

Living With Death and Dying: The Experience of Taiwanese Hospice Nurses

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Compared to Western countries, the idea of hospice and palliative care is relatively new to Taiwan. In 1990, the first inpatient hospice in Taiwan was opened to provide end-of-life (EOL) care for terminally ill patients with cancer. Since then, the number of hospice and palliative care programs has grown to include 37 inpatient care units, 50 homecare services, and 38 hospice shared-care service programs (Taiwan Hospice Organization, 2007). "Shared care" refers to a model in which a hospice care team provides services to the dying on nonhospice inpatient units. Challenges encountered by Taiwanese hospice and palliative care professionals include meeting the needs of a growing number of terminally ill patients with cancer and other illnesses, solving the difficulties associated with high-quality hospice and palliative care, and developing a culturally specific model of care (Lai, 2004).

Many studies of hospice and palliative care nursing have been conducted in Western countries (Barnard, Hollingum, & Hartfiel, 2006; Brannstrom, Brulin, Norberg, Boman, & Strandberg, 2005; Dunniece & Slevin, 2002; Gaydos, 2004; Georges, Grypdonck, & de Casterle, 2002). Most of the studies used a phenomenologic approach and focused on homogenous samples in terms of gender (dominant female), age, experience, and practice setting. Major findings included the importance of providing holistic care, having a good nurse-patient relationship, encountering stress and challenges, undergoing transformation, and applying stress-management strategies. The participants provided comfort care and respected and supported the decisions of dying patients and their families. Two published studies conducted with Taiwanese hospice nurses focused on job stress and coping strategies (Liao, Wu, Luan, Fu, & Lai, 2005) and spirituality (Chang, Wang, & Chen, 2006). In a third study that investigated the lived experience of 13 Taiwanese hospice nurses, Tsai, Tsai, and Liu (2006) used a hermeneutic, phenomenologic approach to investigate self-care as a response to death anxiety. They found that the self-care response involved the discovery of

Purpose/Objectives: To explore and describe the experiences of Taiwanese nurses who care for dying patients in hospices, a relatively recent healthcare option in Taiwan.

Research Approach: Qualitative, hermeneutic, phenomenologic approach.

Setting: Six hospices in central and southern Taiwan.

Participants: 14 Taiwanese hospice nurses.

Methodologic Approach: Interviews were audiotaped and analyzed with Colaizzi's guidelines.

Main Research Variables: Caregiving experiences of Taiwanese hospice nurses.

Findings: Four main themes emerged from the analysis: entering the hospice specialty, managing everyday work, living with the challenges, and reaping the rewards. Three subthemes of managing everyday work were providing holistic, meaningful care through close relationships; confronting and managing negative beliefs about hospice; and managing the dying process.

Conclusions: The fundamental structure of the caregiving experiences of Taiwanese hospice nurses is a dynamic, multidimensional process that evolved over time. The hospice nurses demonstrated how they achieved balance in their daily nursing practice within the Taiwanese cultural context.

Interpretation: Improved end-of-life education for the Taiwanese public, nurses, and other healthcare professionals that includes hospice concepts is needed. Administrators should provide adequate support to encourage and empower their nursing staff in hospice settings.

the primordial self, a coming to terms with frustration and anxiety, self-reflection, and self-transcendence. Of note, the study was framed as an investigation of death anxiety and did not examine a broader experience of hospice nursing. However, little is known about the caregiving experiences of Taiwanese hospice nurses. Research is needed to better support Taiwanese hospice nurses in the provision of high-quality EOL care within the Taiwanese cultural context. Therefore, the purpose of this hermeneutic, phenomenologic study was to explore the experiences of Taiwanese nurses who care for patients who die within hospice settings.

Methods

A hermeneutic, phenomenologic approach was used to explore the experience of being a Taiwanese hospice nurse. The phenomenologic framework, founded on the principle that individuals interact with a meaningful world, is concerned with conscious experiences of events or situations (Kvigne, Gjengedal, & Kirkevold, 2002). With its open, naturalistic, descriptive, and constructivist approach, the method allows the researcher to capture, interpret, and understand lived experiences.

Sample and Setting

A snowball sampling technique was employed for recruitment. Inclusion criteria were Taiwanese RNs who currently were working in hospice settings in Taiwan and had worked as hospice nurses in direct caregiving roles for at least one year in the prior five years. Ultimately, 14 nurses who met the inclusion criteria were interviewed. When no new themes emerged from analysis of the final two interview transcripts, the sample size achieved theoretical saturation.

Procedure

After an institutional review board approved the study, three Taiwanese hospice nurses assisted the researchers by recruiting potential participants. The principal investigator (PI) provided the assistants with recruitment packets that included a cover letter, a reply form, and a self-addressed stamped envelope for return to the researcher. Nurses who expressed interest in participating mailed the reply form or called the PI directly. After each interview was completed, the participants were asked whether they would like to identify other nurses who might wish to take part. If so, the nurses were given recruitment packets accordingly.

After written consent was obtained, the PI conducted face-to-face, audiotaped interviews (see Figure 1 for the interview guide) in Chinese that lasted 45–95 minutes. Demographic data also were obtained from the participants. After each interview, the PI recorded field notes.

Data Analysis

The PI transcribed the interviews verbatim in Chinese as soon as possible after each interview and translated them into English. A bilingual Taiwanese American and the PI checked the English transcripts against the Chinese versions to ensure accurate representation and equivalence of meaning of the narrative in the translation process. In addition, the PI consulted several native English speakers to review the translation for clarity and linguistic appropriateness to maximize the accuracy of the data. Thematic data analysis was completed with Colaizzi's (1978) guidelines for analyzing phenomenologic data.

- Please tell me what motivates you to be a hospice nurse.
- Tell me about your experiences in taking care of dying patients at work. What do you find good, bad, or difficult in this line of work?
- What meaning does your work hold for you?
- How has your work with dying patients affected you?

Figure 1. Interview Guide

Tools to promote study trustworthiness included use of preunderstanding, an audit trail, and peer review. The presuppositions (or preunderstanding) a researcher brings to research must be examined and explicated. Hence, the PI identified and reflected on personal experiences with caring for dying patients and their families as well as assumptions and other personal prejudices that might influence the study. An audit trail was used to record the PI's personal experiences and biases, interactions with the participants and their stories, and insights and decisions regarding data analysis and synthesis. The study coinvestigator reviewed the transcripts and analysis to ensure that the experiences and viewpoints of participants were presented accurately. Finally, four doctorally prepared nurse researchers reviewed the study results to ascertain the appropriateness and representation of the participants' experiences.

Findings

All 14 participants were women, with a mean age of 32.1 years (range = 24–41). Most participants were single ($n = 10$), had a religious affiliation ($n = 12$), and held a bachelor's degree ($n = 9$). The average length of time spent in nursing prior to becoming hospice nurses was 3.9 years, with 6.1 years in hospice nursing (range = 2.5–8.7). Hospice practice specialties were inpatient care ($n = 7$), shared care ($n = 4$), and home care ($n = 3$). The fundamental structure of Taiwanese hospice nurses' caregiving experiences is a dynamic, multidimensional process that evolved over time. Four themes emerged from thematic analysis of the 14 stories: entering the hospice specialty, managing everyday work, living with the challenges, and reaping the rewards.

Entering the Hospice Specialty

Entering the hospice specialty refers to a nurse's decision to care for dying patients and their families in a hospice and the process of becoming an experienced professional. Nurses in the current study based the choice on many factors, including an expectation of providing a higher quality of holistic care to dying patients and families, the humanitarian aspect of hospice care, and a sense of a calling or mission.

Hospice care stresses that we can't divide human life into parts, especially that we can't focus on

physical aspects but ignore the others. I like this idea. Hospice care is close to the kind of nursing job I wanted originally.

When I worked in a medical ICU [intensive care unit], I always did the same work, such as feeding, changing patients' positions, and doing regular two-hour duties, all of which seemed to be very mechanical actions. Finally, I applied to work at a medical ward, but I found that I only attended to patients' diseases. Then, I thought about the concept of holistic care.

Although the nurses had varying reasons for the specialty choice, hospice care was a new specialty for them. Initially, they lacked the knowledge and skills needed to care for terminally ill patients. All of the nurses made an effort to advance their professional knowledge and skills through attending workshops, in-service training, and mentoring. One nurse recalled that when she began her work in hospice, she was very impressed by the care and patience a senior nurse provided.

I remembered an old female patient who was a farmer with calluses on her feet. That's the first time I saw a nurse help a patient cut her nails and rubbed her calluses with a file while they were chatting. The patient was very happy. Wow, it's nursing. I was touched by this scene.

Managing Everyday Work

Managing everyday work refers to a nurse's role and daily nursing practice in hospices, a multidimensional process as evidenced by three subthemes.

Providing holistic, meaningful care through close relationships: Through close and trusting relationships with patients and their families, the nurses provided physical, psychological, and spiritual care; facilitated communication among patients, their families, and healthcare professionals; and respected the wishes of patients and their families.

Close relationships provided the nurses with thoughtful insights of patients' experiences. "We are good listeners. If you treat them as your family, you will find it seems easier to care for patients," a nurse said. Many nurses described reciprocal relationships and special feelings when they interacted with patients and their families.

I didn't know why I had a special connection with some patients' families. After the patients died, their families hugged me and cried just like I was part of their family.

The nurses tried to help dying patients discover meaning in their lives and make sense of their suffering and impending death.

Most of the time we help patients find their meaning of life because of their suffering. We always help

patients inspect their relationships with themselves, others, God, and the environment.

The nurses strove to fulfill the wishes of dying patients and their families. The wishes could be things patients had to do before death, including the desire to say good-bye to loved ones. For example, one nurse recalled an experience with a dying patient who wished to return to his home, which he had built on a mountain by himself.

I spent a vacation day to go with him and stayed one night with him at his home. . . . At that time his pain was not managed well, so he needed to carry PCA [patient-controlled analgesia] with him. . . . The main purpose of this trip was to attend his elder daughter's engagement. He was very serious about it.

Confronting and managing negative beliefs about hospice: The second subtheme refers to encounters with the negative views and conceptions of hospice held by patients, families, nonhospice physicians, and the nurses' own families. The nurses spoke of work to change people's opinions of hospice care within a social-cultural context in which death is taboo and hospice represents a place of hopelessness for those waiting to die. In that context, hospice care often is rejected as a viable option. Moreover, many patients refused hospice because they associated it with death rather than with comfort and dignity. Not surprisingly, some physicians misunderstood or lacked knowledge about hospice care, resulting in their hesitation to make referrals.

"Filial piety" is a traditional Chinese belief that children, particularly the eldest son, have a great obligation to protect, care for, and respect their parents. Therefore, negative beliefs about hospice care can result in problems for patients' families who decide to send patients to hospice. A nurse described a patient's daughter who rejected hospice care despite the fact that the patient's children were well educated.

They thought they were not showing filial piety if their father didn't receive any resuscitation at the final stage. They preferred that their father tolerate discomfort in a general ward rather than have him receive any hospice care. Their expectations were for the patient to receive endotracheal intubation, electric shock, or cardiac massage when he couldn't breathe.

For Taiwanese people, death is associated with bad luck. They avoid the subject of death in casual conversation. Such cultural and social avoidance of the idea of death and negative conceptions about hospice care affected the study participants. For example, some of the nurses were questioned about their selection of hospice nursing as a specialty by their own families and friends. One participant recalled that her mother disagreed with her hospice job because caring for dying persons is considered bad luck in Chinese culture.

My mom said, "You are so young. Do you want to care for dead persons and help them put on their shrouds? Hospice is bad."

Managing the dying process: The third subtheme refers to attempts by nurses to fulfill the wishes of actively dying patients and their families within the Taiwanese cultural context. In that process, the nurses experienced the challenges of managing the imminent death of patients and helping them to transition from life to death. One challenge specific to the Taiwanese culture is the common custom of "discharge due to terminal" or DDT status, which refers to the practice of discharging hospitalized hospice patients back to their homes when they are imminently dying. In Taiwanese culture, many people believe that the dying should die at home surrounded by their families. Therefore, some dying patients are quickly discharged from inpatient hospices and returned to their homes before they die.

The challenge of managing the imminent death of patients becomes particularly difficult when nurses try to predict when patients will die to notify the families for DDT. Sometimes, patients' families may have conflicting opinions about DDT.

Some families feel stressed and can't make up their mind to decide on DDT or not. Therefore, their patients will probably die before they arrive home. The family members get angry in that situation. It is also a big stress for hospice professionals. The family members wonder why we can't help their patients to be discharged more quickly.

In addition, the nurses emphasized the importance of providing postmortem care for dead patients and their families. Through the rituals of pre- and postmortem care, the nurses helped the patients to accomplish the transition from life to death, and they bid farewell to the dead patients.

It was the last moment, so we hoped the patients' families had the best memory at the last moment. Thus, postmortem care is very important for the patients.

Clearly, culture, religion, and society influence nurses' care of the dead. In Taiwanese culture and within certain religious beliefs, the dead must have various layers of shrouds put on and be kept undisturbed on the bed where they died for six to eight hours after death. In some instances, families request that the dying patient be placed in shrouds in the hours before death. Several nurses reflected on memorable experiences associated with the customs.

When I saw the patient's face, I was scared and stunned. The senior nurse didn't tell me the patient had become stiff and her face's skin color was bad because she died over six hours before. It was 3 am; I was too scared to see her. In that situation,

I couldn't cry but only finished my job. I couldn't believe how the senior nurse could do that job and how we put on seven shrouds.

Living With the Challenges

Living with the challenges refers to the way the nurses managed stress, difficulties, and challenges on the job. This is a complex process that encompassed care of dying patients and their families, the emotional impact, the negative beliefs about hospice, and the workload. All of the nurses expressed a desire to provide a higher quality of care to help dying patients experience comfort, peace, and dignity. When that goal of care could not be achieved, they felt stressed and upset.

The greatest difficulty is when patients still feel discomfort after we have applied all of the strategies. What can we do then? We felt restless as if we were sitting on a pin cushion.

Not surprisingly, the nurses sometimes questioned their career choice and subsequently began making decisions to stay or to leave the hospice specialty.

Sometimes I want to quit the job because it is an arduous job. You come off duty late and devote your body, mind, and spirit to this job. Actually, I have struggled to decide whether to quit the job or not. In my first and second years, I thought that I earned a low salary but spent much more time than eight hours, a working shift, on this job. We need to attend continuing education programs, spend a lot of time to care for patients', and attend meetings. In the third and fourth years I hit a bottleneck because I couldn't alleviate some patients and their families' suffering at the time of death. At that time I felt very tired. I worked every day and often faced death and grief, which are negative things.

Despite the existence of some unavoidable stresses and challenges associated with hospice work, the nurses described effective coping strategies to prevent themselves from succumbing to burnout. For instance, all of the participants discussed the importance of having support from their colleagues, families, and friends. One described the importance of support from the hospice team.

When we feel frustrated and stressed, the team members can support, understand, and accept us. When I talk about my thoughts, the team members can forgive me, listen to me, accept my crying, and give me a hug.

Religious belief and support were important for the nurses, particularly when they confronted and questioned the challenges in their work. The nurses who described greater reliance on religious beliefs tended to deal with the job-related stress, such as the unexpected

death of a patient, in a positive and purposeful manner. In addition, lifestyle strategies were essential to replenish the nurses in physical, emotional, psychological, and spiritual ways to overcome their stress. Strategies included eating healthful foods, sleeping well, exercising regularly, and engaging in relaxing activities.

Reaping the Rewards

The final theme refers to receiving positive feedback from dying patients and their families, feeling happy and energetic, and having a sense of self-worth from work. Nurses reflected on themselves and their changes in temperament, attitudes about life, and personal values while they cared for dying patients.

I have worked in the hospice for a long time and understood that I could provide good care to patients to help them have a good death. Their families also were well prepared for the death of their loved ones and felt calm and relaxed about dealing with this situation. The patient's feedback, the learning experiences I've had, and the caregiving experiences have touched me.

Through assisting patients and families to adjust to death and dying, the nurses not only experienced work satisfaction but also came to understand well how to care for and communicate with their own families.

I've learned how to interact with my family and plan my future. I didn't express my ideas often before. After working in the hospice, I communicate better with my mom and have more physical contact with my dad than before.

All of the nurses valued the learning and experiences they received from their patients. "Patients are like books. We can learn from our patients regardless of their good or bad experiences," a nurse said. Witnessing death and dying on a daily basis creates opportunities for the hospice nurses to reflect on themselves and search for the meaning of life and death. Most of the nurses said they became more open minded, learned what is important and what is not, and came to focus on the present. Many nurses stated that they became more empathetic, sensitive, and tender after working in hospices.

I remember that I was so easy to lose my temper before. But I have become more aware of myself after working in the hospice. I was always impetuous before, but now I'm patient while listening to others.

Discussion and Implications

All of the participants expressed a moral commitment to caring, to helping patients die with comfort and dignity, and to supporting the families in coping with the

death of loved ones. The commitment and motivation for being a hospice nurse to provide quality EOL care found in the current study are supported by nursing studies from Western countries (Ablett & Jones, 2007; Rosser & King, 2003). Numerous works emphasize the importance and meaningfulness of the nurse-patient relationship in hospice and palliative care (Barnard et al., 2006; Hawthorne & Yurkovich, 2003; Johnston & Smith, 2006). Through a good rapport with patients, nurses spoke of assisting patients with their search for meaning in life, experiencing their humanity in the face of death, and enriching their life experiences in their final days. The findings are congruent with other findings that support the value of a trusting nurse-patient relationship (Dunniece & Slevin, 2002; Georges et al., 2002; Mok & Chiu, 2004).

Despite hospice becoming an accepted form of care in Taiwan, the findings of the current study revealed several major barriers to late referrals or underutilization of hospice service. The barriers are congruent with studies from other countries, including negative beliefs about hospice, a lack of knowledge about hospice, and difficulty in accepting terminality (Sanders, Burkett, Dickinson, & Tournier, 2004; Schockett, Teno, Miller, & Stuart, 2005). The study participants spoke of common negative beliefs about hospice as the end of medical care, a sign of "giving up," only for patients who are imminently dying, or a place for those waiting to die, rather than as a form of comfort care that improves QOL for dying patients.

Death and dying are not only medical events but also sociocultural processes. Culture shapes individuals' attitudes toward a terminal diagnosis vis-a-vis advance directives, choice about resuscitation, hospice, and EOL care. Based on collectivistic orientation, family is paramount in Taiwanese culture, and family members are key players in hospice care. In this study, the nurses demonstrated an understanding of the values and wishes of patients and their families and respected their perspectives and ambivalence about accepting a terminal diagnosis and use of hospice care.

Dying at home is important across cultures for many dying patients and their families (McGrath, 2007; Tang, 2003). From the Chinese perspective, dying at home has a unique cultural meaning. The Chinese sayings "Die a natural death in your own place" and "Die surrounded by your children" represent a good death that ensures the dead will not become wandering spirits (Hsin & Macer, 2006; Tang, 2000). The traditional Chinese belief motivated some families to bring the dying patients home from hospice when death was imminent. The phenomenon of DDT presented a challenge for the nurses, particularly because they could not accurately estimate the time of death.

The nurses encountered additional cultural beliefs that patients and their families wanted to be upheld. For example, the nurses helped the dying patients to put on

several layers of shrouds or postponed the action until the patients had been dead six to eight hours. Some of the nurses recalled the experience and acknowledged it as special or challenging when they were novices in the hospice. However, the nurses consistently linked the philosophy of hospice and hospice care with Taiwanese cultural traditions and respected the wishes and cultural beliefs of the dying patients and their families.

Many factors contributed to the participants' experiences of stress. Stressors included unrelieved loss, grief, suffering, and indignities of dying patients and families; inadequate resources; a high workload; and a lack of staff. The findings are congruent with studies that have revealed stress and burdens associated with hospice nursing in other cultural settings (Hawkins, Howard, & Oyeboode, 2007; Payne, 2001). In addition, the emotional impact of hospice nursing on the participants was influenced by the nature of the nurse-patient relationship, their emotional investments, frequent exposure to loss, particular patients and families with whom the nurses identified, and the characteristics of patients such as patient age, diagnosis, and disease trajectory. The study findings are consistent with other Western studies that described similar stressors (Georges et al., 2002).

Although hospice care is demanding and challenging, the nurses experienced a sense of self-worth, job satisfaction, and changed attitudes about life. Feeling competent and happy in their nursing care gave them a sense of accomplishment and helped them to find and create meaning in their work. More importantly, the nurses valued the knowledge they gained from their patients and seemed to acquire an expanded awareness of environment and self. As they encountered patients close to death, they took the opportunity to reflect on the realities of loss, grief, and their own mortality. This was a turning point that enabled the nurses to develop a personal philosophy of death and a sense of meaning in life. The findings are supported in other studies of hospice and palliative care nurses across cultural settings (Ablett & Jones, 2007; Barnard et al., 2006; Dunniece & Slevin, 2002; Gaydos, 2004; Kirstjanson et al., 2001; Tsai et al., 2006).

The study findings suggest a number of opportunities to improve EOL care in Taiwan. Physicians and nurses play an important advocacy role in fostering the discussion of hospice and palliative care with patients and families. The provision of academic courses and continuing education programs regarding hospice and associated communication skills is a vital need for students and healthcare professionals. Nursing has an excellent training model within in the End-of-Life Nursing Education Consortium (ELNEC) program (www.aacn.nche.edu/elneec/index.htm). ELNEC initially was focused on improved EOL care within the United States but has since expanded its international outreach activities. Similarly, physician training has been led by the Education in Palliative and End-of-Life Care (EPEC) project (www.epec.net/EPEC/Webpages/index.cfm).

ELNEC and EPEC programs could be adapted and expanded for wider use within Taiwanese academic and clinical programs. As Taiwanese professional organizations such as the Hospice Foundation of Taiwan and the Taiwan Hospice Organization grow, international collaborations will enhance global delivery of quality EOL care.

Organizational climate and values are important strategies for stress reduction and staff retention. A hospice with well-defined policies and consensus on the mission and values rooted in a philosophy of hospice and a supportive atmosphere can enhance the collaboration of a hospice team. Administrators should provide adequate support, feedback, and shared rewards to encourage their staff through continuing educational programs, support and discussion groups, and counseling sessions for individuals. Structures and incentives for pairing senior nurses to mentor novices could enhance recruitment and retention of nurses new to the hospice specialty.

Limitations

Selection bias might be an issue in this study because the participants were referred to the researcher by several volunteer hospice nurses who might have their own reasons for choosing those they referred to the study. Although the study findings enhance understanding of the day-to-day experience of a small number of Taiwanese hospice nurses, they cannot be considered representative of Taiwanese hospice nurses beyond those interviewed.

Conclusion

The current study revealed the caregiving experiences of Taiwanese hospice nurses as an evolving journey. When a nurse opted to select the hospice specialty, she embarked upon an impressive journey that continually evolved. Death as a taboo is a traditional belief for Taiwanese people. Within this context, participants expressed respect for patients' autonomy and a desire to help them die with dignity and comfort within Taiwanese culture. Presence with the dying and respect for individual preferences and culture were seen as important to the nurse participants. The uniqueness of being Taiwanese hospice nurses reflected their need to respect and incorporate belief systems regarding the nature of death and dying into their practice within the Taiwanese cultural context.

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