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ORIGINAL ARTICLE

Intensive care nurses' experiences of end-of-life care

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Withdrawal and withholding of treatment

Summary
Purpose: To explore intensive care nurses' experiences of end-of-life care in adult intensive care units.
Design and methods: An exploratory, descriptive qualitative approach was utilised. Purposive sampling method was used to select nurse participants ($n = 24$) working at the selected intensive care units in the three academic affiliated, tertiary specialist hospitals in the Johannesburg and Pretoria regions, South Africa. Using a focus group guide, three focus group discussions were conducted. Data were analysed using the long-table approach (Krueger and Casey, 2000). Trustworthiness of the study was ensured by following the criteria set out by Lincoln and Guba (1985).
Findings: Five major themes related to nurses' experiences of end-of-life care emerged. These included: ''difficulties we experience'', ''discussion and decision making'', ''support for patients'', ''support for families'' and ''support for nurses''.
Conclusion: End-of-life care can be difficult and a challenging process. Nevertheless, this study has highlighted some of the interventions and support systems that could be incorporated for improved caring process. Whereas the dying patients and their families need to be continuously supported, critical care nurses too need to be taken care of for them to continue providing the best possible end-of-life care.
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Implications for Clinical Practice

- Relieve the nurse of all other responsibilities in order for him or her to have time to focus on caring for the dying patient and the family.
- As a form of collegial support, senior and experienced nurses should mentor the junior and newly qualified nurses to improve end-of-life care and enhance their coping abilities.
- As a nurse's coping strategy, let a group of nurses take turns caring for a dying patient by means of change of shifts on a daily basis.

Introduction

Whereas critical care physicians and nurses care for critically ill patients with the primary goals of saving lives and restoring function (Festic et al., 2010), there is evidence that approximately 20% of intensive care unit (ICU) patients die in this setting each year (Coombs et al., 2012). Many of these deaths involve withholding or withdrawing life-sustaining therapies and, in these situations, the role of ICU nurses shifts from providing life sustaining measures to end-of-life care (Espinosa et al., 2010).

ICU nurses' involvement in end-of-life care differs from setting to setting. For example, in a European study that comprised of 162 respondents, the majority ($n = 145/158$, 91.8%) indicated direct involvement in end-of-life patient care, 73.4% ($n = 116/158$) reported active involvement in the decision-making process while 78.6% ($n = 125/159$) expressed commitment to family involvement in decisions (Latour et al., 2009). A South African study that involved 100 participants revealed that 76% ($n = 68/90$) of nurses had had direct involvement in end-of-life care of patients, 35% ($n = 24/68$) had been actively involved in the decision making process whereas 86% ($n = 85/99$) were committed to family involvement in decisions (Langley et al., 2013). In a study from Turkey, all ($n = 602$) nurse participants stated that they had had direct involvement in end-of-life care of patients. Of these nurses, 25.2% ($n = 152$) had been actively involved in discussions about end-of-life decisions while 78.4% ($n = 472$) were committed to family involvement in decisions (Badır et al., 2015).

Nurses are in a central position to improve care for dying patients and their families by challenging current end-of-life practices in their settings (Zomorodi and Lynn, 2010). King and Thomas (2013) state that nurses accept the reality of death and express strong commitment to making it as comfortable, peaceful and dignified as possible. However, providing the best possible care at end-of-life is a challenge to intensive care nurses (Coombs et al., 2012). The care process exposes ICU nurses to grief and human suffering (Ranse et al., 2012), creates anxiety and uncertainty on how to cope with the procedures that surround death (Peters et al., 2013) as well as burnout and emotional exhaustion (Ryan and Seymour, 2013).

While nurses play a pivotal role in helping both patient and family to have positive and meaningful experiences at the end-of-life (Ranse et al., 2012), nurses have reported difficulties in this role (Iglesias et al., 2013). They have expressed difficulty in balancing their professional role and personal feelings, leaving them questioning whether they are 'doing the right thing' (Efstathiou and Walker, 2014). Nurses have also identified barriers to providing optimal care contributing to their frustrations (Espinosa et al., 2010; Festic et al., 2010).

Critical care nurses report a lack of preparation in dealing with end-of-life care in the intensive care environment (Zomorodi and Lynn, 2010), a report that could be associated with inadequate education about end-of-life care at pre-registration level (Cavaye and Watts, 2014). The care patients receive in the ICU is highly dependent on the ICU nurse's knowledge, skill and comfort level in caring for the dying patient and the family (Harris et al., 2014). For this reason, education and training opportunities are essential to ensure ICU nurses develop the right knowledge and attitude to provide high-quality end-of-life care (Efstathiou and Walker, 2014).

There is a report that insufficient emotional and organisational support may influence the care provided and affect nurses' experiences of end-of-life care, stress and ability to cope (Ranse et al., 2012). Harris et al. (2014) mention that nurses are the caregivers who provide the most direct care and spend the most time with patients and their families thus, it is essential that they feel empowered and are given the necessary support to provide optimal end-of-life care.

Compared to the developed and other developing countries, South Africa has a quadruple burden of disease specifically because of its added burden of injuries and HIV/AIDS (Econex, 2009). An ICU mortality rate of 31.5% (De beer et al., 2011) shows that death and dying is a common occurrence in this setting. A previous study revealed that nurses have direct involvement in end-of-life care of patients and families in this setting (Langley et al., 2013). Despite of this, little is known about ICU nurses' experiences of providing end-of-life care. This study thus aims to explore South African ICU nurses' experiences of end-of-life in order to provide a basis for the development of interventions and support systems in the provision of quality end-of-life care.

Method

Research design, setting, sampling and sample

An exploratory, descriptive, qualitative design was utilised. Nurses working in general (medical—surgical), trauma and cardiothoracic adult ICUs at three academic affiliated tertiary (referral) hospitals in the Johannesburg and Pretoria regions were purposively selected. Three focus group discussions (one from each hospital) were conducted. In total, twenty-four nurses participated in the study. The inclusion criteria were: nurses who had more than six months' experience in the unit, permanently working in the adult ICUs at

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