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Negotiated reorienting: A grounded theory of nurses' end-of-life decision-making in the intensive care unit

International Nurses' End-of-Life Decision-Making in Intensive Care Research Group
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ABSTRACT

Background: Intensive care units (ICUs) focus on treatment for those who are critically ill and interventions to prolong life. Ethical issues arise when decisions have to be made regarding the withdrawal and withholding of life-sustaining treatment and the shift to comfort and palliative care. These issues are particularly challenging for nurses when there are varying degrees of uncertainty regarding prognosis. Little is known about nurses' end-of-life (EoL) decision-making practice across cultures.
Objectives: To understand nurses' EoL decision-making practices in ICUs in different cultural contexts.
Design: We collected and analysed qualitative data using Grounded Theory.
Settings: Interviews were conducted with experienced ICU nurses in university or hospital premises in five countries: Brazil, England, Germany, Ireland and Palestine.
Participants: Semi-structured interviews were conducted with 51 nurses (10 in Brazil, 9 in England, 10 in Germany, 10 in Ireland and 12 nurses in Palestine). They were purposefully and theoretically selected to include nurses having a variety of characteristics and experiences concerning end-of-life (EoL) decision-making.
Methods: The study used grounded theory to inform data collection and analysis. Interviews were facilitated by using key questions. The comparative analysis of the data within and across data generated by the different research teams enabled researchers to develop a deeper understanding of EoL decision-making practices in the ICU. Ethical approval was granted in each of the participating countries and voluntary informed consent obtained from each participant.
Results: The core category that emerged was 'negotiated reorienting'. Whilst nurses do not make the 'ultimate' EoL decisions, they engage in two core practices: consensus seeking (involving coaxing, information cuing and voice enabling); and emotional holding (creating time-space and comfort giving).
Conclusions: There was consensus regarding the core concept and core practices employed by nurses in the ICUs in the five countries. However, there were some discernible differences regarding the power dynamics in nurse–doctor relationships, particularly in

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relation to the cultural perspectives on death and dying and in the development of palliative care. The research suggests the need for culturally sensitive ethics education and bereavement support in different cultural contexts.

What is already known about the topic?

- A three-stage EoL trajectory in ICUs has been identified: hope of recovery following admission; move from treatment to care; and to 'a controlled death' (Coombs et al., 2012);
- Doctors make treatment withdrawal decisions and nurses are 'tasked with operationalising' the decision-making in ICUs (Long-Sutehall et al., 2011);
- Ethical dilemmas occur in relation to the withholding and withdrawal of treatment and there are variations in practice across countries (Sprung et al., 2003);
- Nurses employ a range of strategies and roles in EoL decision-making (Adams et al., 2011).

What this paper adds

- This cross-cultural exploration of nurses' involvement in end-of-life ethical decision-making practices in ICU extends knowledge of common factors in five diverse cultures: Brazil, England, Germany, Ireland and Palestine;
- The study offers a grounded theory of nurses' EoL decision-making practices in the ICU context identifying a core category of *negotiated reorienting*;
- The findings support consensus regarding the core category and core practices (*consensus seeking* and *emotional holding*) that enable reorientation to occur in relation to EoL decision-making. There are also suggestions of cultural and professional differences in relation to nurse autonomy in the ICU, religion, attitudes to death and dying, the provision of palliative care and resource constraints.

1. Introduction

Intensive Care Units (ICUs) provide increasingly sophisticated treatments to those who are critically ill. Nurses who work in these areas require a high level of knowledge and skill to negotiate technical and pharmacological interventions designed to save and extend life. When life-prolonging interventions are considered futile or to prolong the suffering of patients and families, decisions are required regarding their cessation and the move to comfort or palliative care. Given their proximity to patients and families, nurses working in ICU have an important role in end of life decision-making. These decisions are ethical in nature as they relate to quality and sanctity of life and to balancing ethical principles such as respect for autonomy, do good, minimise harm and treat people justly (Beauchamp and Childress, 2013). Although there has now been significant research in Europe, Australia and North America regarding nurses' roles in, and experience of, ethical decision-making in EoL situations in the ICU (for example, Halcomb et al., 2004; Inghelbrecht et al., 2009; Latour et al., 2009; Long-Sutehall et al., 2011; McMillen, 2008; Oberle and Hughes, 2001; Westphal and McKee, 2009) there has been little research exploring nurses' EoL decision-making practices across cultures, particularly between European countries, South America and Western Asia. This study aimed to begin to remedy this research deficit.

2. Background

The ICU has been described as the 'highest mortality unit' in any hospital (Lee IHPS 2013). Estimates of the percentage of patients who die in the ICU vary. In the US it is estimated at between 8% to 18% (ibid) and in Australia the death rate is estimated as between 15% and 20% (Halcomb et al., 2004). The UK death rate is 17.1% of admissions (ICNARC, 2010). For patients admitted to ICU the overall mortality rate is 19% in Ireland (The Irish Critical Care Trials Group, 2008). For the countries in our study, the overall score in the 'Quality of Death Index' (Economist Intelligence Unit, 2010 p. 11) puts the UK (1st/best), Ireland (4th) and Germany (8th) high on the overall index score and Brazil (38th) relatively low. The Index scores countries in relation to 4 categories: basic EoL healthcare environment; availability of EoL care; cost of EoL care; and quality EoL care. Palestine is not scored. The report emphasises the importance of combating the stigmatisation of death and, by association, of palliative care in some cultures and the need for more training in palliative care.

A definition of EoL decision-making was proposed by Thelen (2005 p. 29) as: 'the process that healthcare providers, patients and patients' families go through when considering what treatments will or will not be used to treat a life-threatening illness'. Such decision-making becomes more challenging in contexts of uncertainty and when a transition from therapeutic intervention to EoL or palliative care is considered (Coombs et al., 2012). Exploration of the practices of nurses in EoL decision-making and the factors affecting their decisions can serve to raise awareness of and improve EoL care. International comparison of the nursing role in EoL decision-making in ICU highlights challenges and requires consideration as to how to ensure that ethical and compassionate care is a global reality in ICU. It has been argued that 'understanding ethical decision-making is an important part of understanding professionals' enactment of their moral agency' (Rodney et al., 2002 p. 76). Ethical and clinical decision-making are inextricably linked and whilst not all EoL decisions raise ethical problems, they all raise ethical issues. These issues relate to quality and sanctity of life and