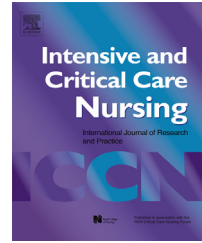




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ORIGINAL ARTICLE

Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study



Richard B. Arbour^{a,*}, Debra L. Wiegand^b

^a In-Patient Liver Transplant Coordinator, Thomas Jefferson University Hospital, Philadelphia, PA, USA

^b University of Maryland School of Nursing, Baltimore, MD, USA

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KEYWORDS

Palliative care;
End-of-life;
Nursing roles;
Family presence;
Patient/family
advocacy

Summary

Background: Critical care nurses frequently care for dying patients and their families. Little is known about the roles experienced and perceived by bedside nurses as they care for dying patients and their families.

Objectives: The purpose of this study was to understand the experiences of critical care nurses and to understand their perceptions of activities and roles that they performed while caring for patients and families during the transition from aggressive life-saving care to palliative and end-of-life care.

Methods: A descriptive, phenomenological study was conducted and a purposive sampling strategy was used to recruit 19 critical care nurses with experience caring for dying patients and their families. Individual interviews were conducted and audio-recorded. Colaizzi's method of data analysis was utilised to inductively determine themes, clusters and categories. Data saturation was achieved and methodological rigour was established.

Results: Categories that evolved from the data included educating the family, advocating for the patient, encouraging and supporting family presence, managing symptoms, protecting families and creating positive memories and family support. Participants also identified the importance of teaching and mentoring novice clinicians.

Conclusions: The results of this study have important implications for clinical practice, education and research for optimal preparation in providing end-of-life care.

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* Corresponding author. Tel.: +1 215 549 1158; mobile: +1 267 243 1470.
E-mail address: RichNrs@aol.com (R.B. Arbour).

Implications for Clinical Practice

- Many nurses may be unprepared for roles they encounter providing care for dying patients and their families.
- Study benefits include improved education for nurses in caring for dying patients and their families.
- Education about anticipated roles may better prepare nurses for the demands of patient and family care at end-of-life.
- Study findings can be incorporated into nursing orientation/preceptorship, undergraduate and graduate nursing education.
- Future research should be directed at best practices to mentor, teach and prepare nurses to provide optimal end-of-life care.

Introduction

Critical care nurses provide care to dying patients and their families. In critical care units the mortality rate ranges between 6.04% and 14.4% depending on diagnosis (Society of Critical Care Medicine, 2012). One context of care for dying patients and their families is when a patient dies despite aggressive curative care. A second context is caring for dying patients and their families when decisions have been made not to pursue aggressive curative care or resuscitation. This second circumstance applies to most patients who die in critical care units as decisions to withhold and withdraw life-sustaining therapies are made by families and health care teams with patient care transitioning from life-saving to palliative and end-of-life care (Wiegand, 2008).

Several factors influence how nurses care for dying patients and their families as well as roles and role expectations during the transition from aggressive curative to palliative and end-of-life care. Nurses may be influenced by prior experiences such as the death of a family member as well as death and dying in the clinical setting. If nurses perceive role confusion during the care of dying patients and their families this increases the degree of stress experienced, limiting effectiveness in providing care and compounding their grief responses (Stayt, 2007). The degree of coping effectiveness in response to imminent and actual patient death may also be affected by role confusion and stress experienced during care of dying patients and their families (Stayt, 2007). Avoidance and compartmentalisation of feelings and grief without expression may lead to cumulative stress, ineffective coping and burnout (Gerow et al., 2010). Nurses have reported that ritualistic caring practices such as ceasing unnecessary monitoring, discontinuing aggressive treatments and making the deceased or dying patient look "good" or "presentable" for the family helps with coping (Shorter and Stayt, 2010).

Nurses provide vital care to patients and families at the end-of-life. Researchers have described the important role that critical care nurses perform when they "plant the seed" beginning pivotal discussions regarding goals of care (Fridh et al., 2009; McMillen, 2008; Norton & Bowers, 2001). After nurses plant the seed, important meetings are often held so that discussions can occur with families, advance directives can be discussed and end-of-life decisions can be made (Fridh et al., 2009; McMillen, 2008). Additional vital aspects of family care include ensuring that patients do not suffer, helping relatives feel less uncomfortable and more accepting of the dying process as well as using nursing "presence" so families feel comforted and supported (Fridh

et al., 2009). Critical care nurses have a vital role in facilitating meetings between families and the critical care team.

After decisions are made to cease aggressive, curative treatment, critical care nurses play an active role in facilitating the timing of withdrawal of aggressive treatments as well as ensuring that families have time to spend at the patient's bedside to say good-byes (Fridh et al., 2009; McMillen, 2008). Coordinating optimal timing of treatment withdrawal is important to family members and communicates dignity and compassion (McMillen, 2008). Addressing symptoms of distress, making the environment more comfortable for the patient and family, facilitating a comfortable death and managing one's own emotional state are important across multiple disciplines (Waldrop and Nyquist, 2011).

Although critical care nurses frequently care for patients and their families as care transitions to palliative and end-of-life care little is known about how this is experienced by individual nurses with particular regard to the roles they perform. The purpose of this study was to improve understanding of the role perceptions experienced by critical care nurses during transition from aggressive, life-saving care to palliative and end-of-life care. Understanding the roles performed by critical care nurses during these transitions is important in the education, training and orientation of critical care nurses.

Methods

This descriptive, phenomenological study sought to answer the question, "What do critical care nurses experience and what are their perceptions of their roles while caring for patients and their families during the transition from aggressive, life-saving to palliative and end-of-life care. Coliazz's methodology (Coliazz, 1978; Sanders, 2003) for conducting phenomenological research was used to guide the investigation. Following research proposal development and review, the protocol, with supporting documents, recruiting tools, scripted interview questions and demographic questionnaire was submitted for approval to the Institutional Review Board of Albert Einstein Medical Center, where this study was conducted. Following IRB approval, participant recruitment and data collection began. One investigator (RA) conducted all interviews. The investigator encouraged study participants to describe the lived experience of caring for dying patients and their families. A broad question was asked initially followed by additional follow-up probing questions to gain further insight into the lived experience to understand each nurses perceptions of their roles. This research reported in

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