Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal
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Intensive care nurses' experiences of providing end of life care after treatment withdrawal: a qualitative study

Abstract

Aim. The purpose of this study was to explore the experiences of intensive care nurses who provided end of life care to adult patients and their families after a decision had been taken to withdraw treatment.

Background. End of life care following treatment withdrawal is a common phenomenon in intensive care. Less is known about nurses' experiences of providing care for the dying patient and their family in this context, when compared to specialist palliative care.

Design. Descriptive exploratory qualitative study.

Methods. A purposive sample of 13 intensive care nurses participated in a semi-structured face to face interview. Transcribed data was analysed using the principles of Interpretative Phenomenological Analysis.

Results. The essence of nurses' experiences of providing end of life care after the withdrawal of treatment was interpreted as "doing the best to facilitate a comfortable and dignified death''. Four master themes included: caring for the dying patient and their family; providing and encouraging presence; reconnecting the patient and family; and dealing with emotions and ambiguity. Uncertainties were evident on processes and actions involved in treatment withdrawal, how to reconnect patients and their family effectively and how to reduce the technological environment.

Conclusions. Providing end of life care after a decision has been taken to withdraw treatment was a common aspect of intensive care. It was evident that nurses were doing their utmost to support patients and families at the end of life, despite the multiple challenges they faced.

Relevance to clinical practice. The interpretive findings from this study should assist ICU nurses to better understand and develop their role in providing high quality end of life care after treatment withdrawal. Practice guidelines should be developed to reduce ambiguity and support the delivery of high quality care for adults as they approach the final stages of life in ICU.

Key words: end of life care, critical care, intensive care nurses, experiences, interpretative phenomenological analysis, withdrawal of treatment

What does this paper contribute to the wider global clinical community

•Provides insights into intensive care nurses' experiences of providing end of life care following treatment withdrawal.

•Provides knowledge to support the development of practice guidelines for end of life care following treatment withdrawal in intensive care.

INTRODUCTION

Despite the technological advances in medical treatment, death and dying remain a reality in intensive care units (ICU). Very often dying in ICU is associated with a decision to withdraw treatment due to the exhaustion of technological interventions and the failure of the patient's body systems to respond to treatment (Vanderspank-Wright *et al.* 2011a).The time from discontinuing life support until death depends on the level of support patients receive and their condition. The time can vary from an average of 1.5 hours (Rocker *et al.* 2005) to 2 hours (Wunsch *et al.* 2005) or as reported by Wind *et al.*'s (2012) prospective study, 83% of the patients died within 2 hours after withdrawal of treatment. The process of treatment withdrawal may be controlled to ensure timely and optimum end of life care. However, the whole process places extreme emotional stresses to nurses and the patients' families (Efstathiou & Clifford 2011).

BACKGROUND

Among all members of the healthcare team, it is suggested that nurses are bearing the most stress in caring for the dying patient due to their constant presence at the bedside (Beckstrand and Kirchhoff, 2005). Death in ICU may not be viewed as ideal by nurses due to factors such as: the environment which is orientated towards saving lives, communication problems between healthcare professionals and family members, lack of time, lack of education in end of life care and difficulties in keeping the patients comfortable (Beckstrand *et al.* 2006, Efstathiou & Clifford 2011). Death in ICU may also be perceived as failure (Nelson, 2006), yet nurses have described the opportunity to care for a patient and their family at the end of life as a privilege and honour (Ranse et al. 2012, Vanderspank-Wright *et al.* 2011b). Shorter and Stayt (2010) suggested that a good death in ICU can be achieved if it consists of expectedness, control of the procedures and practicalities surrounding death, and good nursing care. Expectedness and control are not always attainable; hence nurses generally believed that good deaths in ICU are not routinely possible (Beckstrand *et al.* 2006).

Research into intensive care nurses' experiences of end of life care by Forsberg and Bergdom (2009) suggested that nurses tend to do their 'utmost' to provide the best nursing care possible. Best care generally involves provision of physical care, dignity and comfort for the dying patient. Hov *et al.*'s (2007) study emphasised physical care and the appearance of the patient, who has to look clean and fresh. In Kongsuwan and Locsin's (2009) study, nurses believed that cleaning the body and making the dying patient look presentable also reinforced dignity. The 'pathic' touch during physical care was regarded as a means to establish connection with the patient, to confirm them as a unique person and to enhance humanity and dignity for the patient (Hov *et al.* 2009). In addition to physical care, emphasis has also been given to promoting comfort and relief of pain for the dying patient (Beckstrand *et al*. 2006, Kongsuwan & Locsin 2009).

Wilson et al. (2006) suggested that extending care to the critically ill patient's family promotes a dignified death and allows privacy. Indeed, nursing in the adult ICU has evolved from a patient-centred model to a holistic approach which recognises the needs of the families as inseparable from those of the patient (Stayt 2007), thus placing additional responsibilities on nurses to fulfil patient and family needs. Simpson (1997) suggested that the nature of the ICU environment, the appearance of the patient and emotional stresses result in separating the patient from the family. Critical and intensive care nurses perceived family presence as essential during death in their attempt to 'reconnect' the patient with their family (Beckstrand *et al.* 2006; Fridh *et al.* 2009). Nurses have reported developing a bond with dying patients and their families and associated this with the provision of good nursing care. However, the subsequent death and grief experience may be more upsetting as a result of this bond (Shorter & Stayt 2010).

Balancing human closeness and professional distance can be difficult, hence nurses have revealed instances when distancing themselves was demonstrated by focusing on completion of physical tasks while offering end of life care (Stayt 2007, Stayt 2009). Emotional disassociation seemed a necessary means of protecting nurses' emotional wellbeing, and this has been more obvious in certain cultures (Yu and Chan, 2010).

Despite relatively high mortality rates in ICU, less is known about intensive care nurses' experiences of providing end of life care following treatment withdrawal, compared to experiences of nurses based in specialist palliative care settings. The aim of this study was to explore the experiences of intensive care nurses who provided end of life care to adult patients and their families after a decision had been taken to withdraw treatment.

METHODS

Design

A qualitative approach was chosen to explore human experiences. This was deemed appropriate given the sensitive and complex subject of end of life care within an environment where limited research had previously been undertaken. More specifically, a descriptive exploratory qualitative research approach (Polit and Beck, 2010) was used to explore the end of life care experiences of intensive care nurses. This approach was considered useful in summarising and understanding the selected area of interest. This study formed part of a post-doctoral project to investigate consumers' and providers' satisfaction with end of life care in critical care.

Participants

Purposive sampling was used to target intensive care nurses with experiences of providing end of life care for adults following treatment withdrawal. Participants were recruited from a major University ICU facility that provided neurosurgical, trauma and general intensive care in three separate, yet integrated environments. The research nurses of the ICU facility assisted the recruitment of participants by promoting the study, registering the details of interested nurses and bringing the participants in contact with the researcher.

Data collection

Semi structured face to face interviews were used to collect data. One academic researcher (NE) conducted the interviews. As a former intensive care nurse, the interviewer was familiar with the culture of ICU, but had no work experience in the intensive care units where the study was conducted. Data was collected over a period of three months (June to August 2010). All interviews took place in the ICU where each participant worked and carried out during the interviewees' rostered shift. Questions were developed to guide the interview using guidelines suggested by Smith and Osborn (2003). Participants were asked to describe: (1) what end of life care meant to them and (2) situations where they provided end of life care. Participants were encouraged to talk in detail about their experiences and were probed on important individual topics which arose. Interviews lasted between 30 to 50 min. The interviews were digitally recorded and transcribed verbatim.

Ethical considerations

Local ethical approval was sought and obtained for the study. Potential participants were verbally approached by intensive care research nurses and interested participants received information about the study in writing. Informed consent was obtained for each participant. Anonymity and confidentiality were guaranteed. Anonymity was maintained by using a pseudonym (Nurse 1-13) when reporting the results.

Data analysis

The transcribed data was analysed using a process derived from Interpretative Phenomenological Analysis (IPA) (Smith *et al.* 1999). The IPA approach was selected to facilitate the generation of a descriptive and interpretative account of nurses' experiences. Reading each interview transcript and listening to the audio recordings helped to familiarise the analyst with the content and context of the data. After the initial reading of the first interview, preliminary interpretations were recorded in the left-hand margin of the transcript. Further reading of the interview aided in identifying

preliminary themes which were noted in the right-hand margin of the script (Smith and Osborn, 2003). These preliminary themes were then transferred on a separate sheet of paper and potential connections were considered between them (Smith *et al.* 1999). The same process was followed for each interview. The themes from each transcript were brought together into a consolidated list, where patterns could be established. A table of subordinate and master themes was created for all the transcribed interviews as suggested by Biggerstaff and Thompson (2008) (Figure 1). The master themes were clearly evident in the majority of the transcripts. Experts in IPA and qualitative research and two ICU researchers reviewed the themes to ensure that they were grounded and well presented.

RESULTS

Thirteen nurses consented to participate. Participants were primarily female and had worked a considerable time as nurses (Table 1). Five nurses had attained some form of training in end of life care after their professional qualification.

The essence of nurses' experiences of providing end of life care after the withdrawal of treatment was interpreted as "doing the best to facilitate a comfortable and dignified death''. Care activities associated with providing a comfortable and dignified death were grouped to form the following four master themes: 'caring for the dying patient and their family', 'providing and encouraging presence', 'reconnecting the patient and family' and 'dealing with emotions and ambiguity'.

Caring for the dying patient and their family

Most of the participants' accounts referred to the provision of physical care and symptom management for the dying patient in the pursuit of a comfortable and dignified death. The nursing interventions included bathing, pressure area care and administration of analgesics and sedatives. These interventions are generally considered as fulfilling basic standards of patient care:

... you have to think about comfort for the patient primarily...I think primarily, it's comfort for the patient and doing those little things like turning them, mouth care, all those little things and making them look as comfortable, and hopefully they are as comfortable as possible.(Nurse 4)

The patient has to appear very well cared for physically and has to be comfortable and pain-free... (Nurse 6)

During the provision of physical care participants suggested minimum communication with the dying patient, although no explanation was given. The lack of communication was identified as a worrying issue by the participants, which was also seen as a barrier to effective end of life care provision. Caring without communication with the sedated or comatose patient was considered less fulfilling:

Ideally, because we know that people in a coma can sometimes hear you, I think, we ought to explain to the patient that they're dying but I've never seen anybody do that in 20 years.(Nurse 13)

Participants frequently emphasised the importance of caring for the family, which was seen equally or even more important than the care of the dying patient. The care involved the development of an intimate relationship with the family, listening and providing information and offering reassurance:

I think that the relatives' care is something that we do not necessarily talk about, but it is important that they feel as they are being cared for and that all of their needs are being taken into consideration... (Nurse 3)

...we also have a lot of involvement with the family. Giving a lot of support to the family, telling them what is going to happen, what is going to happen next... (Nurse 2)

I had only met him that day and by lunchtime we had withdrawn and by 1.00 pm he had died, so it quite upset me because of sitting with the son and he was telling me about this guy's life... And you have to be there to listen to relatives and support them and to go at their pace. (Nurse 4)

Providing and encouraging presence

The physical presence of the family during the dying phase was regarded essential by the nurses who also suggested that in the absence of family members, a nurse should be with the dying patient all the time. Dying alone was not considered a desirable death in ICU, and treatment withdrawal was sometimes withheld or deferred until family members were present:

... and I suppose to ensure they don't die alone as well. Sometimes the family can't be there, so it is important that a nurse should be there at all times with the patient. (Nurse 2)

…there is always time given to people who want to bring certain family here or people who are waiting for offspring, children to come back or even children that are in prison, you know. Whatever the scenario, time is allowed, for the whole immediate requirements of that family involved to be able to attend. (Nurse 6)

In some cases however, delaying the withdrawal of treatment created moral questioning to nurses:

I mean from the patient's point of view, you know, you are keeping somebody alive just for the relative's benefit... I do feel a bit uncomfortable sometimes keeping patients going for the sake of relatives turning up but in most cases it is not too long. (Nurse 13)

When the family of the dying patient was present, participants' descriptions suggested that they were available but at the same time were making every effort to allow private time for the dying patient and the family:

...and how much they want you to be involved because sometimes they just don't want, they want to be left alone and they want you to sort of stay outside of the curtain so that they can have their time. (Nurse 9)

Reconnecting the patient and family

Reconnecting the patient and family was a master theme with three subordinate themes: creating a less technical environment and reducing technical care; reducing distance between the patient and their family; and increasing privacy and proximity.

Most of the participants recognised that the ICU environment created barriers between the patient and the family. For example, monitoring equipment and invasive lines can restrict family access to the patient. There was an attempt to remove perceived barriers at the last stages of life either by creating a less technical environment and/ or involving the relatives in the physical care of the patient:

When it comes to family involvement, as much as you want them to be involved, sometimes there's just so many things. I mean, in a bed space when a patient is really poorly and the risk is full-on, there are loads of equipment, and it can be like a barrier for them to actually touch the patient because of all the equipment. (Nurse 12)

... and it's very important to empower the family and their loved ones to take back their…that person they love. (Nurse 8)

...taking away as much of the ICU as you possibly can and for the relatives giving their…giving them back to their relatives... (Nurse 10)

Allowing the time and space for intimacy was regarded by some participants as essential to reconnecting the patient and family at the last stages of life. A participant, in a noticeable emotional state, described how she facilitated intimacy for a patient and his partner:

I closed the curtains and didn't let anybody in, ... she cuddled him and stayed with him in his last moments really. And I've had feedback from that later, that that's all they wanted to do and I have done that a couple of times I must admit. (Nurse 8)

Dealing with emotions and ambiguity

Dealing with emotions and ambiguity as a master theme included the subordinate themes of uncertainties on relationships and 'what is the right thing to do'. Uncertainty was found in the relationships that participants described between ICU nurses and family members and the emotions these relationships induced. Two participants described their uncertainties, clearly affected by the withdrawal of treatment taking place on the day of them been interviewed:

But it's also getting that right, getting the balance right. Not inflicting your feelings onto the family because they have got their own feelings and emotions they are going through. (Nurse 2)

Sometimes I just have to step away, and sometimes, yes that's fine, it's okay in certain situations to let your emotions to be shown I think. It shows you're compassionate and that you actually do care... (Nurse 8)

Questions were also raised on how long this relationship should last. A nurse described how a relationship did not resolve with the patient dying and the bereavement support offered to the relative shortly after, questioning personally the length of time and the level of involvement one may invest in end of life care .

The complexity of intensive care nursing and the lack of clear end of life care guidelines at the ICU where the study was conducted placed nurses in a position of uncertainty about what is right or best to do during treatment withdrawal. Nurses were not sure about the process for deciding and carrying out treatment withdrawal, or what the best approach to this was. There appeared to be a lack of clear communication between doctors and nurses about the processes following the decision to withdraw treatment. Senior nurses felt more confident and on several occasions, participants said they would resort to what they would like to be done for their loved ones or relied on practices that had worked well in the past:

There have been questions like: should we stop the feed, or not? Who's going to turn off the inotropes, is it us or is it the doctors? Who's going to speak to the family – although it's mostly the doctor who does that. But, you know, there are like grey areas.(Nurse 12)

I think also, really you have to take it back down to grass roots and you have to think, "What would you want if it was your relative?" (Nurse 1)

I've done like different things that have gone well and I've done different things that haven't gone well and I use all those things. (Nurse 10)

As ICU is associated with technical care and haemodynamic monitoring, there was some uncertainty as to whether monitors should be removed or be left to demonstrate that nurses still looked after the dying patient:

We perhaps leave a monitor on, possibly because we don't want the relatives to think that we've suddenly gone from all support to absolutely nothing, that we're still actually watching, looking, caring for that patient... (Nurse 7)

Before the decision to withdraw treatment, the patient seemed to be the centre of care for nurses in this study. After the decision was made, the family tended to become the main focus of care. This created great uncertainty on whether the focus of care should be the dying patient or their family:

Because, at the end of the day I am taking care of the patient, not their family and you have to remember that sometimes, that my priority is the patient but … you cannot take away from the fact that the family are a huge part of the patient's life and it is such a sad time and losing somebody especially in intensive care when it is such a shock... (Nurse 3)

DISCUSSION

The purpose of this study was to explore the experiences of intensive care nurses who provided end of life care to adult patients and their families after a decision had been taken to withdraw treatment. End of life care was seen as an important aspect of intensive care and was identified as a privilege by most of the participants.

The element of caring in the last stages of life in ICU materialised in the form of physical care for the dying patient and emotional care for the family. Physical care to provide comfort for the

dying patient has been described by Ranse *et al.* (2012). This aspect of care shows respect to the patient and provides comfort to the family as the social significance of the patient is acknowledged (Seymour 2001). Details of specific interventions associated with physical care were not explained by the participants or by Ranse *et al*. (2012), possibly because these interventions were considered as common practice. Sabo (2011) identified physical care for the patient as a provision of service rather than caring, arguing that emphasis is placed on fulfilling a task rather than establishing a connection with the patient. It appears that meaningful caring for the unconscious patient is difficult given the patient's inability to express needs and engage in caring activities (Finfgeld-Connett 2008). However, caring is more evidently offered to the family. According to Wilkin and Slevin (2004) caring for a family member in ICU included listening, providing information and offering reassurance. Participants in our study referred to these attributes in their descriptions of caring for the family. Finfgeld-Connett (2007) adds that caring is characterised by expert nursing, interpersonal sensitivity and intimate relationships. Vanderspank-Wright *et al.* (2011b) have described this act of caring for the family as 'stepping in' where nurses support families and establish a rapport which creates a sense of familiarity and makes end of life care less complex. Other qualitative studies have also demonstrated the importance of caring for the family, with nurses' narratives about caring for the family occupying significant proportion of the interviews (Ranse *et al.* 2012, Vanderspank-Wright 2011b). It is not surprising that caring for the family has been identified as an important aspect to achieve quality end of life care in ICU (Kirchhoff *et al.* 2000).

Participants also regarded family presence at the end of life as essential. Finfgeld-Connett (2008) described presence as an interpersonal process characterised by sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstances, reflecting some of the participants' narratives in this study. Family presence at the end of life is a common theme in studies in a variety of settings (Gannon & Dowling 2012, Calvin *et al.* 2009). Participants suggested that presence of the family was so important that the process of withdrawal of treatment was delayed to accommodate the arrival of family members. However, the morality of this practice was questioned. Similar concerns were

raised in Ranse *et al.*'s (2012) study with ICU nurses who found the delaying of withdrawal of treatment disrespectful for the patient.

Closely related to the master theme of family presence was the theme of reconnecting the patient and family. It has been long recognised that the ICU environment creates barriers between patients and their families (Simpson 1997). Participants felt that it was important to reconnect the dying patient with their family at the last stages of life. Some of the measures used for reconnecting included manipulating the technical environment and involving relatives in the care of the dying patient. Ranse *et al.* (2012) and Long-Sutehall *et al.* (2011) have described similar interventions. Vanderspank-Wright *et al.* (2011b) suggested that encouraging intimacy and privacy between patients and their families helped to increase memories that would be remembered the most.

Generally, interventions in ICU are guided by well-established evidence. However the research study site was bereft of any guidelines to inform the process of treatment withdrawal or pathways such as the modified Liverpool Care Pathway (LCP), to inform the process of care. Although some participants were aware of the LCP and were willing to implement it, a recent report in the UK suggests that a pathway approach is not useful and the LCP should be abandoned (DH, 2013). Further research into nurses', patients' and families' experiences of end of life care in ICU is arguably needed to inform best practice. The development of practice guidelines may help to overcome ambiguity concerning nursing care and responsibilities during and following the process of treatment withdrawal; as previously recommended by Long-Sutehall *et al.* (2011). Education and training opportunities are also essential to ensure ICU nurses develop the right knowledge, skills and attitude to provide high quality end of life care.

Participants expressed difficulty in balancing their professional role and personal feelings. This in turn left nurses questioning whether they were 'doing the right thing' and experiencing feelings of ambiguity. Stayt (2007) also identified conflict between the nurses' professional role and the personal self when caring for families with relatives in ICU. These uncertainties however are not confined in the area of ICU. Sabo (2011) identified similar conflict of roles in hematopoietic stem cell

transplant nursing. Regardless of the conflict nurses experience between their professional and personal role, Lind *et al.* (2012) argued that relatives value the closeness developed between nurses and families in the end of life process. An additional uncertainty for participants included whether caring for the family should take priority over the care of the dying patient. The increased focus on family care during end of life in ICU created moral questioning among the participants. The dilemma of treating families over patients while withdrawing treatment in ICU is also documented in Pattison *et al.*'s (2013) study. Stayt (2007) discussed the difficulty of balancing care activities in ICU, explaining that families can verbalise their demands in contrast to the sedated and ventilated patient. All these uncertainties can create stress to ICU nurses and lead to emotional exhaustion (Rocker *et al.* 2010, Ryan and Seymour 2013). Building resilience in health professionals via education and workplace learning would be advisable (Mc Allister and McKinnon, 2009).

Limitations

Although the sample size was appropriate for a qualitative study, the fact that it was recruited from one local University hospital in UK may limit the transferability of findings. However, as the themes emerged it was apparent that the results were congruent with those of past related studies and congruent with studies in other fields of nursing indicating some transferability (Shenton, 2004). All participants were self-selected and their motivations for taking part may have originated from very positive or very negative experiences. Only one nurse was from a non-white background which may have placed limits on capturing aspects of cultural diversity. Despite the issues raised above, the experiences that we explored offered rich insight into the challenges faced by ICU nurses when providing end of life care after treatment withdrawal.

CONCLUSION AND RELEVANCE TO CLINICAL PRACTICE

Providing end of life care after a decision has been taken to withdraw treatment is a common aspect of care for ICU nurses. During this time, it is evident that nurses are doing their utmost to facilitate a

comfortable and dignified death for the patient and their family. However there are aspects of care that challenge nurses and may lead to emotional exhaustion. Areas worthy of further investigation include: exploration of nursing actions during treatment withdrawal, nurses' emotional resilience in situations of dying and death and interventions to effectively reconnect patients with their family as they approach the end of life.

The interpretive findings from this study could help ICU nurses to better understand their role in providing end of life care after a decision has been taken to withdraw treatment. Given that the nurse-patient-family relationship is usually well established and the time frame from treatment withdrawal to death is normally short, it is important that staffing levels are adequate in ICU to allow nurses to exercise presence and care for the dying patient and their family. Communication pathways between nurses and doctors need to improve and practice guidelines should be developed to reduce ambiguity and support the delivery of high quality care for adults as they approach the final stages of life in ICU.

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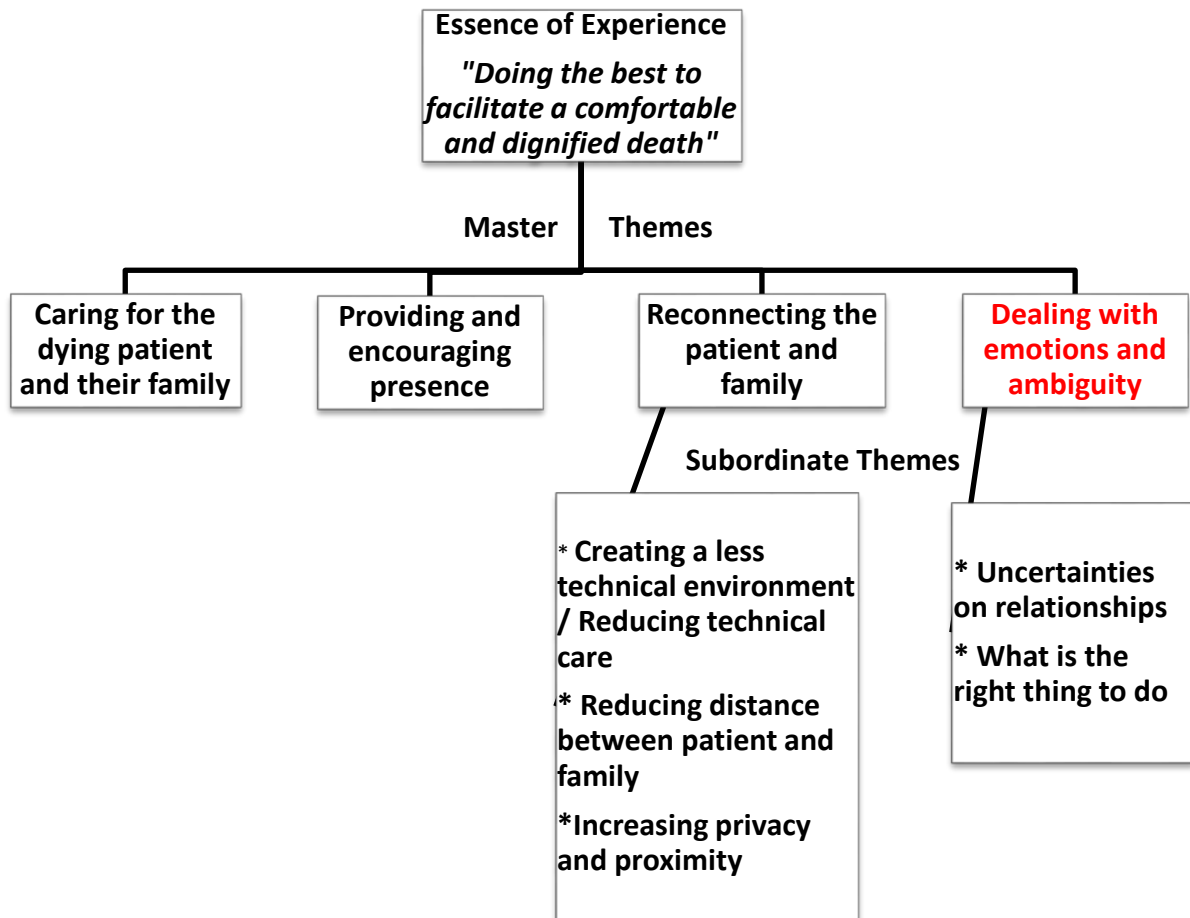**Figure 1. Essence of experience, master and subordinate themes**

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                    ┌─────────────────────┐
                    │ Essence of Experience│
                    │  "Doing the best to  │
                    │ facilitate a comfortable│
                    │  and dignified death"│
                    └─────────────────────┘

              Master  │  Themes

   ┌──────────────┐ ┌──────────────┐ ┌──────────────┐ ┌──────────────┐
   │ Caring for the│ │ Providing and│ │Reconnecting the│ │ Dealing with │
   │ dying patient │ │ encouraging  │ │  patient and  │ │ emotions and │
   │and their family│ │  presence   │ │    family    │ │  ambiguity   │
   └──────────────┘ └──────────────┘ └──────────────┘ └──────────────┘
```

Subordinate Themes

```
   ┌─────────────────────┐      ┌─────────────────────┐
   │ * Creating a less   │      │ * Uncertainties     │
   │ technical environment│      │ on relationships    │
   │ / Reducing technical │      │                     │
   │ care                │      │ * What is the       │
   │                     │      │ right thing to do   │
   │ * Reducing distance │      │                     │
   │ between patient and │      │                     │
   │ family              │      │                     │
   │                     │      │                     │
   │ *Increasing privacy │      │                     │
   │ and proximity       │      │                     │
   └─────────────────────┘      └─────────────────────┘
```

Table 1. Demographic characteristics of study participants

No	13
Female/Male	11/2
Mean age in years (range)	37 (28-59)
Length of time in profession	
6-10 years	3
11-15 years	3
16-20 years	1
21-25 years	5
26+ years	1
Length of time in ICU	
2-5 years	2
6-10 years	5
11-15 years	2
16-20 years	4
End of Life Care further education	5