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ORIGINAL ARTICLE

Perceptions of a good death: A qualitative study in intensive care units in England and Israel

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Summary
Objectives: To explore factors perceived to contribute to 'a good death' and the quality of end of life care in two countries with differing legal and cultural contexts.
Design and methods: Multi-centre study consisting of focus group and individual interviews with intensive care nurses. Data were analysed using qualitative thematic analysis; emotional content was analysed using specialist linguistic software.
Settings/participants: Fifty five Registered Nurses in intensive care units in Israel ($n = 4$) and England ($n = 3$), purposively sampled across age, ICU experience and seniority.
Findings: Four themes and eleven sub-themes were identified that were similar in both countries. Participants identified themes of: (i) timing of communication, (ii) accommodating individual behaviours, (iii) appropriate care environment and (iv) achieving closure, which they perceive prevent, and contribute to, a good death and good quality of end of life care. Emotional content showed significant amount of 'sadness talk' and 'discrepancy talk', using words such as 'could and 'should' when participants were talking about the actions of clinicians.

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Conclusions: The qualities of a good death were more similar than different across cultures and legal systems. Themes identified by participants may provide a framework for guiding end of life discussions in the intensive care unit.

Implications for Clinical Practice

- There is much discussion in the literature about patient and family involvement in decision-making; our findings emphasise the need for simple communication with families and patients at key points in the patient's intensive care journey.
- Nurses can play a part, not just in decision-making (Benbenishty et al., 2006), but in supporting physicians to communicate with patients in the process of dying and initiating this process with their physician colleagues.
- Whilst the guidance for end of life care in the United Kingdom (UK) has recently been subject to a major review (Leadership Alliance for the Care of Dying People, 2014), this does not relate specifically to the intensive care unit. Our findings indicate that clearer guidance for end of life care in the intensive care environment in both countries would be of value.

Introduction

The goal of intensive care unit (ICU) care is to save lives however despite these efforts, recent multi-centre studies show ICU mortality ranging from 10.8% to 19.1% (Capuzzo et al., 2014; Checkley et al., 2014). For many patients who die in the ICU a decision has been made to change the goals of care from saving life to providing a quality death. However, identifying patients who are likely to die is not easy, given the often complex and dynamic disease state (Coombs et al., 2012). While a consensus has been reached regarding what is considered quality end of life (EoL) care (Nelson et al., 2006), previous studies have demonstrated variability in EoL care across countries and between intensivists within hospitals (Esteban et al., 2001; Ferrand et al., 2001; Wunsch et al., 2005). In an earlier phase of the current study, the authors used the palliative quality measures (PQM) for ICU, developed through an extensive programme of work in the United States (Nelson et al., 2006), to examine applicability in ICUs in Israel ($n = 4$) and the UK ($n = 3$) (Endacott et al., 2010). Pain assessment and management were the PQM most commonly documented across the two countries; documentation practices for measures such as social work support and spiritual support were different between the two countries, indicating that the PQM was not necessarily sensitive to the structures and practices of these countries (Endacott et al., 2010).

Different preferences and expectations for EoL care in ICU have been reported between patients, the public and clinicians (Endacott and Boyer, 2013; Sprung et al., 2008), with families having a myriad of factors, such as cultural beliefs about life and trust in doctors' decisions, that may influence their perspective (Stonington, 2013). Whilst conflict between clinicians is more likely to be reported when a patient has died (Azoulay et al., 2009), landmark international comparative studies — ETHICUS (Sprung et al., 2008) and ETHICATT (Sprung et al., 2007) — showed differences in EoL actions (Sprung et al., 2008) and attitudes (Sprung et al., 2007) between northern and southern Europe; England and Israel, respectively, contributed data to these two categories of countries. There are also key differences in the medico-legal framework and extent of public awareness surrounding EoL issues in the two countries, for example overt religious involvement in development of the legal framework and presence of committees to consider ethical dilemmas arising from care (see Table 1). We sought to examine in-depth whether legal and cultural differences between England and Israel were reflected in nurses' views of what is considered a good death in the ICU or what factors are associated with quality of EoL care in both countries. As nurses commonly illustrated their responses with patient stories, we also examined the language used in the patient stories for emotional content. Therefore the aims of this study were to: (1) identify factors that nurses perceive to contribute to a good death and quality of ICU EoL care in England and Israel, (2) examine whether experiences differed by ICU or by country and (3) explore emotional content of patient stories relayed by nurses.

Methods

We designed a qualitative study employing semi-structured individual and focus group interviews with ICU nurses in England and Israel. Data collection took place between 2011 and 2013.

Settings

The study was conducted in three general ICUs in England and four ICUs in Israel.

Participants

Using a purposive sampling strategy, Registered Nurses (RNs) in the participating ICUs were invited to take part in a focus group or individual interview lasting approx. 45—60 minutes. Study information was provided by local investigators (JB,

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