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

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### **ABSTRACT**

#### 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.

#### Results

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.

## 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 ICU.

## Keywords

Communication, End of life, intensive care unit, linguistic inquiry, nurse, qualitative research, focus groups

Abstract: 194 words

Main text: 3524 words

## 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%- 19.1% (Checkley et al 2014, Capuzzo 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 EoL care (Nelson et al 2006), previous studies have demonstrated variability in EoL care across countries and between intensivists within hospitals (Wunsch et al 2005, Ferrand et al 2001, Esteban et al 2001). 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 & 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.

INSERT TABLE 1 HERE

## 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 2011-2013.

### 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, FG, MB, HR, WC, CB) and study recruitment was undertaken by the lead investigator (RE) and the local investigator who explained the study in detail. The sample included RNs across age range, ICU experience and seniority.

### Data collection

The interview schedule for individual and focus group interviews was modelled on work undertaken in the United States to develop a quality measure for EoL care in ICU (Nelson et al 2006). Interviews in both countries were conducted by the lead investigator (RE), an experienced qualitative researcher, with a local co-investigator, and were audio-taped. Data collection ceased when data saturation was achieved.

Interviews were conducted in English in both countries. In Israel, most nurses speak English well however when participants did not understand a comment or question by the interviewer, a translation was given by the co-investigator who attended the interview. When a participant shifted from English into Hebrew, the co-investigator translated, to allow the interview to progress; this took place in the presence of the original speaker, who then verified that the translation was correct. In addition the content was later transcribed and translated verbatim to ensure the original meaning was captured.

Trustworthiness (or reliability) of the focus group interviews was addressed through use of a consistent process over the data collection period (stability), consistency of moderators and coders (equivalence) and consistency of overall responsibility (internal consistency) (Kidd & Parshall 2000). Further, the use of patient stories by participants

to supplement a view put forward by another group member indicates consensus, as distinct from simple acquiescence (a threat to the validity of focus group data) (Onwuegbuzie et al 2009).

The study was approved by human ethics committees in both countries and was conducted in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All participants gave informed written consent prior to their inclusion in the study. Details that might disclose the identity of the participants are omitted.

### Data analysis

Audio tapes were transcribed verbatim and analysed using thematic analysis through the five step process of: familiarization with data, generating initial codes, searching for sub-themes and themes among codes, reviewing themes, defining and naming themes in order to produce the final analysis (Braun & Clarke 2006). All data were initially coded by the lead author (RE); trustworthiness of the coding was established by two further members of the research team (FG, JB) independently coding 20% of the data, resulting in Kappa of 0.85. The full analysis was then checked by other members of the research team, with full team discussion when reviewing, defining and re-naming the themes until consensus was reached regarding the final themes and sub-themes.

A second form of analysis, using textual analysis software – Linguistic Inquiry and Word Count (LIWC) – was used to examine the emotional content of interview transcripts (Pennebaker et al 2007). LIWC is a word-based software programme designed to analyse word and word stems in order to examine the emotional, cognitive, structural and process components of written text or speech (Pennebaker et al 2007). Narratives relating to individual patient stories were extracted from the interview

transcripts and the unit of analysis was the individual narrative. LIWC is often used as a supplement to other quantitative measures of emotion (Hexem et al 2013) or qualitative analysis (Monrouxe et al 2014) and has also been used as a measure in its' own right (Thompson et al 2015). For this study we were interested, as a secondary aim, to examine whether there were any differences between the emotional content of patient vignettes according to the topic of the vignette and the country in which the interviews were conducted.

## FINDINGS

Fifty five RNs participated in the study, 45 in Focus Groups (eight focus groups in total) and 10 in individual interviews. The option of individual interview was taken up by nurses who were unable to attend a Focus Group. In both countries RNs from across a wide age range (23-54 years), experience (6 months-30 years) and staffing hierarchy (junior nurse to ICU Nurse Manager) participated in the study. There were no discernible differences in the types of responses according to type of interview (individual or focus group) or the experience or seniority of those who attended. Thematic analysis resulted in four themes - Timing of Communication, Accommodating Individual Behaviours, Appropriate Care Environment and Achieving Closure for families and staff – and eleven sub-themes. Examples of data excerpts for the four themes are presented at tables 2-5. Quotations are annotated with country, Unit, type of interview and interview number.

### Timing of communication

The first theme, 'Timing of Communication' referred to times when the actions of clinicians such as giving information, preparing the family or calling the family when death is close may have had considerable impact (Table 2). This theme included three



sub-themes: appropriate communication, timely decision making and timely actions.

*Appropriate communication* included reference to communication during critical events, such as the first visit of the family to ICU, moving a dying patient to a ward or the first discussion with a consultant, with examples such as ‘doctors will sometimes say “well they may not get better” or “they’re unlikely to improve” when actually the patient is going to die’ (UK/B/FG2). Another sub-theme, *timely decision making* included examples where management plans were needed before the night shift started or frustration was expressed at the lack of decision-making during the weekend. *Timely action*, the third sub-theme, focused on ensuring the patient received appropriate care, or that family were allowed to visit freely when their loved one was dying.

INSERT TABLE 2 HERE

#### Accommodating individual behaviours

The second theme, ‘Accommodating Individual Behaviours’, encapsulated differences in the way that patients, families and colleagues reacted to the impending death of the patient and the extent to which this was respected and managed (Table 3). Subthemes related to: *patient responses*, *family responses* and *colleague responses*. *Patient responses* were identified as quite difficult to manage. However, participants were respectful of the need to accommodate individual *family responses*: “It’s about accepting .... you do see somebody who perhaps collapses to the floor, or is absolutely distraught; that that might be absolutely the right thing for that person’s grief” (UK/B/FG1) and *colleague responses*: “It is important that the staff know their limits; some of the staff will say ‘do you mind if I don’t take him [care for that patient] today’? I’d rather they say that than do it not so well; at least it shows that they realise how important it is for the family to get it right” (Israel/A/S2). There was also an

appreciation that clinicians have to use their judgment to know when to step back and let the family have time with the patient but also the need for clinicians being ‘ready to let the patient go’ (Israel/B/FG1). Individual reactions of clinicians and families to the impending death could be accommodated when communication was effective; findings suggest that the extent to which this happened was variable across ICUs and countries.

INSERT TABLE 3 HERE

#### Appropriate care environment

The next theme ‘appropriate care environment’ (Table 4) encompassed sub-themes of providing a care environment that was *appropriate for dying patients*, enabled *culturally sensitive care* but identifying that sometimes *treatment taken too far* caused distress. An environment *appropriate for dying patients* included “having respect for somebody’s last hours. It doesn’t sit comfortably, whether it’s protocol or not, to have people laughing and joking outside the curtains when somebody’s dying” (UK/A/FG1). In terms of symptom control, pain management was the key goal, but this had other benefits: “Enough pain killers, oral sedation, to allow the family to be close to the patient, even if it is not so comfortable for the [clinical] team. .. it allows the patient to die with dignity more than when they’re alone, if they’re surrounded by their family” (Israel/B/S3). Participants also described in detail steps taken to ensure that they provided *culturally sensitive care* for patient and family. The perception of *treatment taken too far* was a recurrent theme across ICUs and countries: “One patient, he just went on forever, didn’t he? I’d go in and he’d say ‘I just want to die’ and his wife would be crying, saying ‘I just want him to die, I really think it’s cruel, I don’t want this...’ ” (UK/B/FG1). However, none of the participants reported intervening on behalf of the patient and family in these circumstances.

INSERT TABLE 4 HERE

### Achieving closure

The final theme, ‘achieving closure’, included sub-themes of finished or unfinished business for *staff* and *family* (Table 5); participants were more likely to articulate efforts to achieve closure for the family than for the staff. For example, “the family need to feel they can leave here and carry on because of how we have made the ending” (Israel/A/S1) but sometimes not for staff “We don’t get feedback and we don’t get debriefed on... especially the really horrendous cases” (UK/C/FG1). There was consistency in these findings between ICUs and countries.

INSERT TABLE 5 HERE

### Analysis of emotional content

A total of 250 patient stories were extracted from the interviews for LIWC analysis, 138 from the UK interviews and 112 from the Israel interviews. The main topics of the patient stories were: family centred care (n=77, 30.8%), clinician actions (n=132, 52.8%) and the patient journey (n=41, 16.4%). The emotional content of the patient stories showed a significant amount of ‘sadness talk’ in narratives about clinician actions ( $Z=-2.346$ ,  $p = 0.019$ ,  $R = 0.148$ ) or the patients journey ( $Z=-1.805$ ,  $p=0.071$ ,  $R = 0.114$ ), albeit with small effect sizes. There was also a significant amount of ‘discrepancy talk’ (using words such as ‘could’ or ‘should’) in narratives about family centred care ( $Z=-2.123$ ,  $p = 0.034$ ,  $R = 0.134$ ) or clinician actions ( $Z=-2.084$ ,  $p = 0.037$ ,  $R = 0.132$ ). The overall mean scores were higher for negative emotional content in the Israel transcripts (1.715 vs 1.54,  $p=NS$ ) and higher for positive emotional content in the England transcripts (3.372 vs 2.724,  $p= 0.049$ ).

DISCUSSION

We interviewed 55 nurses in Israel and England using focus group and individual interviews and identified 11 sub-themes perceived to contribute to a good death and good quality EoL care, grouped into 4 themes. Some of the sub-themes have been described in previous studies, for example differences in clinician attitudes and decision-making at EoL (Sprung et al 2007, 2008). However, data analysis yielded two important findings: firstly, despite clear differences in the legal context for dying in the two countries (Table 1), nurses in the UK and Israel identified similar factors that they perceive prevent, and contribute to, a good death and good quality of EoL care. Second, whilst textual analysis was used as an adjunct to thematic analysis, it did shed light on the impact on nurses in terms of behaviours, such as asking not to care for a dying patient, and emotional response, for example the sense of sadness when recounting the patients journey or actions taken by the clinicians.

The continuation of treatment when it seems futile was a thread running across all four themes and across findings from both countries. This is one of the difficulties that the Israeli law (Steinberg and Sprung 2006) and the end of life pathway in England (Walker & Read 2010) were intended to address; our findings suggest that these efforts have had limited success in the ICU. Moreover, the intensity of treatment at end of life has previously been negatively correlated with quality of death and dying (Glavan et al 2008) indicating that patients for whom active treatment is continued may not receive optimal care. Analysis of the emotional content of stories offered by study participants suggests that this may also have implications for nurses' wellbeing.

Transition to EoL care has been reported to cause tension between doctors and nurses (Azoulay et al 2009, Long-Sutehall et al 2011) and between ICU and referring teams (Coombs et al 2012). The importance of communication to ameliorate the tensions surrounding EoL care is not new (Curtis & White 2008). The ethos in cancer care that communication should be a process of ‘mutual influence’ (Epstein & Street 2007) is equally applicable with ICU patients approaching end of life to enable patient wishes to be met, without necessarily expecting that the patient or family will be involved in decision-making (Ek Dahl et al 2010). The ambiguous communication reported by our participants highlights the need for nurses and physicians to be cognisant that family members may have an ‘optimism bias’ in which bad news may be viewed positively (Lee Char et al 2010, Zier et al 2012). A communication intervention developed for families of dying patients was found to enable them to have more realistic expectations (Kirchoff et al 2008); our findings indicate that initiatives of this type should be more widely applied.

Patient and/or family involvement in decision-making has received much attention over the past decade (Azoulay et al 2004, Heyland et al 2003, Lee Char et al 2010). A three step-approach has been proposed for patient-centred decision-making in ICU (Curtis & Vincent 2010): assess prognosis and certainty, assess family preference for role in decision making and adapt strategy according to patient and family factors. Our findings suggest that the first of these steps doesn’t always happen. Prognosis, or at least the willingness to communicate prognosis, appeared to be a key missing element in the communication between clinicians and families and was a source of concern for study participants. The delivery of bad news can be stressful for clinicians (Fallowfield & Jenkins 2004), with clinicians sometimes deliberately exaggerating positive prognosis

when communicating with cancer patients and families (Lamont & Christakis 2001) possibly because of their own discomfort (Miyata et al 2005). The extent to which this applies in ICU is not clear. However, this practice can leave families misunderstanding basic information about prognoses, diagnoses or treatments after discussion with clinicians (Azoulay et al 2000).

Communication between clinicians is essential to enable understanding of each other's views; however, variability in inter-professional and inter-disciplinary decision making about EoL care has been reported previously (Azoulay et al 2009, Embriaco et al 2007, Studdert et al 2003), with personal beliefs and values of clinicians cited as a confounding factor impacting on decisions at end of life (Coombs et al 2012). Our findings provide specific examples of areas in which this communication is problematic. Handling unrealistic requests from family members is a key task in end of life communication (de Haes & Teunissen 2005); however, managing the dual agendas of providing hope and conveying a realistic prognosis have also been reported as the most difficult aspects of communication (Feudtner 2005). Our findings reveal that ICU nurses also find this challenging, particularly when physicians have not provided clear prognostic information to families. The emotional and cognitive demands made on team members when transitioning to EoL care warrants wider acknowledgement and exploration (Coombs et al 2012).

Our participants' response to continued 'futile' treatment is similar to the finding of Coombs et al (2012) that nurses reported patients as 'actively dying'.(p525); our findings add weight to their suggestion that reframing futility to include a diagnosis of dying might facilitate more timely decision making. Nurses in this study were conflicted

by their need to advocate for the patient and need clearer guidance. Findings from a single-site ethnographic study indicate that nurses' relationships with each other can hinder opportunities for advocacy (Sorensen & Iedema 2007). This warrants further investigation, possibly in the context of an intervention to improve inter-professional communication with patients and families towards the end of life.

### Limitations

Our study has some limitations. The Units recruited into the study were not necessarily representative of their countries but were of varying size and patient casemix. The interviews were all conducted in English; in Israel this generally wasn't the participants native language and they occasionally drifted into Hebrew, which wasn't the interviewer's native language. However, this was anticipated during the planning stage and steps were put in place to mitigate. Interview participants in Israel were from different cultural backgrounds whilst the UK participants were all caucasian; we do not know whether this may have influenced findings, although table 2 illustrates similar findings across the participant groups.

### CLINICAL IMPLICATIONS

Our findings have some important implications.

- 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 ICU 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 UK guidance for EoL care has recently been subject to a major review (Leadership Alliance for the Care of Dying People 2014), this does not relate specifically to ICU. Our findings indicate that clearer guidance for EoL care in the ICU environment in both countries would be of value.

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### Conflict of Interest

The authors declare that they have no conflict of interest.



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