



# From vulnerability to passion in the end-of-life care: The lived experience of nurses



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## ABSTRACT

**Purpose:** End-of-life (EOL) care is considered to be inherently difficult and vulnerable for patients and nurses. It also seems hard to develop passion for care during these problematic times. This study elucidates how EOL nurses interpret their care experience and how they transform their experience and mindset.

**Methods:** This study was conducted by organizing a reflective group based on the concept of group analysis for oncology and hospice nurses to share their experience. Thirteen registered nurses were enrolled from a medical center in northern Taiwan. Data drawn from the group dialogue was derived from six digitally recorded sessions and then analysed alone with the researcher's diaries and participants' feedback sheets. Interpretative Phenomenological Analysis (IPA) was used to analyze the data.

**Results:** The results showed that nurses who provide EOL care actually experience suffering by witnessing patients' suffering. However, the suffering authentically drives the nurses to encounter their own inner selves, to induce the shift of mindset, and then allow them to continuously provide and maintain the passion in EOL care.

**Conclusions:** This study provides a new viewpoint for understanding of EOL nurses' experiences, indicating that this line of work may be recognized as a privilege. We recommend that the setting of a nurse reflective group is important and it may be considered in providing EOL care training for nurses. Hopefully the study results could shed lights for future policies regarding EOL care.

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## 1. Introduction

It is difficult to be a nurse in times of nursing shortages and modernization of the medical workplace. In the 21st century, modernization and advanced technology represent the mainstream contemporary form of medicine and have generated unique features in the clinic (Armstrong, 1987; Nairn, 2015). When the focus of modern medicine is on saving or prolonging life rather than caring the personal demands of patients, appropriate care and humanity may be ignored. The aforementioned situation raises profound challenges in nursing, especially in end-of-life (EOL) care, although the hospice movement has developed from a reaction against this longstanding trend (Brummen and Griffiths, 2013).

Consequently, conflict can arise between the nursing paradigm and humane care, and complex ethical and moral dilemmas may emerge (Goh, 2012; Johnson and Gray, 2013). Meanwhile, critical global issues surround work-related traumas, such as compassion fatigue within nursing practice, particularly in certain areas such as the intensive care unit (ICU), the emergency room (ER), oncology wards and hospice units (Ablett and Jones, 2007; Mealer and Jones, 2013). Nurses who provide EOL care are recognized as high-risk professionals in terms of compassion fatigue (Corso, 2012) due to the demands of this type of care (Wilson, 2014), which means that these nurses can easily become distressed and run-down in the workplace. Therefore, it may seem difficult to maintain passion for care during these problematic times, but passion is essential for nurses to stay within the profession.

EOL care is considered inherently difficult for both patients and nurses. Nurses who work within the field are frequently exposed to various levels of negative experiences, such as emotional pain, overload or work-related stress (Ablett and Jones, 2007; Boroujeni

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et al., 2008; Johnson and Gray, 2013). For nurses themselves, the most difficult part of these experiences is not only the physical labour but also the emotional and spiritual labour that includes anxiety, powerlessness, uncertainty, distress, grief, and frustration (Browall et al., 2014; Luxardo et al., 2014; Wilson, 2014). Suffering also comes from witnessing patients suffer. Performing cardiopulmonary resuscitation (CPR) is an example of direct patient care and is said to be a traumatic experience; some nurses have described this intervention as torturous (Mealer and Jones, 2013). Indirect exposure, such as the observation of patients suffering or inevitable death, can also add to the emotional pain of a nurse (Browall et al., 2014; Mealer & Jones, 2013).

Traditional nursing education trains nurses to care patients with compassion, altruism and competence. However, such training fails to teach nurses how to live within the modern practice environment that emphasizes economics, efficiency and task-orientation (Ruth-Sahd, 2014). Moreover, nurses are assumed to have the ability to take care of themselves including manage the conflicts and the emotions generated in such environments (Dahlke and Stahlke Wall, 2016; Newham, 2016). Most nurses do not leave themselves enough time to reflect on what happens after a patient's death. Because they do not have time to deal with these circumstances, the nurses also feel that their managers do not appreciate the stress caused by EOL care (Wilson, 2014). Additionally, traditional Chinese culture does not encourage nurses to discuss issues associated with death; instead, nurses are expected to give hope to EOL patients (Dong et al., 2016). Therefore, nurses who provide EOL care could be viewed as vulnerable or as “the caretakers of suffering” (Luxardo et al., 2014). Nurses need to be supported adequately by regular staff meetings and continuous education (Wilson, 2014; LeBaron et al., 2017).

However, previous studies have verified suffering as an opportunity for nurses to transform or modify their personal and professional selves, which allows nurses to embrace their suffering and to value it rather than dismiss it (Huang et al., 2016). As indicated by Browall et al. (2014), nurses view the experience of EOL care as a privilege, giving them new insight into their own lives. Nonetheless, for some nurses, dismissing the experience is the only option (Hanson and Taylor, 2000).

Currently, most research efforts have concentrated on EOL patients' needs, feelings and the quality of care. Instead, less attention has been paid on EOL nurses' feelings and how they maintain passion while providing EOL care. Thus, the goal of this study was to explore nurses' lived experiences in the provision of EOL care.

## 2. Methods

This study used Interpretative Phenomenological Analysis (IPA), which is an inductive approach to qualitative, experiential research (Smith et al., 2009). Our study examined how EOL care nurses make sense of their major lived experiences by exploring nurses' relatedness to, or involvement in, a particular event or process (phenomenon). Based on IPA perspectives, participants can set their own agenda and talk about their own priorities in their own terms. This study included a reflective group based on the concept of group analysis. Group analysis is a psychotherapeutic technique that is theoretically founded in psychoanalysis (Pines, 1996). The reflective group in this study was unstructured and unrestricted, focusing on the here and now, with the only set question being like “Does anyone want to share something today?” The researcher acted as the facilitator for the group interaction, but did not impose on the group dialogue (Buber, 1988; Foulkes, 1991). Therefore, the participants could speak freely with reflectivity. In our six group dialogues, although the topics and interview guidelines were not previously established, the participants usually shared their

working experiences and their lived experiences. Some issues emerged repeatedly in different sessions. The relationships between the six sessions are interwoven and interconnected.

### 2.1. Participants

An intentional sampling of 13 female nurses was conducted at a 1800-bed military hospital in northern Taiwan. Including the main campus, the hospital consists of four branches which are distributed in different locations. Participants were invited by flyers that the researcher brought to wards related to EOL care. At the meeting with the nursing staff, the researcher explained the purpose of this study and how the study would be conducted. Nurses who were interested could contact the researcher to sign written consent forms. All participants were trained nurses, and the majority of their nursing experiences included providing direct nursing care to EOL patients. However, most of them had not received formal training related to palliative or hospice care. The nurses had provided care in settings such as cancer, hospice, and paediatric oncology wards. The average age of the participants was 38.4 years, with an average number of working years of 12.6. Regarding education, six of the participants held bachelor's degrees, five held master's degrees, and two had degrees associated with a nursing college. Only 3 participants were married. Five participants joined all six sessions, and the others joined at least 3 sessions. The average number of sessions joined was 4.5.

### 2.2. Ethical consideration

The study was conducted in accordance with the Helsinki Declaration and was approved by the Institutional Review Board on human subjects for the National Taiwan University Hospital (201208HS014). Permission to conduct the study was obtained from the head of the medical center where the study took place. All participants were fully informed about how to protect confidentiality and the anonymity of the data. Additionally, the participants were free to withdraw at any time. In addition, personal counselling was provided to the participants when they needed psychological support during and after the six sessions for six months.

### 2.3. Data collection and analysis

The first author served as the conductor, facilitated the group dialogue sessions every week for a total of six sessions. The length of each session ranged from 90 to 120 min. The group dialogue was recorded digitally and transcribed, and the data from the six sessions were analysed, including the researcher's diaries and the participants' feedback sheets. The transcript was analysed using thematic analysis techniques from the IPA. The primary concern of the IPA is the lived experiences of the participants and the meaning that the participants took from them. The end result is always an account of how the researcher thinks a participant is feeling, which is a double hermeneutic process (Smith et al., 2009). The analysis process was conducted as follows. First, the researcher listened to the audiotape of each group dialogue and created transcripts. Each transcript was read line by line several times, and key descriptive, linguistic and conceptual comments were noted on each transcript. The task of this level was the management of data changes to identify emergent themes as the researcher simultaneously attempted to reduce the volume of details to map the interrelationships, connections and patterns between the initial notes. The preliminary themes were abstracted and clustered into groups of themes according to common features in terms of meaning. After analysing the first transcript, the researcher reanalysed the themes as part of the dialogue context to verify whether

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