

ARTICLE

An exploration of the views of staff on cultural aspects of end-of-life care in Japanese long-term care facilities: a qualitative study

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Abstract

Long-term care facilities are increasingly important places for palliative and end-of-life care provision in Japan. While the importance of culture has been noted for palliative and end-of-life care, an exploration of its influence on care provision in long-term care settings has received little direct attention in Japan. Exploring staff views and beliefs in palliative and end-of-life care in these settings can potentially enhance our understanding of culturally oriented care and facilitate the development of tailored and more effective support practices. This study aimed to explore the cultural views and beliefs regarding palliative and end-of-life care among the staff in Japanese long-term care facilities. A qualitative exploratory study was conducted using focus groups with facility staff (N = 71) and semi-structured interviews with facility managers (N = 10) in the Kanto region of Japan. Thematic analysis was conducted according to Braun and Clarke's approach. The findings are presented in five key themes: 'Changes in society's and family's end-of-life perspectives', 'Values and beliefs regarding death and dying', 'Anxiety and regret', 'Tensions in doing the right thing' and 'Ways of alleviating pressure'. The findings indicate that the provision of palliative and end-of-life care is underpinned by cultural nuances that influence care providers' approach and delivery. Recognising and understanding the cultural beliefs of staff around death, dying and end-of-life care are important in meeting the needs of residents. Palliative care education for staff in these settings should include cultural considerations that reflect changing societal views on death and dying.

Keywords: palliative care; residential facilities; long-term care; culture; Japan; qualitative research

Introduction

Japan has been identified as one of the world's rapidly ageing countries. This, combined with a shift in care responsibilities, has led to an increase in the use

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and importance of long-term care facilities (World Health Organization, 2015). A long-term care facility has been defined as a collective institutional setting that provides care for older people over a 24-hour period, seven days a week for an undefined period, and provides on-site personal assistance with activities of daily living, and nursing and medical care (Froggatt and Reitingger, 2013).

The proportion of people who need palliative and end-of-life care in these settings is increasing (Tolson *et al.*, 2013). Recent figures from 2020 in Japan indicated that 11 per cent of deaths occurred in long-term care facilities, while 70 per cent took place in hospitals and 16 per cent took place at home (Statistic Bureau, 2021). Although the proportion of deaths in long-term care facilities in Japan is relatively low when compared to European countries, such as Norway (44%), the Netherlands and Switzerland (34%), Iceland (31%) (Broad *et al.*, 2013) and England (21.8%) (Public Health England, 2018), it is important to note that this figure has doubled in the last 10 years (Statistics Bureau, 2021). Although medicalised hospital deaths were common in the last half of the 20th century, a more natural course of death has gradually become accepted among the Japanese people (Long, 2004; Shimada *et al.*, 2016). In addition, since 2006, the Japanese government has incentivised end-of-life care provision in long-term care facilities (Ministry of Health, Labour and Welfare, 2018a). This incentive provides a bonus payment for facilities that meet several government requirements in relation to staffing levels, 24-hour access to nursing/medical care, in-house end-of-life care guidelines and staff education on end-of-life care (Ministry of Health, Labour and Welfare, 2018a, 2018b). This incentivisation programme resulted in a decrease in hospital deaths by 8.7 per cent between 2007 and 2014, as well as an increase in deaths in long-term care facilities (Sato *et al.*, 2021). Therefore, the provision of quality palliative and end-of-life care in long-term care facilities is becoming an increasingly important issue.

Similar challenges to those reported in other countries have been noted in Japan (Kawakami *et al.*, 2019). These include residents' experience of unmet care, poor pain assessment and management, and access to palliative care medicine (Achterberg *et al.*, 2010; Takai *et al.*, 2010; Lukas *et al.*, 2015; Kutschar *et al.*, 2020). Most staff working in these settings are care workers (who may be nationally certified), workers who have received vocational training, or those with no prior education and training. Although care workers are expected to work under professional supervision, evidence suggests that this does not always happen, leading to stress, particularly when caring for dying residents (Karacsony *et al.*, 2015; Anstey *et al.*, 2016; Young *et al.*, 2017). Suboptimal educational opportunities for staff regarding palliative care have also been reported (Smets *et al.*, 2018). Evidence suggests that, without formal education and training, the staff rely on their cultural way of viewing palliative and end-of-life care as their single reality (Cain *et al.*, 2018).

Culture is defined as a

dynamic, adaptive, ecologically based multilevel and multidimensional system for a population that creates a social structure, which provides its members with a set of beliefs, expectations, and tangible means to achieve a sense of safety, identity, and meaning of and for life. (Cain *et al.*, 2018: 1410)

Culture influences care preferences, communication patterns, meaning of suffering and decision-making processes in palliative care (Kagawa-Singer *et al.*, 2014; Cain *et al.*, 2018). Research suggests that the culture-bound views of health-care professionals and society can impede palliative care provision (Cable-Williams and Wilson, 2017). Many cultures have their own distinct cultural beliefs (Lunn, 2003), and a lack of understanding of cultural beliefs has been found to damage care relationships (Givler *et al.*, 2020).

Japanese beliefs regarding death differ from those in Western societies. For example, although most Japanese people do not follow a specific religion, Buddhism, Confucianism and Shintoism have contributed to their beliefs about their continued existence after death as an ancestor, Buddha, or spirit (Long, 2004; Oshita, 2007). Therefore, how and in what condition one dies is believed to influence one's next life (Kanayama, 2017). Although views and opinions about what constitutes good end-of-life care have identified some similarities between Western society and Japan, approaches and priorities towards achieving a good death vary between different cultures (Nishimura *et al.*, 2020).

Globally, many studies conducted in long-term care facilities have focused on the effectiveness of palliative care interventions for improving staff knowledge and staff and family satisfaction (Ogawara *et al.*, 2016; Iida *et al.*, 2021). The importance of understanding patients' and families' beliefs regarding pain has been highlighted (Martin and Barkley, 2016; Giezendanner *et al.*, 2017), in addition to the influence of culture on palliative care provision in long-term care facilities (Cable-Williams and Wilson, 2017). However, despite the importance of culture in palliative care provision, there remains a dearth of research on this topic (Selman *et al.*, 2014; Speck, 2016; Cain *et al.*, 2018; Willemsen *et al.*, 2021). Few studies have explored the cultural aspects of palliative and end-of-life care provision in Japanese long-term care facilities. Exploring long-term care facility staff's views on palliative and end-of-life care can enhance our understanding of how culture can influence practitioners' perceptions and care provision, while also adding to the evidence base on this topic.

Method

The aim of this study is to explore the cultural views and beliefs of staff regarding palliative and end-of-life care in Japanese long-term care facilities.

Design

Because of the potentially sensitive nature of the study and focus on an in-depth exploration of Japanese culture in relation to palliative and end-of-life care, a qualitative approach was deemed the most appropriate for data collection. Facility staff members' views on palliative and end-of-life care were explored using focus groups, while the views and opinions of facility managers were elicited via semi-structured interviews. Focus groups were chosen because they are considered an effective way to explore research participants' views and beliefs about a particular topic, and because they create an environment that stimulates group interactions (Mason, 2018). This was important for the present study because focus groups enabled long-term care facility staff members to share their views, beliefs, feelings and thoughts

about the daily care they provide and further deepened the discussion through group interaction, especially the focus on palliative and end-of-life care provided to residents. Semi-structured interviews with facility managers were conducted because staff members might have felt pressured or challenged when talking about their views and experiences freely and honestly in front of their managers during a focus group. Furthermore, semi-structured face-to-face interviews enabled an in-depth exploration of managers' perceptions from the facility management perspective.

Sample

This study was undertaken in a metropolitan area (Kanto region) in Japan. A publicly available list of long-term care facilities (one of the four types of facilities categorised as 'residential care' under the national long-term care insurance system and called welfare facilities for older people) was used to recruit facility staff and managers for the study. A purposive sample of facility staff and managers was invited to participate provided they met the inclusion criteria (Table 1). The researcher initially phoned the facility manager and, if agreeable, followed up with an appointment to explain the study in further detail.

Table 1. Inclusion and exclusion criteria

Facility staff:	
Inclusion	<ol style="list-style-type: none"> 1. Direct care staff working in a long-term care facility (registered nurse, licensed practice nurse, certified care worker, unlicensed care worker, social worker, therapist). 2. At least one year of work experience in a long-term care facility. 3. Employee of the recruited facility. 4. Over 18 years of age.
Exclusion	<ol style="list-style-type: none"> 1. Agency staff. 2. No experience of working with a resident needing palliative and end-of-life care.
Facility manager:	
Inclusion	<ol style="list-style-type: none"> 1. Work as a facility manager or equivalent. 2. At least one year of work experience in a position of facility management. 3. Employee of the recruited facility.
Exclusion	<ol style="list-style-type: none"> 1. Not having regular contact with direct care staff and residents. 2. No experience of working with a resident who needs palliative and end-of-life care.

Data collection

Focus group and semi-structured interview schedules were developed and used to guide the data collection process. The schedules were informed by the integrative review (Iida *et al.*, 2021) and expert elicitation of Japanese palliative and end-of-life and long-term care experts conducted by the authors (Iida *et al.*, 2022).

They included participants' current palliative/end-of-life care practices, challenges, opportunities experienced and views on palliative/end-of-life care in their facility. A pilot study was conducted for both the focus groups and individual interviews. This was done to anticipate answers to questions, identify areas that needed additional probing, check participants' understanding of questions and to gauge the general timeframes needed for questions. The research team reviewed the data collection procedures and schedules. Data were collected until no new information was forthcoming from the participants, at which point data saturation was deemed to have occurred. The focus groups and interviews were conducted from June to November 2019. Each focus group included 3–12 participants and lasted between 45 and 90 minutes. Each interview lasted between 30 and 45 minutes. All focus groups and interviews were carried out by the researcher (KI) in the participants' workplaces during their working hours. Focus groups and interviews were conducted in Japanese with permission, were digitally recorded and field notes were taken. Participants completed a demographic questionnaire prior to the data collection.

Ethical approval for the study was obtained from Ulster University in December 2018 and Chiba University in February 2019. In addition, permission for the study was granted by managers of participating long-term care facilities. All participants received an information sheet and signed an informed consent form. Participants were informed about their right to withdraw, confidentiality and disclosure of sensitive information. Confidentiality and anonymity were maintained by allocating pseudonyms, and data were kept in accordance with the Data Protection Act. Lone worker protocols were adhered to throughout the process. This study involved sensitive topics, such as palliative and end-of-life care in long-term care facilities. The researcher recognised that asking staff members and managers to talk about their experiences with this topic could have been distressing, therefore, careful consideration and planning were required. This was addressed by the development of a distress protocol that was used as a guide to manage potentially difficult situations and included recommendations such as taking a break and providing participants with access to support services, if needed.

Data analysis

The focus groups and interview data were transcribed verbatim and analysed using Braun and Clarke's six-phase framework for thematic analysis (Braun and Clarke, 2006, 2013) (Table 2). Thematic analysis was chosen as the analytical approach for this study because it is a flexible approach to analysing qualitative data that can be used on its own, or as a process to be implemented within different analytical traditions (Braun and Clarke, 2006). As all focus groups and interviews were conducted in Japanese, a researcher conducted the initial coding in the original language and then discussed it with a second independent researcher. The analysis was then translated into English and further discussed by the research team.

Ensuring rigour

To ensure methodological rigour, the techniques for establishing credibility, transferability, dependability and confirmability recommended by Lincoln and Guba

Table 2. Braun and Clark's thematic analysis framework and analysis process (Braun and Clarke, 2006, 2013)

Thematic analysis steps	Process
1. Familiarising oneself with the data	Transcribed interviews were checked against the original digital recording. The researcher actively read and re-read each transcript, to appreciate the scope of the content and to begin the process of identifying recurrent themes, patterns and relationships.
2. Generating initial codes: coding interesting features of data	Initial ideas were generated based on the researcher's interpretation of the most interesting data elements. Each initial idea was inserted into an Excel spreadsheet with extracted transcripts. They were then sorted into broadly similar groupings. Repeated patterns with relevance to the study aims, theoretical context and other key literature were identified as codes. A second researcher checked the codes against the data to enhance rigour and credibility.
3. Searching for themes: collating codes into potential themes	The list of codes was sorted into potential themes. The use of a mind map provided a way to illustrate connections and patterns among codes and themes and enabled the researcher to develop and refine ideas continually. At this stage, potential themes, codes and related relevant transcripts were translated into English for discussion amongst the researchers.
4. Reviewing themes: generating a thematic 'map' of analysis	Codes were further checked and refined, renamed, redefined and merged. Some were discarded. Themes were further refined to ensure that the codes/data within them were coherent, adequately reflected the meaning intended and there were clear distinctions among the themes.
5. Defining and naming themes: ongoing analysis to refine	The collated data extracts for each theme were examined and analysed. Refinement of the main themes continued until it was clear that each of the themes was distinct, logical, covered the scope of the codes belonging to them, and covered the breadth and depth of the meanings and patterns across the dataset.
6. Producing the report	Final analysis and writing of the report.

(1985) were used to increase trustworthiness. The credibility analysis was enhanced by peer debriefing sessions, and a random selection of interview transcripts was read independently by another Japanese researcher to identify themes. Then, the selected translated interview transcripts, codes and themes were shared with other research team members during the peer validation process. All focus groups and interviews were recorded to allow for an objective measurement of their findings and then comprehensively transcribed by the researcher to enhance transferability. To evaluate the accuracy of the findings, interpretations and conclusions were supported by the data, and audits of the findings were carried out by a

researcher outside the research team to establish dependability. Regarding the confirmability of the study as to whether the neutrality and findings were derived from participants and not from researchers' biases, this was maximised by keeping detailed field notes on all aspects of the research process pertaining to data collection and analysis, and by the involvement of an external researcher in the interrogation and interpretation of findings. Rigour and trustworthiness were further assured by the inclusion of health-care providers and managers from different institutions to triangulate sources of data (Patton, 1999). Verbatim quotes were provided to enhance the transferability and credibility of the study (Lincoln, 2004).

Findings

Participant characteristics

Seven facilities granted the researcher access to interviewing both facility staff and managers. Three facilities agreed only to manager interviews. The size of the participating facilities ranged from 29 to 108 beds, and they were situated in urban and suburban areas. All facilities, except one, were eligible for the end-of-life care incentivisation programme (Table 3). A total of 71 staff and ten facility managers participated in this study (Table 4). As there is limited literature on multi-disciplinary views on palliative and end-of-life care in Japanese long-term care facilities and to ensure that the data reached saturation, 71 participants were included in the focus groups. Most staff participants were care workers (62%), both nationally certified care workers and those who only had vocational or local training, and nurses (11.3%), including registered and licensed practice nurses. Care managers (9.9%), advisors who have a co-ordinator role among staff, family, and external facilities and organisations (7%), dietitians (5.6%) and therapists (4.2%) also participated in the study. All the managers were licensed social work officers, as this is a requirement for a facility management post, with a background in certified care workers (N = 5), social work (N = 4) and nursing (N = 1).

Five key themes were generated from the data analysis: 'Changes in society's and family's end-of-life perspectives', 'Values and beliefs regarding death and dying', 'Anxiety and regret', 'Tension in doing the right thing' and 'Ways of alleviating pressure'.

Theme 1: Changes in society's and family's end-of-life perspectives

Until recently, active treatment up until death was a common practice in Japanese hospitals, and residents of long-term care facilities were often taken to a hospital when their condition deteriorated. However, participants reported their perceptions of recent changes in society's and families' perspectives on end-of-life care. They believed that compared to the past, people now tend to accept and have more respect for a natural course of death, and most families prefer not to engage in any active treatment or medical intervention when the resident approaches death:

In the past, when we asked family members about whether they wanted active intervention or not when the resident deteriorates, many families said that they wished for an active treatment. But now it's becoming a rare case, and we just carry on to end-of-life care. It is a long-term care facility, and residents are older in age, so families expect a natural process. (Care worker, focus group (FG) 5)

Table 3. Overview of participating facilities

Facility	Location	No. of beds	Staffing (full-time equivalent)	End-of-life care incentivisation programme	Staff focus group/manager interview
A	Urban	82	CW 41, NS 5.5, physician 0.1	Yes	Staff focus group and manager interview
B	Suburban	75	CW 46.6, NS 5.7, physician 0.2	Yes	Staff focus group and manager interview
C	Urban	67	CW 40.6, NS 5.7, physician 0.3	Yes	Staff focus group and manager interview
D	Urban	90	CW 41.8, NS 6.9, physician 0.1	Yes	Staff focus group and manager interview
E	Suburban	100	CW 44.4, NS 10.6, physician 0.3	Yes	Manager interview
F	Suburban	29	CW 22.8, NS 2, physician 0.1	Yes	Staff focus group and manager interview
G	Urban	108	CW 55.2, NS 7.7, physician 0.2	Yes	Staff focus group and manager interview
H	Urban	50	CW 25.5, NS 5.1, physician 0.1, physiotherapist 1.1	No	Staff focus group and manager interview
I	Suburban	100	CW 58.9, NS 6.6, physician 0.2	Yes	Manager interview
J	Suburban	100	CW 56.7, NS 8.8, physician 0.5	Yes	Manager interview

Notes: CW: care workers (including certified and non-certified care workers). NS: nurse (including registered nurse and licensed assistant nurse).

Table 4. Demographic profile of staff focus groups (N = 71) and manager interviews (N = 10)

	Staff	Manager
	<i>Frequencies (%)</i>	
Gender:		
Female	42 (59.1)	6 (60)
Male	29 (40.9)	4 (40)
Age group:		
20–29	11 (15.5)	0
30–39	26 (36.6)	0
40–49	20 (28.2)	4 (40)
50–59	11 (15.5)	3 (30)
60–69	3 (4.2)	3 (30)
Education:		
Junior high school	1 (1.4)	0
High school	15 (21.1)	0
Professional training college, upper secondary specialised training school	27 (38)	4 (40)
Junior college	6 (8.5)	3 (30)
University (Bachelor's degree)	22 (31)	3 (30)
Role:		
Care worker	44 (62)	–
Nurse (including licensed practice nurse)	8 (11.3)	–
Care manager	7 (9.9)	–
Advisor (<i>seikatu soudan in</i>)	5 (7)	–
Dietitian	4 (5.6)	–
Physical therapist/trainer	3 (4.2)	–
Licence, registration (multiple answer):		
Certified care worker	54 (76.1)	7 (70)
Social work officer	22 (31)	10 (100)
Care manager	14 (19.7)	9 (90)
Registered nurse	9 (12.7)	1 (10)
Licensed practice nurse	2 (2.8)	0
Certified social worker	5 (7)	4 (40)
Registered dietitian	4 (5.6)	0
Other (physiotherapist, judo therapist, massage therapist, clinical dietitian, dietitian)	5 (7)	1 (10)

(Continued)

Table 4. (Continued.)

	Staff	Manager
Have experience in attending palliative and end-of-life care training/education	44 (62)	9 (90)
Years of experience in health and social care (average)	15.3	26.2
Years of experience in current institution (average)	10.7	13.6
Years of experience as facility manager (average)	–	8.4

It's just my feeling, but generally, families are more prepared than before for the death of their parents. Now, families gradually accept death related to senility and simultaneously prepare for death as they see their parents steadily deteriorating. (Manager 8)

Furthermore, participants reported that an increasing number of residents and families regard long-term care facilities as an alternative to living at home. Death is a part of one's life, and especially for those living in long-term care facilities, it is in the not-so-distant future. Therefore, dying in this setting was viewed in a similar manner to dying 'at home'. Consequently, the staff did not consider end-of-life care as 'special', but rather considered it to be a part and continuity of the usual care they would receive at home:

Even when a resident approaches the end of their life, we do not change our care in any significant way, but just continue our usual care. Terminal care or end-of-life care ... I think we do not have to consider it as anything special ... it is just a continuity of the daily care at his/her house, with a little more support. I think that is something the residents and families want. (Care worker, FG8)

Before, we tried to and thought we should do more for dying residents, but we finally realised that, of course, extra consideration is needed for dying residents, but we do not need to be overwhelmed by that or do something special for it. We simply continued good care as usual. (Manager 4)

One of the participants attributed these changes in attitude towards death and dying to the influence of a renowned Japanese physician who advocated for a peaceful/calm death (*Heionshi* in Japanese). This concept has been widely recognised among both care professionals and the public:

Dr Ishitobi [a Japanese physician and facility manager, who is widely recognised for his pioneering publications on *Heionshi* for older people], his works on *Heionshi* inspired us and our care. No injections or painful things ... just support for sending them on peacefully without unnecessary procedures. (Manager 7)

Generational differences among older people and their families are also discussed. Managers observed that they occasionally noticed differences in the views and opinions of younger and older family members. For example, people over 80

years appeared to prefer more active interventions until death. In contrast, younger people, particularly those under 70, were more aware of and indicated a preference for a natural course of death without suffering. However, although family members demonstrated an increased understanding of the natural course of death, which meant they were more ready to discuss future care preferences, they still experienced hesitation and indecision when they realised that the death of their loved one was imminent:

For our residents in their eighties and nineties, and their families, they show resistance to talking about end-of-life and death. The idea of 'not doing anything before allowing death' is something that they cannot accept. However, for younger residents and younger family members, they understand the natural course of death quite fast and prefer not to do anything. They simply ask for comfort care. I feel that there is a generational change. (Manager 4)

This generational gap in the views and opinions of families about palliative and end-of-life care was also reflected in the views of the care staff. Thus, each staff member's attitude towards end-of-life care changed as they came to view providing end-of-life care naturally, as part of their duties:

Staff are becoming more diverse, and their views on end-of-life care also differ based on their roots. There are also generational gaps, even among staff members. (Manager 5)

I feel like people are becoming more accepting of death in long-term care facilities, so staff are also accepting of residents' deaths and providing end-of-life care for residents with fewer burdensome feelings. (Manager 8)

Participants also reported that the roles and responsibilities of families towards their older relatives were changing. Whereas in the past, adult children were responsible for caring for their parents until death, increasingly adult children no longer saw this as their role, with parents also not wanting to become a burden to their children and relatives:

I think relationships within families are changing. It used to be that living with family and family looking after their seniors until death was important for most people, but now, individual family members value privacy and their own lifestyle. It seems that people prefer a certain distance, even from family members, and living together is no longer a priority. (Manager 6)

This theme illustrated that the staff of long-term care facilities experienced gradual changes in both society's and families' attitudes towards death, dying and end-of-life care. Today, people are more accepting of the natural course of death in facilities, rather than expecting a medicalised death. The generational differences among families and facility staff members concerning their values and beliefs towards death and end-of-life care illustrated that a mental shift has been taking place in this care setting.

Theme 2: Values and beliefs regarding death and dying

Participants voiced their values and beliefs about death and dying, which had an important influence on their care delivery. They believed that letting the resident die alone was the worst thing that could happen and felt very saddened when this occurred. They did their best to call family members to stay by the resident's side, and if the resident did not have family, or if their family was unable to come, staff believed that they should be there for the resident. This was noted in all focus groups, and the participants unanimously agreed on this:

It is about timing, and it is often difficult for the family to reach in time, but it is best if the family can be there. Then, the family will also feel satisfied with the feeling of sending their loved one to the heavens. (Dietitian, FG11)

Being alone during the last moments of life is too lonely. I do not want our residents to be in such a situation. So, even if the facility is very busy that day, I intentionally visit the resident's room frequently just to see, touch and speak to him/her so they are not left alone. (Care worker, FG12)

In light of the importance of not letting residents die alone and the current staff shortage, the role of technology in supporting residents' care was voiced by many participants. Three of the facilities that participated in this study had installed bed sensor systems (a sensor attached under the bed's legs or under the mattress) to monitor residents' sleep patterns, breathing and heart rates without invading their comfort. Even when a facility doctor confirmed that a resident was approaching death, it was not possible for the staff to know exactly when they would die. The sensors helped care workers feel less anxious about visiting a resident's room and finding him/her already deceased. In addition, the sensors reduced the need for frequent room visits for residents at the end of life, especially during night shifts when staffing is limited. This, in turn, provides a sense of security for staff so that everything possible is done to ensure that residents are not alone:

Bed sensors provide a sense of security by knowing the dying resident's condition. If we notice that his/her heart rate is becoming weaker or unstable, we can call their family, or our staff can stay with him/her. (Manager 1)

Since we started using bed sensors, care workers feel less pressured and more secure because we can at least know whether the resident is breathing or not. Before [using sensors], it was very stressful for them to visit the resident's room frequently, especially during the night shift when only a few staff members were on duty, and this made them very anxious. (Manager 3)

Participants valued providing care for residents to keep them calm and prevent suffering at the end of their lives. They reported the importance of maintaining good health, both physically and psychologically, right up until death. Remaining intact and beautiful (*kirei*) until we die means being both physically and psychologically intact, without suffering and unnecessary things, such as wounds, sores and oedema. Staff regarded it as an important and ideal condition when one

dies and goes on to the next life, which also means the resident received good care. These were fundamental elements of care – good physical conditions can also impact other dimensions:

When I see the deceased resident with a calm and soft face, I think he/she was not suffering when he/she died. When he/she looks glum, I think our care was insufficient. We are no longer able to ask residents, but their appearance tells us how our care was. We want to send them without pain and that's our role. (Care worker, FG6)

I always think that our residents should remain *kirei* until they die. No skin troubles, good oral, face and body care ... That means that he/she was well looked after and cared for by the people that surrounded him/her. (Nurse, FG10)

This theme clarified what the staff valued when providing end-of-life care. They indicated that they believed it was essential to be with their residents at the time of their death, so that they did not die alone. They wanted to support them dying in a *kirei* condition, one free of unnecessary suffering and wounds.

Theme 3: Anxiety and regret

Senior staff members reported that care workers, particularly younger or new staff, expressed fears related to residents' deaths, due to their inexperience in end-of-life care, both personally and professionally. Consequently, they were unable to imagine what it would be like. More experienced colleagues tried to support their junior colleagues by sharing information and projections about residents receiving end-of-life care. Despite this, young or new staff still reported anxiety about how they would cope with this situation and about what it would be like for residents to know that they are at the end of their life:

For those younger or new care workers, they do not have much experience and knowledge about end-of-life care, so they fear the resident's death. They worry so much about something like what will happen if the resident dies during or soon after they have helped them to take a bath or help them to eat. They cannot approach it with an attitude of 'it is what it is'. (Advisor, FG4)

I have experienced many patients' deaths as a nurse and I might be used to it now. But many care workers told me that they had fears of looking after dying residents. Perhaps they did not have much experience with death, either in their private lives or at work, so for them, death was something they could not imagine, and it made them scared. (Nurse, FG10)

Care workers reported that every time they cared for a dying resident, they felt uncertainty and regret about their care because most dying residents were often unable to express themselves. They also felt a sense of regret and guilt because their care might have contributed to the resident's death. They also worried that they could have done something more for the residents to achieve the residents' wishes or to provide comfort. The anxiety experienced by the care workers was

perpetuated by the increasing number of residents with a dementia diagnosis, as these individuals were unable to communicate their needs and wishes, placing additional responsibility on inexperienced staff to interpret their needs in order to maximise the quality of end-of-life care. Having no right or wrong answers from residents about their end-of-life care further contributed to their feelings of anxiety and regret. Although all participating facilities held debriefing and reflective meetings after each resident's death, feelings of regret and anxiety remained among the staff:

There are no right or wrong answers in end-of-life care. We do our best to provide better care to residents by recalling his/her life history and what his/her preferences or likes were when they were well. But there remains a feeling towards the resident that we could have done something different from what we did. (Care worker, FG3)

I always try to do my best with my colleagues by discussing and communicating a lot about care. But, always, after the resident passes away, I cannot help regretting and feeling guilty, telling myself, 'I should have done that, I could do it a better way...' (Care worker, FG11)

Staff members reported their inexperience and lack of confidence about caring for residents with end-stage cancer or those who needed active pain management with controlled medicines, which also created anxiety related to the provision of future care. Residents on active pain management were rare in the participating facilities; however, it was anticipated that the number of residents with those conditions might increase in the near future, and facilities were not yet ready for them:

We are not well experienced with residents who have end-stage cancer, especially those in need of pain management. Therefore, sometimes, we need to ask residents to transfer to a hospital. In most facilities, health-care professionals are not always on-site, and even if they are, we can only provide prescribed pain medicine and when the pain worsens we cannot do anything because doctors are not on-site, and a pharmacy is not nearby. (Care manager, FG6)

I think our facility can provide end-of-life care for residents dying of old age, but there is a limit for those who need an active intervention. If someone had a fixed pain management regime from the hospital, we might be able to accept them as a resident, but if he/she needed ongoing pain assessments and changes in the regime, our facility would not be able to offer it. (Care worker, FG8)

This theme indicates that staff members continued to provide care despite feelings of uncertainty, anxiety and a lack of confidence in end-of-life care. This was expressed by inexperienced staff members and younger care workers who had never before had the opportunity to encounter someone's death.

Theme 4: Tension in doing the right thing

Staff reported internal dilemmas and external dilemmas related to other members of the multi-disciplinary team in the context of conflicting approaches about

end-of-life care provision to residents. Staff reported that if they tried to respond to a resident's dying wish or preference, this often involved taking a risk that it might worsen the resident's condition:

We often experience a dilemma between helping a resident have his/her preferred things and putting them at risk. Because the resident is nearing the end, we want to fulfil his/her wishes, but, for example, most residents love taking a bath in a bathtub, but at the same time, it puts physical stress on them. As a fellow human being, I want to give them what they want, but as a member of staff, I hesitate to do so. (Care worker, FG2)

Although in our mind we want the resident to eat whatever he/she likes, we think about who would take responsibility if the resident suffocated. Therefore, we need to discuss it as a team with the family. Then, we reach a compromise between what we and the resident want to do, and what we can do. (Care manager, FG11)

Care workers spoke about the different opinions and perspectives on end-of-life care held by multi-disciplinary team members. They also voiced concerns about the tension that was created among the team. Care workers often disagreed with a course of action or treatment, believing it not to be in the residents' best interests, and tensions arose when other professional colleagues pursued a particular treatment plan regardless of the views and opinions of the care workers. Although the care workers tried to communicate with the health-care professionals to discuss what they observed from the resident and the plan suggested by the health-care professional, it was difficult for care workers to voice their concerns about other health-care professionals. The organisational culture of professional hierarchy was observed in many facilities:

As care workers are looking after residents every day, we know when the residents are no longer accepting food because they are approaching death, but our dietitian tries to provide other forms of nutrition. I understand that it is her professional role to boost residents' nutritional status, but it's not right, it's just putting an extra burden on dying residents. We share our assessments and discuss what is best for the residents, but it is difficult [to speak up]. (Care worker, FG4)

Furthermore, tensions and hierarchies between physicians and facility staff have been reported. Although most participating facilities' physicians had a policy on withdrawing unnecessary or burdensome medical procedures at the end of a resident's life, some physicians attempted to do more for them. This created tension and concerns among facility staff, particularly care workers, but it was challenging for them to question or challenge the physician's orders due to the professional hierarchy:

Our facility's contract physicians tend to do more [medically] for dying residents. Although we think that the resident will not accept any more intravenous fluids or even subcutaneous fluids, and that it will just increase oedema, we hesitate to tell the physician because there is a hierarchy and boundary between the health-care professionals and the care workers. We feel sorry for the residents ... but the doctor's order is an order. (Facility manager, FG7)

This theme illustrated the dilemmas and frustrations experienced by staff members, and especially care workers. Dilemmas were identified as being between the care that the residents wished for and its possible risks, and the dilemma caused by the difference in the direction of care for the residents caused by differences in positions and ideas with other professions.

Theme 5: Ways of alleviating pressures

Participating staff, particularly young or new staff, who experienced anxiety about end-of-life care, gradually developed coping strategies to help them deal with the anxiety and stress. They reported that the more experience they gained in end-of-life care, the more they became used to residents' deaths, and they developed their own ways of managing their anxieties. Part of this involved accepting that the death of their residents was unavoidable and likely to be a frequent occurrence in the long-term care settings for frail and older people. Therefore, they shifted their focus from reflecting on every aspect of a resident's death to one where they tried to learn from the experience in order to do better the next time. However, some reported their mixed feelings of getting used to residents' deaths and worrying that they might just hide their real emotions and feelings:

As we work in the industry of caring for older people, the deaths of residents are unavoidable. So, I am getting used to it and know how to deal with it emotionally, but it is still heart breaking and makes me feel depressed, especially when the person who has died stayed with us for a long time, or if I have many memories of him/her. But that's how it is and where I work. (Care worker, FG6)

For young or new staff, a resident's death is a sad experience. Some staff who cannot cope with it leave the facility and I used to be like that, but I think I have changed, but I am not sure whether it [me getting used to people's deaths] is a good thing for me or not. (Care manager, FG10)

Raising awareness of teamwork also helped staff members to deal with the pressures they experienced. It was noted that care workers who were on duty the day of a resident's death tended to feel responsible for the death and blamed themselves for these deaths because of their own care. Therefore, staff members intentionally communicated with one another to build a mutual understanding of teamwork and reinforce the notion that end-of-life care is provided by the team, not by a single member of the staff, so no one should feel responsible for a resident's death. In this way, they tried as a team to share the responsibilities and negative feelings that arose from the provision of end-of-life care:

When a resident died soon after a meal, one of the care workers blamed herself because she thought she did not do right when feeding the resident, but this was not true, it was just timing. We follow each other and remind each other that not a single member of staff is to blame him/herself. So, I intentionally communicate to care workers that care is provided by the team, and not just the one staff member who was there. (Nurse, FG11)

We all feel burdened or pressured seeing residents die, so we have been supporting each other emotionally, so that not one staff member is put under pressure, but we all share the pressure. (Care worker, FG3)

When a staff member was on duty at the time of a resident's death, they believed that the resident chose to die on that day and at that time because that staff member was on duty. Residents and staff developed family-like relationships, as the facility was perceived to be a home-like environment. It was a sad experience for staff to see their residents die, but they believed that because of their relationship with the resident, the resident may have taken comfort in dying knowing that the staff member was at their side. This way of thinking also helped members of staff who had little experience in end-of-life care to recover from the emotional damage left by a resident's death:

It is sad seeing a resident die, and it impacts me a lot, but my colleague told me to take it as though I was chosen to stay by his/her side on that day because we had a history and developed a good relationship between us. (Care worker, FG11)

When a resident dies and the staff are upset, I tell them that the resident chose our facility and died peacefully with us. He/she must have felt safe and secure to go because they [the staff] were there with him/her. (Manager 1)

Through the themes presented above, it is clear that while long-term care facilities cannot avoid the deaths of their older residents, staff members gradually developed coping strategies. Strategies for organising staff members' feelings and emotions after providing end-of-life care were described in this theme, including support among the staff, use of technology, and feeling grateful for being with the resident and caring for him or her until death.

Discussion

The findings of this study enhance our understanding of the cultural views and beliefs of staff regarding palliative and end-of-life care in Japanese long-term care facilities. The findings suggest that participants in this study observed a gradual shift in both residents' and families' views about death in old age, moving away from a medicalised death, which had been the norm in the last half of the 20th century in Japan (Long, 2004; Shimada *et al.*, 2016), to a more natural course of death. The participants also observed generational differences regarding end-of-life care discussions and preferences, and noted that residents and families appeared to be moving from what they perceived to be a traditional Japanese viewpoint to a more westernised way of thinking. Furthermore, there was a shift from family to residential care for older people.

As Japan is entering a 'high mortality era', the government has been promoting advance care planning (Ministry of Health, Labour and Welfare, 2018b; Miyashita *et al.*, 2020) and decision-making processes in medical and social care (Japan Geriatrics Society, 2012). These government initiatives which emphasise a peaceful/calm death (Ishitobi, 2015) have increased public awareness and influenced

care practitioners' views and practices. Although these changes are not unique to Japan, it can be said that these were culturally constructed views of a 'good death' in the Japanese context and therefore influenced how people died and how health-care staff interpreted death.

It was clear from this study that the personal values and beliefs of staff influenced what they considered to be a 'good death', which in turn influenced their practice. Dying alone was the last thing that the staff wanted for their residents. Historically, Japanese people regard the co-presence of intimate others and watching over dying as important and critical (Connor and Traphagan, 2014; Danely, 2019). The value placed on dying in a good condition also strongly influenced staff's motivation to provide good end-of-life care. Perfection or intactness of the body when one dies has been valued by Japanese people, because if any part of the body is missing or hurt, it is believed that they will have a tough life in another or the next life (Long, 2004; Ikeguchi, 2007; Oshita, 2007; Kanayama, 2017). In our study, participants were unanimous in their wish for residents to die in a *kirei* condition, that is, not only physically intact and beautiful but also psychologically intact, without physical or psychosocial suffering.

Although these values and beliefs drove staff towards quality palliative and end-of-life care provision, they nonetheless experienced a myriad of challenges such as anxiety, regret, and internal and external dilemmas around death and dying. This is consistent with studies from other parts of the world which also report the negative emotions and feelings that care assistants experience in palliative and end-of-life care, such as helplessness, uncertainty and painful emotions (Matsui and Braun, 2010; Goodman *et al.*, 2015; Cagle *et al.*, 2017; Kawakami *et al.*, 2019). Furthermore, anxiety related to end-of-life care among less-experienced staff members and the professional boundaries and hierarchies that created dilemmas concerning care provision were also common elsewhere (Jones *et al.*, 2020, Standing *et al.*, 2020). These feelings and emotions are inevitable when caring for a dying person, and in some cases, lead to moral distress among the staff in long-term care facilities (Young *et al.*, 2017). Our study and the literature suggest the importance of high-quality mentorship and support for inexperienced staff members.

Participants in our study endeavoured to alleviate these negative experiences and pressures by sharing and reflecting on their practice with team members. Further, the participants took their end-of-life care experience positively and believed that particular staff were chosen by the resident to accompany them on their end-of-life journey. Cagle *et al.* (2017) reported that frontline nursing home staff felt honoured to be able to provide end-of-life care. Providing end-of-life care is not an easy task for any care provider, regardless of education, training or experience. This study demonstrated that the participants found ways to cope with their feelings of anxiety and regret by taking comfort in their culturally held belief that they were meant to care for a particular resident at the end of their lives. However, even with this firmly held belief, care staff still needed to find their own way of coping while also needing support to maintain their motivation to continue their practice.

In this study, monitoring devices enabled care staff to be aware of and present with dying residents. Because of the high value and importance placed on being with residents at their time of death, bed sensors were used to monitor residents,

which enabled staff to notice any changes and go to the bedside to ensure that the residents did not die alone. While the sensors reduced the need to visit residents' rooms, it could be argued that these sensors also facilitated an environment where dying residents were not alone in the last hours of their lives. Therefore, even though the participants' facility installed bed sensors, they intentionally visited dying residents' rooms just to see, touch and speak to the resident to actualise their value and beliefs on not letting residents die alone. The role of technology in supporting older people is complex. Although not initially intended for end-of-life care, the Japanese government has encouraged the development and introduction of technologies, such as care robots, assistive devices and monitoring sensors, both in the homes of older people and in long-term care facilities (Ministry of Economy, Trade and Industry and Ministry of Health, Labour and Welfare, 2017; Ministry of Health, Labour and Welfare, 2020). This gives rise to questions about the ethical issues surrounding the use of assistive technologies in care, such as care-givers becoming too dependent on the devices, the privacy of the care recipients and the proxy consent to use such tools for people living with dementia (Stahl and Coeckelbergh, 2016; Vandemeulebroucke *et al.*, 2018; Suwa *et al.*, 2020). However, in the context of the present study, staff shortages resulted in a need to find a balance between technology use and hands-on care in providing good end-of-life care.

Participants in this study also reported tension and hierarchy among staff, particularly between health-care professionals and care workers. Although the majority of participants in this study were care workers, both certified and uncertified, and on the front lines of resident care, they were hesitant to speak up about their opinions or to challenge decisions made by health-care professionals. This appeared to run contrary to the culture of their workplaces. It was evident in cases even when they strongly believed that the proposed intervention or care plan was not in the best interest of the dying resident, but still, they did not feel able to voice their concerns. Although health-care professionals are educated to advocate for their clients, these findings suggest a need to educate and support care workers to have a more open and honest dialogue with other health-care professionals and respect the dying wishes of the residents in their care. Providing education, training and the necessary support to care staff will not only improve their knowledge and practical skills but will also equip them to cope with the inevitable challenges associated with palliative and end-of-life care provision (Cagle *et al.*, 2017). A culture of care where the expertise of residents, families and all grades of staff is equally recognised would appear to be an important step in the right direction.

In long-term care settings, culture influences health-care decisions and delivery of palliative and end-of-life care, and may help residents and family members adjust to the dying and bereavement. Young *et al.* (2017) reported how the personal values of nursing home staff in relation to a 'good death' were found to have influenced their work. Striving to ensure that residents do not die alone, advocating for family presence, effective symptom management and high-quality care have all been cited as priorities for end-of-life care (Young *et al.*, 2017; Holmberg *et al.*, 2019; Nishimura *et al.*, 2020). Society and culture are changing, and with these changes, the need to enhance our understanding of the way in which these changes impact beliefs and attitudes around palliative and end-of-life care in Japanese long-

term care facilities is necessary. Culturally sensitive and tailored palliative and end-of-life care education programmes may help not only in increasing knowledge but also in enhancing the delivery of culturally appropriate high-quality care.

This study was limited as it was conducted in one region in Japan, and all participating facilities had a policy in place to provide end-of-life care. This may have influenced their willingness to participate in the study. Further research is needed in facilities which do not have specific end-of-life care policies in place. Furthermore, although the analysis and language translation process were supported by another Japanese researcher, some meanings might have been lost during analysis and reporting in English. A strength of this study was that the focus groups appeared to have had a positive impact on the participating staff. Although they regularly discussed residents' everyday care in the course of their day-to-day work, they rarely had an opportunity to discuss palliative and end-of-life care with other members of the multi-disciplinary team. The participants noted that being facilitated to discuss their views on end-of-life care with different professionals was a step in the right direction towards a mutual understanding and sharing of diverse perspectives. Finally, this paper adds significant weight to the literature by providing additional insights into staff members' experiences, generational differences and cultural influences in palliative and end-of-life care in long-term care facilities.

Conclusion

Recognising and respecting both professional and personal cultural beliefs related to death and dying is important to providing quality care that meets residents' and families' needs. Education for practitioners that includes cultural considerations which also reflect changing societal views on death and dying will be important in increasing awareness of such beliefs about practice, and ultimately care provision. Future research should explore care recipients' and family members' cultural perceptions of palliative and end-of-life care in Japanese long-term care facilities. Furthermore, there is a need to strengthen the support system for less-experienced staff members at the policy and practice levels to equip them with the skills and knowledge required to deliver palliative and end-of-life care in Japanese long-term care facilities.

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