

THE MEANING OF THE DEATH AND DYING OF TAIWANESE NURSING HOME RESIDENTS: THE NURSING STAFF'S VIEW

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Abstract: *Background:* The number of people living in long-term care (LTC) facilities has been rising in many parts of the world, and most current residents will end their lives in LTC facilities. The perceptions of residential care and practices in most current research of nursing homes (NHs) in Taiwan are based on evidence from an ego-centric rather than socio-cultural-centric model. *Objectives:* This study was designed to address the overlooked cultural aspect in NHs research and thereby advance understanding of how the NH staff in an East Asian setting perceive NH resident death and dying. *Design:* A qualitative study was designed in line with the hermeneutic phenomenological method. Data were collected via in-depth semi-structured interviews. *Setting:* The research was conducted in five hospital affiliated nursing homes and seven independent nursing homes in central and southern Taiwan. *Participants:* Through purposive sampling, twenty-five participants were recruited for interview, twelve registered nurses (RNs) and thirteen nursing aides (NAs). *Measurements:* An interview guide was used to produce the digitally-recorded contents, which was then transcribed verbatim and translated. The hermeneutic phenomenological analysis was conducted such that authors went back and forth through every interview text (parts) and the research questions (whole) until they reached a comprehensive understanding of the subject matter in terms of reduced, emerging themes. *Results:* Four themes were identified in the data analysis. They were 'impact of a resident's death,' 'reflections on entangled feelings,' 'insufficiencies,' and 'tremendous pressure of informing death.' *Conclusion:* This qualitative study confirmed previous findings of non-Asian studies about the significance of 'assessment of dying' and 'family communication' in quality NH care. In addition, NH nurses were in need of palliative training in dying care. The nurses' felt pressure due to family requests to send residents home for their 'last breath,' which was both the nurses' most challenging work of care and the most culturally grounded aspect of it.

Key words: Death and dying, nursing home, nursing staff, phenomenology.

Introduction

Concomitant with the growing elderly populations in many countries, the number of people living in long-term care (LTC) facilities has been rising in many parts of the world, and most current residents will end their lives in LTC facilities (1). Nursing homes (NH), as a particular type of LTC, will be important for end-of-life care for the foreseeable future. However, the research literature indicates that NHs often provide sub-standard care due to high staff turnover, high nurse-patient ratios and stressful environments (2). The result is end-of-life care of questionable quality for too many residents. In 2018 Taiwan is faced with a similar situation where the ratio number of elderly has reached 14.5%, the threshold of an aged society (3). The need for long-term care will also soar up to a historical high level.

In 2015 Taiwan was ranked 6th out of 80 countries worldwide, and 1st in Asia, in end-of-life care (4). While this could indicate end-of-life palliative care in Taiwanese NHs is well-developed, evidence shows that this might not be the case. A comparison of 2012 and 2016 figures revealed a marked increase in the number of NHs (447-511, 14%) and residents (27,056-36,020, 33%) (3). According to the official regulation, there were no on-site physicians, and the ratio of registered

nurses (RNs) and nursing aides (NAs) was about 1:3, with one RN for every 15 residents, and one NA for every 5 residents (5). Importantly, palliative care training is not provided to NH staff in Taiwan. Therefore, NH personnel whose main responsibility is end-of-life care lack appropriate skills in facing the death of residents. In fact, most end-of-life care in Taiwan takes place in hospices (mostly within hospitals), at home [with the help of foreign caregivers (due to the shortage of less expensive manpower)] or in emergency rooms.

A significant number of studies have focused on the provision of palliative and end-of-life care in NHs in North American or European countries (6). Researchers have paid little attention, however, to the end-of-life palliative care carried out specifically by NH nursing staff, or even wondered whether or not they have received such training—perhaps under the assumption that every facility has an end-of-life care trainer (7,8). Therefore, the main objective of the current research is to explore NH nursing staff perceptions of death when faced with dying residents in Taiwanese NHs where nursing staff receive no palliative training.

There is a growing body of research focused on the emotional and stress-related experiences of NH nursing staff surrounding resident death and dying. The literature indicates that negative emotions and a sense of personal loss are common

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when residents die (9). The impact of resident death has been categorized as a type of 'moral distress' (10). Other studies have treated resident death as a clinical issue from which nursing roles in the dying care were examined (11). Further, specific clinical problems have been noted as NH nursing staff attend to the dying of residents. Among them, 'assessing dying' has been considered very important for NH carers (12). Also, communicating about death is a major source of stress, apparently leading many nurses to seek emotional detachment.

A variety of intervention programs have been proposed in order to provide systematic training for 'assessing dying.' The Liverpool Care Pathway (LCP) and the Gold Standards Framework for Care Homes (GSFCH) are notable examples in the UK. NHs have implemented programs either individually or in an integrated fashion (13, 14). Other programs have focused on palliative care skills, such as in a project in Canadian NHs (12), or by improving pedagogical methods, such as in a Danish project (13). Nonetheless, the clinical effectiveness of these approaches remains a debatable issue. Some major challenges in implementing these programs have been identified and discussed (15).

Another area of research deserving more attention is the cultural dimension. There is limited research available to help caregivers in NHs deliver high quality care in Chinese cultural contexts because research perceptions of residential care and practices in East-Asian societies are typically constructed by evidence from ego-centric rather than socio-cultural-centric studies (Lee 2010) (16). There is relatively scarce nursing science literature focusing on the Chinese cultural context. This issue of death demonstrates the importance of addressing the sociocultural values of specific societies in residential care provision. In the current research, we explore our assumption that elucidating Taiwanese NH nursing staff perceptions of death when faced with dying residents in NHs is to some extent shaped by local Taiwanese cultural values.

Chan and Kayser-Jones drew upon the few nursing home studies that deal with cultural issues to develop their study of the experiences of care for terminally ill ethnic Chinese residents in the US, identifying various factors that influence end-of-life care (17). According to this research, the most significant factors influencing the care Chinese residents received were communication barrier, dislike of Western food, and the differing cultural beliefs and customs. These findings help develop and implement interventions to improve the terminal care of Chinese elderly individuals in nursing homes. Another study described the culturally-embedded meaning of death through coping acts of NH nursing staff seen in normally undocumented care given to dying residents (18). That study revealed the import of behaviors of socialization, interaction, communication and superstition between staff and dying residents.

East Asian countries influenced by Chinese culture share a death-denying cultural context (19) in which people tend to adopt religious ceremonies that help them avoid bad luck

or death. Past research has shown that Chinese death beliefs, which mostly consisted of traditional religious thoughts, are related to death anxiety. It was further confirmed these "superstition" were the only factor that could predict death anxiety in the Chinese context (20). As an example, in Taiwan, the "zhougian" ritual is an exorcism constitutive of a process of regaining the lost spirit and soul of a person who has been frightened (21). This cultural aspect is by and large overlooked in NH research. As the secondary objective, this study will also attempt to explore how the NH staff in an East Asian setting perceives NH resident death and dying.

Methods

This qualitative study analyzes 25 NH nursing staff members' perceptions of the essential meaning of death through narrative reports of their end-of-life care experiences. It adopted a research approach informed by interpretive phenomenology. This approach was selected because the researchers were concerned about the subjective meaning of residents' death to the nursing staff. Hermeneutic phenomenology aids in a deep understanding of the human condition by structuring the study of "how people interpret their lives and make meaning of what they experience" (22). This method allows the exploration of the essential meaning of how NH nursing staff perceives resident dying and death as they provide end-of-life care.

Five Hospital Affiliated Nursing Homes & seven Independent Nursing Homes in central and southern Taiwan were included. Purposive sampling was used. The inclusion criteria were as follows: Participants (i) provided direct care for dying residents, (ii) worked in an NH in the targeted region, (iii) had worked on the current unit as a full-time NH nursing staff member for at least 3 months, and (iv) could communicate in Chinese fluently.

The research was approved by the Institutional Review Broad (IRB) of a hospital. Participants were interviewed after they had each signed an informed consent form. They were informed that they were free to withdraw at any time. To ensure anonymity, pseudonyms were adopted.

Data were collected through semi-structured interviews in Chinese. An interview guide (see Table 1) was used to conduct a 50-minute dialogue, on average, with each participant. The digitally-recorded content was then transcribed verbatim and translated. The hermeneutic phenomenological analysis followed that of Cohen (22). The authors (SLT, CHT) went back and forth through every interview text (parts) and the research questions (whole) until they reached a comprehensive understanding of the subject matter in terms of reduced, emerging themes.

To ensure research rigor, the study also followed Packer and Addison's 'four evaluation approaches' for interpretive research (23). The research addressed the risk of bias by remaining close to the original text, and by uncovering biases for scrutiny. Texts with analyzed themes were shown to

Table 1
Background of participants

Name	Age	Position	Experience on unit (year)	Previous nursing experience (year)	Level of education	Type of institute
Chin	22	R.N.	1.5	0.5	College	HANH
Chung	32	R.N.	10.1	1.0	College	HANH
Ding	58	Nursing Aide	12.0	3.5	Junior high	HANH
Feng	38	Nursing Aide	3.4	2.0	Senior high	HANH
Haw	60	Nursing Aide	9.5	2.0	Elementary	HANH
Hsian	40	Nursing Aide	0.3	0.0	Senior high	HANH
Hsio	43	Nursing Aide	7.5	1.5	Senior high	HANH
Hwei	30	R.N.	2.5	4.0	College	HANH
Kan	50	Nursing Aide	10.0	0.5	Junior high	HANH
King	60	Nursing Aide	0.3	25.0	Elementary	INH
Kwei	50	Nursing Aide	1.0	5.0	Elementary	INH
Lili	22	R.N.	1.0	0.5	College	INH
Lin	54	R.N./H.N.	12.0	11.0	College	INH
Liu	48	Nursing Aide	0.6	2.0	College	INH
Lonyu	49	R.N.	8.5	2.0	College	HANH
May	22	R.N.	0.5	1.0	College	HANH
Ming	35	R.N.	8.0	4.0	Senior high	HANH
Ping	50	R.N./H.N.	6.4	14.0	Bachelor	HANH
Sheili	49	Nursing Aide	0.4	1.5	College	HANH
Shu	36	Nursing Aide	0.5	0.0	College	HANH
Susu	40	Nursing Aide	2.0	7.0	College	HANH
Wein	26	R.N.	1.5	4.5	College	INH
Ya	53	Nursing Aide	9.1	0.0	Elementary	HANH
Yang	36	R.N./H.N.	10.0	5.0	Bachelor	HANH
Zhi	22	R.N.	1.0	0.3	College	INH

*IHN(independent nursing home); *HANH(hospital affiliated nursing home)

participants to make sure they fit their subjective experience. Then, the text was read inter-subjectively among the author-researchers to reach a coherent interpretation of the meaning of resident death for NH nursing staff.

Results

There were 25 participants, including 12 RNs and 13 NAs. Ages ranged from 22 to 60 years old (average age = 45 years). Relevant characteristics are listed in Table 1. Four themes were identified in the data analysis. They were 'impact of a resident's death,' 'reflections on entangled feelings,' 'insufficiencies,' and 'tremendous pressure of informing death.' The essential meaning of NH resident death and dying for nursing staff can be summarized as being a strong impact that has made them aware of the need for proper education on end-of-life care, especially incorporating cultural background.

Impact of a resident's death

This first theme was revealed in a common situation where participants felt ill-prepared for a resident's death. The RNs and NAs in this study had received no palliative training. As a result, participants reported substantial emotional shock when faced with the unexpected death of a resident. A new NA, Kwei, described her shock:

It's just that a grandma over 90, who was pleased with us, suddenly stopped breathing one morning. There was no heart-beat, no blood pressure. I was frightened to death. I hurried to get help from the nurses. (Kwei, NA)

Unexpected death also troubled experienced nursing aides. Ya, despite being in her 9th year on the job, struggled to care for a resident with paralysis and breathing trouble due to the latter's old age and lack of educational background (graduate of elementary school) and proper training in palliative care. Major shock holds true for registered nurses, too. Lili offered

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this experience:

A four-year old boy was diagnosed with cerebral paralysis (CP) and had just checked in ... for one or two days. I remembered he came in the daytime. When I was on the night shift, I found his skin color was abnormal. It had turned purple. We immediately gave him CPR and sent him to the hospital. It was too late, though. He was pronounced dead on arrival. I kept sobbing on my way back to the NH. (Lili, RN)

NH nursing staff also described suffering from nightmares, especially when the dying process was a struggle or not peaceful. Ding's nightmares hinted at trauma suffered during her first resident death:

I had no experience dealing with that. I had nightmares in which I heard him calling my name (in my ears) all night. I was afflicted That was my first dying case. His last sounds were full of suffering and sorrow. (Ding, NA)

She thought the death might be her fault. The patient did not have the good death Ding had expected for him. The result was that she was haunted by the resident's death for a long time. It had to do with her sense of guilt resulting from the lack of dying care experience.

Table 2
Interview guide

Question1	Would you please describe your general working experience in the nursing home?
Question2	Have you ever experienced the death of a resident or family member?
Question3	If yes, would you describe the feelings you experienced?
Question4	Would you describe your experience of caring for a dying resident and your feelings?
Question5	How do you deal with the feelings?

Reflections on entangled feelings

The second theme to emerge was '*reflections on entangled feelings.*' Gradually, nursing staff found their worldviews becoming jaded, leading to pessimism regarding dying. This rather negative attitude towards life was perceived when dealing with residents' circumstances:

Life is short. Watching them die like this made me feel worthless. A pet's death may be a little more valuable than a resident's. I just felt that people seemed to have no value or dignity as they became old. (Shu, NA)

Some participants blamed themselves because they felt guilty. However, they often worried most about possible lawsuits resident family members may file. Chung described the following:

When we informed the family about the resident's death in the evening, they couldn't accept it because they had just paid a visit to the resident in the morning. They suspected this death might have to do with our negligence or malpractice. I was

really afraid of being sued for that and doubted my own care. The mental pressure was truly huge. (Chung, RN)

Still, some NH nursing staff managed to find some positive meaning out of their dying care in their clinical circumstances. Liu's description puts it succinctly: '*I altered my attitude toward life and came to realize the changeability of life*' (Liu, NA). Such thoughts apparently worked well at reducing anxiety. Hsian said:

They are ill in bed, so letting them go is better for them. This is life. This is his fate. He was suffering from chronic disease, and death would be his escape route. (Hsian, NA)

NH staff also reinforced their self-worth by telling themselves that they were doing the right thing for residents no matter what happened:

In my opinion, this job is charity work. We do a lot that the residents' families do not know about. I tell myself, 'I am doing well. I am helping them.' (Lili, RN)

Insufficiencies

The third theme was awareness of their own insufficiencies. This was revealed in part when participants expressed a strong need to gain palliative care skills. Nursing staff often found ways to improve death care. The most prominent learning avenue was through gaining experience:

I knew I had to check on the resident's vital signs after I found he/she had some physical syndrome. Because I have had such an experience before, I knew how to deal with it when a similar situation occurred. (Feng, NA)

Assessing signs of dying was the training they most desired. For example, Hsian described constantly checking the vital signs of a resident with liver cancer during the terminal stage because she was afraid that the resident would suddenly die. Had there been related training, Hsian may have had less anxiety. Ming said, '*[we] hope to know how to take good care of them*' (Ming, RN) during the terminal stage.

Truth-telling and grief-comforting were also considered important to learn. This training would involve communication with bereaved families, a resident's roommates, and comforting NH colleagues. In contrast, the usual response was avoidance:

In facing an empty bed, everyone sensed the atmosphere of grief. It seemed I had to do something, but I didn't know what to say, how to comfort them [roommates of the resident]. The deceased resident seemed to mirror their own future. (Susu, R.N.)

It is in this context that NH nursing staff most strongly expressed the need to add dying care into their training program. With no physicians in NHs, nursing staff are expected to assume greater responsibilities than those in European and North American countries, especially around signs of dying and the death event. Monitoring the dying is a difficult task for already over-worked staff, and any improvement in this area would seem to rest upon providing specific palliative training.

Tremendous pressure of informing death

The fourth theme is '*tremendous pressure of informing death.*' In Taiwanese NHs, resident families demand that nursing home staff inform them of imminent death so patients can be discharged to their homes as expected in accordance with Taiwanese Taoist-Buddhist folk custom. However, this is extremely challenging. A senior nurse said, '*We can assess the resident's general condition based on our experience, but we are not God*' (Yang, RN). Ming's description helps illustrate this point:

The pressure was really incredible because we didn't know the actual timing of their last breath. We were afraid to trouble family members if we informed them too early. We were also afraid not to be able to help the residents reach home in time if we informed them too late. (Ming, RN)

All participants acted instinctively, resorting to cultural resources first because they had not been equipped with palliative nursing training. For instance, Ding's peculiar behavior well illustrates this point:

Since the first time encountering the death of a resident and having nightmares, I have smiled to the residents, but do not introduce myself and do not tell them my name. I just tell them to call me 'Miss'. (Ding, NA)

She justified her reaction and shaped it based on the folk belief that by means of calling names ghosts can collect human spirits. '*Praying to deities,*' '*wearing a charm,*' and '*reciting sutra or mantra*' were among the common practices of the interviewees, practicing Taiwanese folk religions. One registered nurse was frightened and said she '*felt much better after I went to pray at a temple*' (Zhi, RN). Some participated in a ritual called '*zhougian,*' which literally means 'recalling the frightened soul.' Having had nightmares about a deceased resident, Lonyu participated in '*zhougian*' to pacify her mind:

I talked to my father-in-law, a spirit medium. He performed a 'zhougian' ritual for me. The quality of my sleep has been greatly improved since then. (Lonyu, RN)

Many NH nursing staff recommend this folk ritual to novice caregivers who are fearful of the dying process. For them, '*this could at least comfort the soul*' (of the nurse) (Susu, RN).

Discussion

This paper explicitly explores the cultural elements of the experiences of ethnic-Chinese Taiwanese from a hermeneutic-phenomenological perspective, and explores how this maps to, and contrasts with European and North American cultural values and analyses of this issue. The meaning of the death and dying of residents in NHs from a nursing staff perspective in Taiwan can be understood in terms of '*impact of a resident's death,*' '*reflections on entangled feelings,*' '*insufficiencies,*' and '*tremendous pressure of informing death.*'

'*Impact of a resident's death*' indicates the disturbance felt by nursing staff when a resident is dead. This characterization fits well with 'emotional labor'²⁴ or 'emotional burden'²⁵

found in the literature, but nursing staff's responses and adaptations in Taiwan also reflect some unique qualities of the Taiwanese cultural context. The meaning of death in Taiwanese nursing homes carries slightly different meanings when compared to European and North American countries. No physician on site, no palliative training, and cultural expectations that the dying resident will ideally die at the ancestral home define the basic setting for end-of-life care of NHs in Taiwan. A primary responsibility of NH nurses is to make a judgement on when the dying resident should be sent home or to the hospital. Poor performance in this area might be due to insufficient training on 'assessing dying,' which is an ambiguous and legally tenuous area of nursing practice. The pressure on nursing staff is compounded by family demands to have the resident's final hours be at home rather than at the NH or hospital.²⁶ Taiwan Ministry of Health and Welfare statistics in 2018 show that 36% of people died at home, a number much higher than in Western countries.²⁷

Dying assessment is a common challenge acknowledged by NH nursing staff internationally. It is identified as an 'important critical skill,'¹⁴ a 'pre-established condition for commencing on a care pathway,'¹⁵ or a condition for arousing 'anxiety' around doing things right.^{15, 28} With cultural background knowledge, one begins to understand the unique meaning of dying assessment experienced by Taiwanese caregivers. To be specific, anxiety identified in other developed systems of care is about whether the NH nursing staff can do as prescribed in the adopted program such as LCP, GSFCH, etc. However, Taiwanese NH nurses feel anxiety simply because they have no such prescribed pattern to follow. By the same token, the second theme, 'reflections on entangled feelings' also revealed how reactions are circumscribed by cultural dynamics.

While some NH administrators expressed the view that NHs can provide effective care without palliative care training, most studies support the view that NH staff need to enhance palliative care skills.²⁹ Nevertheless, since little is known about the care provided by nursing staff with no palliative training for NHs in European and North American countries, it is possible that the established training programs in European and North American countries would fall short if offered as-is in Taiwan. Without palliative training, some studies suggest NH staff would default to culturally-based ritual-like behavior not prescribed by the nursing profession. Examples include 'opening the window to let the spirit go' in an NH in the US,¹⁸ or 'made a sign of the cross' as a patient passed away in an ICU in Rome.³⁰ Such rituals are embedded in the local culture. In this study, when a nurse wished not to be called by name, she rushed to Taoist ritual exorcisms for help and recited a sutra or mantra to pacify her mind demonstrating typical non-prescribed reactions of NH nursing staff in Taiwan. These typify the cultural resources relied on by staff to improve care capacity and lift the burden place on them in the absence of palliative training.

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Regarding insufficiencies felt by NH nursing staff, researchers suggest NH nursing staff should be offered continuous education and support regarding palliative care (31). Monitoring the dying is a difficult task for already over-worked staff, and any improvement in this area would seem to rest upon providing specific palliative training. Though not described here, a recent study provides an illustration of the need for palliative training for nursing assistants (32). Though participants in the present study unanimously hope for palliative training, continuous education for NH nursing staff in Taiwan has many obstacles to overcome such as labor shortages, tuition fees, a high turnover rate, and a lack of a pedagogical approach to training that includes consideration of cultural background.

It appears that the fear NH nurses have of lawsuits is closely related to the family's request of sending the dying resident home for the last breath. It has partly to do with their lack of proper palliative training. However, the findings suggest that the cultural dimension of the meaning of death and dying should be evaluated prior to any development of palliative training. Further, it suggests that education applied in Taiwan, where no palliative end-of-life care in NHs is traditionally provided, should be conducted with sensitivity to cultural nuances such as those elucidated in this study in order to give it the greatest chance of success.

Truth-telling and grief-comforting were also considered important. This training would involve communication with bereaved families, a resident's roommates, and comforting NH colleagues. Bereaved Taiwanese family members have a unique way of expressing grief in that family ethics always plays a more important role than individual concerns. Therefore, any training program for Taiwan must take into consideration such cultural behaviors, as suggested by a study of cultural factors in NHs. The current study further points to a strong need to develop such a culturally well-rounded program. The benefits of greater understanding of embedded cultural factors in NHs warrants further research.

Finally, the major limitation of a hermeneutic phenomenological study is that, while it can give a better understanding of what the issues are and how they come to form the current situation, it will not necessarily aid in prediction.

Conclusion

This qualitative study explored how NH nurses in Taiwan perceive the meaning of NH dying and death. It confirmed the previous findings of non-Asian studies about the significance of 'assessment of dying' and 'family communication' in quality NH care. It also found that the palliative training of nurses for caring the dying resident is much in need. Attention should be paid to the pressures put on nurses' by family requests, based on folk belief to send dying residents home for the last breath. While this unique situation of dying care holds true for NH

nurses in Taiwan, palliative training programs for NH nurses existing in countries such as U. K. and U.S. are still worthy of application, in modified form, to meet the explicitly-expressed needs of nurses in Taiwan.

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