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

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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 analyzed 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 & voice enabling); and emotional holding (creating time-space & 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 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.

Keywords: intensive care, end-of-life decision-making; nurses; grounded theory.
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 operationalizing’ 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, minimize harm and treat people justly (Beauchamp & 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, Long-Sutehall et al 2011, Inghelbrecht et 2009, Halcomb et al 2004, Oberle & Hughes 2001, Westphal & McKee, McMillen 2007, Latour et al 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 Thelin (2012 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 to ethical values such as autonomy and dignity (McCarthy et al 2010).

The literature suggests that nurses engage with the transition from ‘cure’ to ‘care’ in the ICU, utilising a range of roles and strategies to work well with patients, families and colleagues. Research in England by Coombs et al (2012) detailed a three stage end-of-life trajectory for patients in intensive care (from admission with hope of recovery; to transition to end of life care; and to a controlled death). In a grounded theory study using clinical vignettes, Long-Sutehall et al (2011 p.1471) identified ‘the process of negotiated dying’ as the key category with subcategories of: assessing, coordinating, facilitating and operationalising. An earlier UK grounded theory study, exploring nurses’ experiences of caring for ‘hopelessly ill patients in intensive care’ (Simpson 1997), identified ‘reconnecting’ as a core category. This is described as ‘the process by which nurses attempt to overcome the dehumanizing aspects of dying in a technological environment’. The priority is to ensure that death is ‘peaceful’ (p.196).

Decision-making, in relation to the provision of comfort care and to mediation and advocacy decisions with patients and families, is discussed by Bryon et al (2010) who report ‘the formation of a picture’ (p1109) as preceding decision-making, with the nurses assuming the role of ‘initiator’ of the decision-making process. A systematic review of ‘nursing roles and strategies in end-of-life decision-making
(Adams et al 2011), albeit in acute care, identifies three roles: information broker (giving information to physicians, giving information to family members and mediating); supporter (building trust and using empathy; and as advocate (to physicians and to families). The literature highlights the importance of taking into account cultural and religious values and beliefs (Thelen 2005, Morgan 2008, Latour et al 2009).

Whilst recognising the magnitude of decisions to withdraw and withhold treatment and expressing sympathy for physicians’ involved, nurses feel that their opinion should be sought because they spend more time with patients and their families and they are more aware of their wishes (McMillen 2008). In line with previous studies (Simpson 1997), the length of ICU experience was found to affect nurses’ inclusion in decision-making. Nurses’ involvement is such decisions are often subtle, such as planting a seed (Simpson 1997). While doctors bear the burden of making the decision, nurses generally implement it and have to live with the decision made by someone else (Coombs et al 2010). The hierarchical structure of healthcare can render nurses unable to influence EoL decision-making, despite their expertise and involvement with the patient. Nurses can often feel their voice is unheard and this is reported to be a key source of moral distress (Oberle & Hughes 2001; Halcomb et al. 2004).

Our research was conducted in five countries with very particular and different historical, healthcare and cultural contexts. We provide a brief overview of some of the key features of each country: Brazil, England, Germany, Ireland and Palestine.

2.1 End of life decision-making - the Brazilian context

Brazil is the largest country in South America and also the most populated ranking fifth in the world with a population of 180 million people. In Brazil, the death rate in ICU ranges from 5.4% to 33% depending on the admission diagnosis and other clinical criteria (Oliveira et al 2010). Challenges experienced by nurses in ICUs have been reported as relating to: inconsistency in the quality and accessibility of ICU educational provision; the low number of registered nurses working in ICU; the lack of certification required to work in ICU areas; and a paucity of nursing research in this area (Padhilha 2008). Few of these studies have included the experiences of the nurse as a participant and researcher. (Moritz and Nassar, 2004; Moritz, 2005; Piva, Garcia and Lago, 2011; Soares, 2011). In these studies, the doctor is the one responsible for making decisions, although they suggest the need for multidisciplinary discussion. Only one of these studies investigated the position and participation of nurses. (Fumis and Deheinzelin, 2010)

End of life decision-making - the English context

The United Kingdom comprises four countries (England, Scotland, Wales and Northern Ireland) with a population of 63.7 million and much cultural and religious diversity. Over half of all deaths in the UK (58%) occur in acute hospitals (Department Health 2008) and a significant number of patients die in intensive care units (ICU), that is, 17.1% of admissions to ICU (ICNARC 2010). A critical discourse analysis of four key UK critical care documents published between 1996 and 2006 concluded that there is little clear guidance for health care professionals working in
ICU on how to manage EoL care (Pattison 2006). The review of the Liverpool Care Pathway makes a consideration of EoL care timely (Neuberger 2013).

**End of life decision-making - the German context**

Germany has a population of 80.5 million. Nearly half of all deaths in Germany (47.6%) occur in acute hospitals (German Federal Statistical Office 2012) and a significant number of patients die in ICUs each year. As in the other countries, there is also a paucity of guidance in relation to decision-making at the end of life. This is recognised as one of the most difficult tasks in medical care (Marckmann 2007, Synofzik 2007). Other challenges include witnessing suffering, which engendered a moral obligation to reduce that suffering. There is little explicit reference to nurses' involvement in decision-making in Germany.

**End of life decision-making - the Irish context**

Ireland is a predominantly Catholic country (84%) with a population of 4.5 million. Historically, it has been a conservative and monocultural society but this has changed in recent years due to the effects of immigration and emigration. At least half of all deaths in Ireland occur in acute hospitals (48%) (McKeown et al 2010a). The first ever National Audit of End-of-Life Care in Hospitals in the last week of life, suggests that end-of-life care in Irish hospitals compares favourably with that reported by hospitals elsewhere (McKeown et al 2010a). Nevertheless, treatment cessation decisions taken about dying patients in Irish hospitals are less frequent compared to patients dying in other European countries. Decisions to withhold or withdraw life support were taken more frequently in intensive care (53%), compared to other wards (47%). However, this falls well below the European average (Sprung et al cited in McKeown 2010b: 104). Finally, there are high levels of disagreement between nurses and doctors with regard to key aspects of care and symptom management, the quality and focus of communication with patients and relatives, and the degree to which they document and coordinate care (McKeown et al 2010b: iii).

**2.5 End of life decision-making - the Palestinian context**

Palestinians living in the Gaza Strip are a homogenous and conservative population with the same ethnicity and same culture. The great majority (about 97%) are Islamic. The population of Palestine is 4.2 million with 1.6 million living on the Gaza Strip. Until 1990 there were no ICU's in the Gaza Strip. There are now 3 major ICU's in Gaza and 2 small units. Death is considered as a natural part of life and as a transition from our life to the afterlife. In the Gaza Strip, where this research was conducted, palliative care is underdeveloped. There are no specialists in palliative care or any units or health department for providing such care and no nursing homes or hospices. Palliative care is underdeveloped and limited to giving pain medication for oncology patients. Resource constraints are a significant problem.

**3. Design**

Given the aims of the research and the social nature of the setting, grounded theory was chose as the method since it has as its basis the systematic generation of theory from data (Glaser and Strauss 1967). It is also concerned with identifying
how people respond to their own interpretation of reality (Glaser 1978). It is predicated on the idea that researchers should focus on problems that are of concern to participants and not to researchers. Data collection is characterized by openness: to the way participants see the main problem they are confronted with and openness to the relevance of local and professional constructs (Gibson and Hartman 2014). The emphasis in grounded theory is therefore on the experience of participants in that the problem is defined by them not the researcher. Qualitative methodologies are broadly concerned with how to deal with the multiple realities in giving “voice” to participants and how to adequately represent their views through thick description (Murphy et al 1998). However the end product of Grounded Theory is not thick description of what participants do and say but a conceptualisation of how they resolve or process their main concern, by generating a theory that is readily modifiable (Glaser 2001). In contrast to constructivist Grounded Theory, the emphasis in Classic Grounded Theory is on the emergence of a core category.

4. Research aim

The research aimed to understand nurses’ decision-making practices in intensive care units in different cultural contexts.

5. Participants

Semi-structured interviews were conducted between 2012 and 2013 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 decision-making. Nurses were eligible to participate if they had at least 6 months experience of working in an ICU and were currently working in an ICU at the point of recruitment.

In all countries, nurses were initially invited to participate by distribution of a Participant Information Sheet with contact details of researchers.

The interviews were audio-recorded with the participants’ consent and the data transcribed verbatim. During the interview, the participants were asked broad questions regarding their perspectives in EoL care: the EoL decisions they were involved in; and the practices they support. Interview questions were also informed by theoretical sensitivity, where questions were generated by previous interviews. They were invited to describe an EoL situation they were involved with. Field notes, both descriptive and reflective, were recorded by the interviewers in each country. The interviews lasted 40 to 60 minutes and were usually held in a reserved room in a university or hospital.

6. Ethical review of study
The project proposal was reviewed by a Research Ethics Committees or Institutional Review Boards in each of the five countries. Potential participants received information sheets regarding the project and those willing to participate gave written consent. They were made aware that they could withdraw at any time with no adverse consequences and standards of confidentiality were explained.

7. **Analysis**

The project team in each country participated – in person or by Skype – in a two day analysis workshop at the University of Surrey in July 2012 in order to discuss the analysis of each country’s dataset. In September 2012 memos were circulated between countries by email and initial project findings discussed at a team meeting in Izmir, Turkey, in October 2012. Memos with supporting quotes and full transcripts of three interviews from each country were prepared and circulated to all team members. Researchers in each country read all of the transcripts independently and separately coded the data, considering patterns across memos and transcripts. At research team meetings – in person and by Skype - in February and April 2013, the team discussed patterns relating to a core category. In June 2013 a template was circulated with sections for selected memos with supporting examples from interviews in each country. In July 2013, a team meeting in Ireland finalised the core concept and discussed dissemination.

Consistent with grounded theory, data were coded using constant comparison and open coding. Open coding was continued until the core category emerged then selective coding was used. Data collection continued until data saturation, that is, until no new properties were identified and the researchers could understand nurses' experiences (Glaser 1978).

*Rigour and trustworthiness*

Inter-coder reliability was checked throughout the process of analysis. Constant comparative analysis was used to compare the data, to generate categories and concepts. Constant comparison helps to enhance contextual sensitivity because it aids the identification of persistent patterns and differences within and across interviews and enables researchers to identify the features that constitute categories. Consistent with Grounded Theory, direct quotes are provided for illustrative rather than evidentiary purposes.

8. **The Theory**

The core category identified from the analysis is: *negotiated reorienting*. End-of-life situations in ICU involve varying levels of uncertainty with regard to the prognosis of the patient. The shift from uncertainty to greater certainty of impending death implies that activities that are oriented towards the goal of curing (therapeutic interventions) are now ending. They are replaced by a new field of activities that are prompted by the dying process and reoriented towards the goal of ensuring a comfortable death for the patient and supporting the family to come to terms with what is happening. Nurses then have an active role in 'negotiated reorienting', that is, in facilitating the shift from a narrower to broader and more holistic practices, towards activities that are oriented towards curing to a different set of activities that
are oriented towards comfort and support. The negotiation is relational and involves core practices that make the reorientation possible. Negotiated reorienting can then be expressed in terms of two core practices: Consensus Seeking and Emotional Holding.

8.1 Consensus seeking

Through consensus seeking, nurses bring about the realisation and acceptance that a patient is at the end of life despite maximum support. Nurses coax physicians to make decisions to withdraw, de-escalate or limit treatment by directly expressing their views, appealing to other authorities (for example, an ethics council in Germany) or detailing the deteriorating condition of the patient to them. To enable relatives’ involvement in decision-making, nurses figure out and support their understanding of the situation through information cuing and voice enabling. In doing so, nurses talk about the necessity of ‘knowing the reality’ or ‘painting the real picture’ and they engage in consensus seeking practices concurrently and opportunistically until consensus is achieved.

8.1.1 Coaxing

In general, while nurses say they do not wish to see prolongation of the act of dying, they are highly conscious of the moral implications of withholding/withdrawing treatment and this influences their involvement in the decision-making process in EoL care. Their level of certainty as to the futility of the treatment and their religious beliefs influence their level of participation in EoL decisions.

If nurses feel certain that continued treatment is futile then coaxing can bring about the realisation in physicians, who hadn’t initiated the process themselves, that they should consider withdrawing or de-escalating treatment. The greater their experience the more likely nurses will engage in coaxing in four of the five countries our study (not Germany) . Where there is mutual respect or where there is disagreement among physicians there is a greater likelihood that nurses’ opinions will be considered.

Certainly if they hadn’t initiated the process you might start talking about it with them. Like what do you think about this?... And there would be a bit of coaxing. The consultant would be easily coaxed to maybe de-escalate, maybe not de-escalate but certainly not to escalate. (Ireland 1)

Sometimes, there will be some disagreement among the doctors themselves about that case. But if the nurse is an expert with good experience and knowledge, he/she can influence the decision of the doctors. Some physicians consult nurses in these decisions and they consider them (the nurses) as an important part of the team. (Palestine 2)

In addition, through factual reporting of patients’ response to treatment and by giving their own opinion, nurses try to convince physicians that further treatment is unlikely to make a therapeutic difference.
Today I took over a patient and his condition was not the same. It is deteriorating and I will be after the doctor saying that the condition is deteriorating and he has to inform next of kin (Ireland 6)

I’ve kind of got more courage or something and I spoke to the Consultant and when he asked me how she’s (patient) doing I said ‘She’s not doing and this is kind of coming a little bit onto borderline silly cos when we suctioned her, her immortal fear, you can see the fear on her face, real fear, you know […] but we can initiate and sort of put the hard facts in front of them, I’m talking about the clinical colleagues, the medical staff, and again it just depends on the person, if they’re willing to listen to you or not (England 1).

On the other hand, the greater the uncertainty in relation to the prognosis of the patient, the greater nurses’ discomfort with decisions related to withdrawing treatment and, sometimes, they may try to convince doctors to not withdraw or postpone treatment. Their fear that they are engaged in a form of euthanasia is determined by social norms and religious values.

We have the impression that when we take a patient without any prognosis off ventilation, intubation and feeding we’re killing him, shortening his life even more. So I don’t feel very well in this situation. I wouldn’t feel good. I have the impression that I’m shortening the patient’s life (Brazil 3).

Nurses try to ensure that relatives are prepared for and participate in whatever decisions are being contemplated through information cuing and voice enabling.

8.1.2 Information cuing and voice enabling

Nurses are well placed to establish the needs and preferences of relatives and tailor information accordingly and do so through information cuing, where they try to figure out what relatives already know through listening, questioning and being present with them and responding to individual cues for information.

You would look for the cue off the family…..You’ve got to tailor your approach to the people you’re dealing with….. I am having an impression as to how much they want to know. If they ask a lot of questions, then we give them a lot of information. If they don’t, then don’t bombard them. They obviously don’t want to know. Some people don’t want too much information; some people do (England 1)

While relatives have different levels of information and understanding in relation to their loved one’s dying process; they may also have different capacities to communicate their concerns to physicians. Nurses see themselves as having an obligation to enable families to be more involved in decision-making but they vary in the ways in which they meet this obligation.
In settings where nurses’ views are respected and in situations where a doctor has already disclosed the patient’s prognosis to the relatives, nurses are more likely to engage in voice enabling, where they take an active role in developing relatives’ understanding and supporting them to articulate their concerns.

Nurses use a number of strategies to ensure that relatives can articulate their concerns, wishes and hopes to physicians. They do not only share information with families. Nurses also get information from families that doctors do not have the time to elicit. They observe families to detect whether or not they want nursing support, for example, if they wish to have a nurse sit with them. Nurses check relatives’ levels of understanding and sometimes seek approval from relatives as to what is being done on a day to day basis. Nurses try to catch the right moment to give relatives a voice that is to say, they try to open a space for conversation and have relatives put their questions. They share their observations with relatives and this ensures that relatives can more effectively take part in any discussions about the patient such as further treatment, continuing treatment, escalating or reducing treatment.

If I feel the situation needs to be progressed a bit more, I might say to the family: how do you feel about this? Are you happy about what’s going on? Well not really; what’s the point? I might say why don’t we sit down with the consultant and have a chat....’ (Ireland 1)

Alternatively, where nurses’ views are not taken seriously and physicians do not share the patient’s prognosis in a clear and transparent way, nurses feel frustrated and are more likely to take a passive or neutral stance in relation to voice enabling. The Palestinian and Brazilian data, for example, indicated that nurses working in contexts where their views are not taken seriously, might wish to support the family, but are reluctant to confront the doctors.

It’s very difficult, very difficult indeed, because we know what is going on, we know the reality, what will happen to the patient, but the family does not ... So frequently they speak another language, and we have to be very careful with this because you cannot hint to the family that the patient will die... we always have to play along, always ... We should not keep their hopes up, but at the same time we shouldn’t take them away from them. We have to be a bit neutral. [...] (Brazil 9)

Participating in the decision-making related to care at end of life depends on the personality of the doctor. Some doctors will allow nurses to participate in the process and listen to their opinions. They might agree with it or not. But some doctors will not allow nurses to participate in the process. (Palestine 4)

Overall, nurses are generally actively involved in reorienting activities from those focused on cure to those focused on care in end-of-life situations. A successful result of nurses’ consensus seeking activities is a timely de-escalation of futile treatment and the family’s acceptance of the situation and agreement with the clinical decisions made. The second sub-core category is emotional holding.

8.2 Emotional holding
In EoL situations, nurses must face the family’s suffering at the loss of their loved ones at close proximity and over fairly long periods of time. Depending on the power relationships among health professionals, nurses use various strategies to emotionally support families: they prioritize time spent talking with family members by time-space creation; give hints and/or use religious rituals to communicate that the patient is near death; bend rules to create more time and private spaces where families can grieve together. They also draw attention to the need for continuing care, pain relief and comfort measures through comfort giving.

8.2.1 Creating time-space

If nurses perceive that families do not appreciate the seriousness of the situation, the futility of treatment or the imminent nature of death, then through time-space creation, nurses try to bring about acceptance of the situation. Nurses’ first concern is that families are told in a timely way that their relative is dying and this is reinforced through bounded communication and the use of religious rituals. Sometimes this may only involve a matter of hours. Nurses will anticipate when it is important for family members to come in and be with the patient.

*We’re the ones who decided to call the family. We suggested it – we realized that a little earlier, perhaps we realized it just before the medical professionals [...] It is usually the nurse’s job to call the family in these situations and to try to make the patient as comfortable and human as possible for the end-of-life process.* (Brazil 1)

Through time-space creation, nurses make themselves available, where possible, to be with the family and provide support once relatives learn of their loved ones’s prognosis. They assess relatives’ understanding of the situation and related issues by engaging in subtle questioning and active listening. Time-space creation ensures that nurses are able to provide emotional support to relatives, especially when they have been given bad news. Time-space creation also facilitates relatives to absorb what has been said and to provide any clarification.

*I see this as our (nursing) task, that we are not doing the primary informed consent, but give the (so-called) secondary one. That we just go on talking with the patients and the relatives. This is not too much for me. I think it is a pleasure too if we can clarify things for relatives and patients.*” (Germany 10)

In bounded communication, a limit is set on communication and nurses are clear that they only communicate with families in a way that has been predetermined by physicians. It involves reinforcing what the physician has said while not dealing directly with questions about what are considered the medical domain such as prognosis. Accompanying the physician to communicate with relatives enhances this since they know exactly what relatives have been told and they can then reinforce the message while checking that it is understood. Nurses are very cautious; they do not want to deviate from what the physician has said as they fear crossing the boundary into what is regarded as the medical domain.
I said trust me, here they do everything and I can guarantee you, they kind of like to hear that nobody ever comes to this decision lightly. I said it has been thought out a long time, every input has been put into your husband or whatever and I said trust me, this is not a light decision for them and they sometimes feel if you have been there for a while and have been their support they need to hear that and its re-enforcement. (Ireland 9)

Where nurses perceive the family to be religious, they may also appeal to some religious rituals such as prayer or references to religious texts (Holy Quran or Bible) to convey the seriousness of the situation to the family.

In some cases, family request to transfer the patient (who is considered at the end of life and in a very serious condition) to be referred to another medical center outside Gaza Strip and I know from my experience that the patient’s chances to live is very limited, I ask them to pray for the family, emotionally support them and ask them to seek patience from Allah. (Palestine 7)

In time-space creation, nurses also negotiate with doctors and families to delay treatment withdrawal so that a family member can be at the bedside. Nurses try to ensure that the family spends time with the patient to say goodbye even if this means that they must bend the hospital rules to make this happen. For example, usually, there are fixed visiting hours in the ICU and usually, nurses adhere to this policy. However, at the end of life, if the patient requests it, they will allow a family member to visit out of hours. Where possible, they will also let more family members – even children - to visit and in some cases to stay with the patient even overnight.

Where death is imminent and nurses are not too busy they will try to create a more peaceful environment around the dying patient. They are also anxious to ensure privacy for the family. When time allows and it is available, they will move the patients to a single room. They will also pull the curtains around the patient and family even if this leaves the patient unobserved by staff. This is more likely to happen when the nurse is more experienced and more confident.

Then we also tried someway, yes, just how it would be possible in ICU to create a calmer atmosphere. We switched on the lamp on the bedside table, and not the neon light that highlights everything flashy. Yes, so that it would look a little bit comfortable. … So partly we have had really crazy ideas. We took a mobile lamp from the operating theatre … and we did put it into the patients’ room, somehow behind the curtain and then we switched off all the other lights. So it was somewhat dimmed light. And we provided chairs for the family members. And we asked them if they would like something to drink. And we told them, to come to us in case they would need anything else. And (we added), also if they would feel bad (Germany 7).

The second aspect of emotional holding is comfort giving.

8.2.2 Comfort giving

Comfort giving is focused on reducing the suffering of patients and their families. In doing so, nurses draw attention to the need for pain relief and comfort
measures for patients. They remind doctors where necessary to continue to pay attention to the dying patient’s needs for example, they query with doctors the most appropriate forms of pain relief necessary for individual patients. Where doctors are perceived to have sole authority over (their) patients, challenging doctors’ decisions is made more difficult. However, nurses believe that they have a moral obligation to act.

Watching people in pain is something that I don’t like to work with; this just doesn’t exist for me. So I go to the ultimate consequences, I speak to whomever I need to speak, but this is usually not an easy process in a private hospital - to assure that this patient has comfort, but I have to be aware that I did the best I could so that the patient may have a good death.  (Brazil 11)

Comfort giving also include physical acts such as offering alternative diets, keeping good hygiene care, washing and dressing patients.

and getting them positioned right and all the basic things that aren’t necessary people say basic but important. I still cream the lips, I (use) Vaseline.” (Ireland 9)

Nurses talk to patients who may be unconscious, position them, ensuring that they seem comfortable. Comfort giving is also focused on avoiding distress to the family. Where patients’ perceived suffering triggers distress in relatives nurses are anxious to manage symptoms in order to reduce suffering and distress.

Nurses also perform acts of service for families. Comfort giving encompasses practical arrangements as well as very personal and intimate gestures of support. Where the situation prompts it, nurses will arrange for the involvement of other professionals such as pastoral care and social workers. They may encourage and support family members to touch the patient, hold their hand or caress their head. They show the family:

how they can contribute be it simply washing the patient’s face or washing the patient’s hands or encouraging them to hold the patient’s hand even though yourself you might not be convinced it is of any benefit but you realise that it is a lot of benefit to the family member and indeed maybe some benefit to the patient. (Ireland 8)

[...] To learn that sometimes you can remain silent with the patient, but that your presence, your attitude, your look, your touch, can be highly beneficial to these families. (Brazil 5)

Cultural norms influence who provides the comfort. Nurses are very conscious of the comfort that many families find in religious belief and ritual. They will appeal to religious rituals and prayers to help the family to accept their loved one’s death even if they themselves do not believe that it is part of their job to do so.

The family does not know if they cry, if they hold the patient’s hand - it’s a very difficult moment. For those outside this emotional situation, you watch, you can notice things and normally you wonder if they are religious, if so, I wonder
if they want to pray, and generally they accept it right now and then we make a prayer... We have the impression they become more centered. (Brazil 10)

You are in a room with a dying relative, a mother for example, and somebody says to you ‘we will pray, we will start the rosary’ and suddenly your thoughts are ‘hang on a second I don’t feel it is my place to say the rosary’ This isn’t part of my job but yet you might do it because you think this could be a help to the family, so you do it. (Ireland 8)

Comfort giving extends beyond death since nurses are very sensitive to the needs of the bereaved family. For example, they remove any tubes, wash the patient, comb the patient’s hair and make the patient look as well as they can.

9. Discussion

Previous research relating to nurses’ role in EoL decision-making in ICU has detailed the roles nurses assume in transitions from ‘cure’ to ‘care’ and the processes of ‘negotiated dying’ (Long-Sutehall et al 2011) they engage in. The focus of a ‘peaceful’ death and nurses’ attempts to overcome the dehumanizing aspects of ICU are well documented. Nurses’ roles in brokering and mediating information and providing support to doctors and family members have been described in other studies (Adams et al 2011). Previous research also draws attention to the emotional labour involved in EoL care and decision-making (Coombs et al 2010) and in the potential for moral distress (Oberle and Hughes 2001, Daly et al 2004). The idea of ‘reconnecting’, identified by Simpson (1997), as a core category is in accord with the findings from our study where nurses attempted to counter the dehumanizing impact of a highly technical environment and to prioritise a peaceful death when cure is not longer possible.

Our core category of negotiated reorienting resonates with previous research that details the active role of ICU nurses in enabling ethical EoL decision-making. The roles identified by Adams (et al 2011), for example, of nurse as information broker, supporter and advocate appear to be components of the practices of consensus seeking and emotional holding. Similarly, the importance of taking cultural and religious values into account is as relevant to our study as to earlier studies (Thelen 2005, Morgan 2008, Latour et al 2009).

The sub-core categories of consensus seeking and emotional holding suggest are in accord with literature relating to, for example, compassion in care, emotional labour, nurses’ autonomy in EoL care contexts and the influence of religious beliefs on nursing practices.

Our theory is designed to enable ICU nurses to support ICU teams and families to reach consensus, to derive comfort and to have judicious information-giving. This is in keeping with scholarship in care ethics (for example, Roach 1984, Leget et al 2011) and current initiatives to develop compassionate care (see, for example, UK Department of Health 2012). Previous research on emotional labour highlights the demands on ICU nurses as they negotiate with colleagues and families to reorientate towards an EoL decision that is considered compassionate for patients and families (Stayt 2009).
Recent work on compassion points also to the need for attention to self-awareness and self-care. In their discussion of ‘learning to be with the suffering of others’, Austin et al (2013) write of the importance of education that facilitates ‘reflection upon emotions, attitudes and experiences’ and of a view of compassion that ‘the ability to sit with people in darkness because you know your own darkness’ (ibid p.185). As suggested by our theory, nurses’ personal, cultural and religious perspectives on EoL issues contribute to their ability to respond effectively to patients and families during the dying process. The need to have ‘hospitable, habitable health care environments’ with a terrain that is compassionate, humane and dignifying is highlighted as important ‘so that health professionals will feel safe to be compassionate, not overwhelmed and failing in their efforts to be so’ (Austin et al p.187). There is also a need for ‘shelter’ for health professionals in the form of ‘timely breaks, quiet time for reflection on self and practice, team retreats and supportive supervision’ (ibid p.190).

10. Conclusions

This study highlights the importance ICU nurses bestow on relationships and dialogue in EoL decision-making and care. In all five cultures, despite some differences regarding perceptions of nurse autonomy, ICU nurses are actively engaged in negotiating a reorientation from cure to care and towards a broader holistic care orientation. They engage in negotiated reorienting which through consensus seeking and emotional holding enables a consensus to be reached in relation to EoL care. Importantly, the theory suggests how patients and families may be facilitated to have experience of a good death in a technologically focused environment. Despite the challenges of working in an environment that is focused on treatment and cure, the theory suggests that nurses stay focused on the needs and suffering of patients and families.

The theory suggests that nurses have a clearly articulated role to play in EoL decision-making. Further it suggests the complexity of their role in an area of practice that is medically-dominated. The theory suggests the value of culturally sensitive multi-professional EoL ethics education and ethics support. As highlighted earlier, ethical and clinical EoL decision-making are inextricably connected and confidence and confidence in area could be enhanced. Future research could interrogate further the impact of nurses’ cultural and religious perspectives on EoL decision-making. This research highlighted resource constraints and lack of availability of palliative care in Palestine. In Brazil palliative care is not a compulsory component of health professional education and it was suggested by German colleagues that nurses who were more competent in palliative care were more comfortable with EoL decision-making. The research also identified a need for nurses and nursing organisations to advocate for the interests of patients and families where these services are under-developed.
11. References


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