative care culture.

Intercultural dialogue. Due to the changing population structure, intercultural dialogue has also gained in importance in elderly care and in care for the dying in nursing homes.

> It's good to know about the culture of the dying person, if he was religious or not. Dying persons with an immigrant background have different rituals and things that should be paid attention to and relatives play an important role, to accompany them. (FG3, 111–121)

As this quote shows, intercultural dialogue is mostly associated with differences in religion and in family values. For constructive dialogue, it seems essential to know at least a little bit of the language of the persons involved:

> Well, I would say one has to know the most commonly used phrases of different languages. That means at least a dictionary, Russian, Turkish, Spanish, (…). (FG3, 925–932)

In one of the nursing homes, intercultural aspects are officially incorporated into organisational guidelines. The somewhat dispiriting conclusion on intercultural life was that:

> Well (…) similarly to real life, it is a kind of separation. (…) although all that can be done is done within the house (…) but really, the idea that one can say (…) we love each other and everything is just fine, well I can't see it in society nor in the nursing home. (FG3, 936–952)

Relatives appreciate all the culture-specific offers that are made by management and staff of the nursing home, for example religious celebrations. At the same time, they note barriers of communication and a tendency of friendly coexistence between residents of different cultural backgrounds.

Dementia. A high percentage of people living in nursing homes are living and dying with dementia. Therefore talking about palliative care culture with relatives includes questions of caring for people with dementia at the end of their life. An important insight was that communication on an emotional level helps to maintain contact until the end of life even when direct reactions cannot be observed.

> My mother didn't recognise me in the last year of her life, we just had eye-contact (…) communication in our sense was not possible anymore. (FG 2, 122–126)

> I think that people perceive emotions despite dementia … (FG2, 381–382)

A relative reported that her mother, who suffered from dementia, noticed that her husband had passed away:

> Yes, she realised somehow that he was no longer there anymore. We told her, of course, that dad had died but she couldn't react with words. (FG3, 341–343)

This sensitivity towards people with dementia shows the importance of helping them to be involved with the death as so often just speaking about the death is not retained in their memories.

Gender. The social category of gender remains meaningful in the lives of older women and men; it can influence wellbeing in care situations dramatically.

> My mother refuses to be cared for by a male nurse. It was a pity but she was the same at home, where she refused to be approached by a male nurse. (FG4, 1286–1288)
> Well, my experience with my aunt is similar; she says it is inappropriate for her. 'That I have to be washed by a male person at my age of 85' (…) she really feels uncomfortable in such a situation. (FG1, 856–864)

These examples show the importance of gender-sensitive care, especially in situations that are linked to embarrassing experiences such as washing. Other situations highlight the fact that male residents are underrepresented in nursing homes and need adequate responsiveness.

Palliative care culture of the management

Leadership. Relatives observed and reported the important role of leadership and management for a good palliative care culture.

> Even if you need other things than care, when you go to the administration you always find someone who helps and supports your concern. (FG 2, 692–694)

Relatives whose beloved ones have just died are very vulnerable, and it is essential that management also have palliative care competencies.

> And then a representative of the administration offered his sympathy to me and at the same time said 'I have to point you to the fact' literally 'that the contract ends with the day of death'. (…) You have to imagine, my husband just faded away five hours ago and then someone confronts you with that. (FG4, 449–454)

This shows the relevance of empathy and thoughtfulness of management in accompanying relatives after death. It also highlights the enormous economic pressure of management in nursing homes as a daily area of conflict.

As researchers, we observed two types of management philosophies in the nursing homes; these involved where management situated their offices, and the effect on communication and time spent with relatives. In one nursing home the administration and management rooms were situated in a separate wing, behind closed doors. Residents needed an appointment to talk to management, resulting in high barriers to communication. In the other nursing home the management had an office right beside the dining hall with its doors wide open, and staff had lunch together with residents. Residents simply walked into the office when they needed something.

Structural and financial aspects. The high pressure experienced in the everyday work of staff in nursing homes seemed to be a source of concern for relatives. On the one hand they acknowledged the enormous engagement of certain care individuals, while on the other they were critical of the low resident:staff ratio.

Well, you notice it as soon as you enter the nursing home and see, oops, they have 20, 30, 40 persons in need and only two or three care persons in charge round the clock. (FG2, 1307–1309)

I'd wish for more staff, more time (...) (FG2, 1769)

Increasing office work and bureaucracy causes additional time pressure and accounts for time missing in direct care work. High fluctuation of personnel and excessive demands in terms of workload are the consequences.

Costs of care impose great demands on relatives in Germany. By law relatives are obliged to contribute to the costs of care.

Well I think the costs of care are enormous, it's overwhelming. (FG2, 1395–1396)

My mother receives care level 3, but who can afford this? I had to apply for social welfare for her and I have to pay from my small pension towards her care, but the rest is taken on by the social security office. (FG1, 416–419)

These financial aspects reflect the devalued and marginalised position of care work in our society. Palliative care culture is directly impacted and suffers from the lack of infrastructure.

Discussion and conclusion

The presentation of the findings shows that, although the sample is small, which has to be acknowledged as a limitation of the study, important insights can be discussed further. The conditions required to improve the palliative care culture in nursing homes, based on the relatives' perspectives in our results, focus on two important issues. First, nursing homes need to create communication structures that enable relatives' participation in care processes and decision-making. Such communication structures also help to deal with diversity (e.g. Hanssen and Pedersen, 2013), to handle conflicts of care (Reitinger and Heimerl, 2014; Tronto, 2010), to discuss role expectations with relatives in the care process, for example within family care conferences (Durepos et al., 2017; O'Shea, 2014), and to strengthen patient-centred care at the end of life (Brazil et al., 2012). This is an important indicator of a dignified culture of dying within organisations. It represents a key element of organisational development and collective learning (Schuchter and Heller, 2018). This insight is also supported by the arguments of McCormack and McCance (2017) in the context of person-centred practice in nursing and health care. They show the importance of relationships and changes of culture of care in the workplace as a requirement for compassionate, dignified and personalised care. In some ways, this also correlates with the characterisation of a 'caring institution' by the political philosopher and care ethicist Joan Tronto (2010: 169):

The chances are good that the best forms of institutional care will be those which are highly deliberate and explicit about how to best meet the needs of the people who they serve. This requirement in turn requires that such institutions must build in adequate and well conceived space within which to resolve such conflict, within the organization, among the institutional workers and their clients, and more broadly as the institution interacts in a complex world in order to resolve such conflicts.

Second, Joan Tronto's quote also links to our next important point: nursing homes as institutions cannot be understood as isolated care settings. They interact in a complex world and they represent an important factor in the local care network and community. Furthermore, caring situations in nursing homes are mostly embedded in a broad web of everyday (care) relationships and interactions in the community. Improving palliative care culture in nursing homes also requires the awareness of nursing home management to create networks between organisations and to build bridges into the community which relatives and other community members come across in everyday life. On this issue, our findings confirm insights from comparable research on the relatives' perception of care in nursing homes. 'Familiarity' (with the local nursing home) has been identified as a key factor influencing family carers' experience of the nursing home placement of an older relative and thus as an important element of the social capital of the community (Ryan and McKenna, 2013). Former family caregivers wish to 'remain connected despite separation' and to be 'recognised as partners in care' after relinquishing the care of a person with dementia to a nursing home (Johansson et al., 2014) and not as mere 'visitors' (Crawford et al., 2015; Holmgren et al., 2013).

According to Allan Kellehear (2005), compassionate end-of-life care in the community acknowledges that end-of-life care is everyone's responsibility. Dying, death and loss should not be delegated to nursing homes, hospitals and hospices, nor should the responsibility be pushed back into the private sphere (primarily involving women carers). The challenge for the future is to create new forms of care relationships and solidarity in the 'third social space' (Dörner, 2007) – between private households and institutionally provided care in the community. Nursing homes can make a major contribution by expanding their self-image as important hubs and actors in local care networks. Strengthening compassionate communities could be a core mission of nursing homes (Wegleitner et al., 2016). Frail and vulnerable people at the end of their lives deserve to live in respectful communities and be looked after by dignified organisations – and their relatives deserve it too.

Key points for policy, practice and/or research

- A good palliative care culture needs adequate financial and personal resources.
- Leadership philosophy and management have to integrate and support palliative care within the nursing home.
- Communication structures and processes have to support direct contact with relatives, involve them in decision-making and offer space for talking about death and dying.
- The diversity of needs of residents must be acknowledged until the end of life.
- Palliative care culture in nursing homes can contribute to compassionate end-of-life care in the community.

Declaration of conflicting interests

Ethics Statement

The participants of the study were experienced lay-carers. As they don't belong to the group of vulnerable persons according to the precise understanding of the term in the context of health research standards, ethical permission by an ethics committee has not been necessary.

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