



## Research article

# Meaningful experiences and end-of-life care in the intensive care unit: A qualitative study

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## ABSTRACT

**Objectives:** The purpose of this study was to provide a comprehensive exploration of nurses' meaningful experiences of providing end-of-life care to patients and families in the intensive care unit (ICU). The objectives of this research were: (1) To explore what is meaningful practice for nurses regarding end-of-life care; (2) To describe how nurses create a good death in the intensive care unit and (3) To identify the challenges that nurses face that affect their meaningful experiences and ultimately the creation of a good death.

**Research design:** This study utilised an interpretive phenomenological approach using Van Manen's (1997) method.

**Setting:** In-depth, face-to-face interviews were conducted with six intensive care nurses employed in a 32-bed medical/surgical intensive care unit of an academic tertiary care centre in Canada.

**Findings:** The overarching theme from the analysis of this experience was "being able to make a difference" which was intricately woven around contributing to a good death. Three main themes were identified and included: creating a good death, navigating the challenges and making it work.

**Conclusion:** The findings reveal how intensive care nurses provide good end-of-life care and create good deaths for patients and families.

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## Implications for clinical practice

- Good communication and teamwork are essential for nursing practice and the provision of end-of-life care.
- Building trusting relationships with families is crucial in caring for dying patients in the intensive care unit.
- Continuity of care during end-of-life care fosters relationships between nurses and families.

## Background

Death in intensive care units (ICU) is prevalent due to the severity of illness, injury and often-unpredictable responses of critically ill patients to treatment strategies. In the uncertain and fast-paced environment of the ICU, registered nurses (RNs) are the principal providers of end-of-life care (EOLC) to patients and their families. As front-line care providers, ICU nurses work collaboratively

within an interdisciplinary team to provide holistic care and advocate for patients' wishes at the end-of-life (Canadian Association of Critical Care Nurses [CACCN], 2017). Intensive care unit nurses provide EOLC on a regular basis and often learn to do so through experiential learning (Holms et al., 2014; Puntillo and McAdam, 2006; Vanderspank-Wright et al., 2011a; Zomorodi and Lynn, 2010).

### The role of ICU nurses in End of Life Care

In contrast to other areas of clinical practise, formalisation of the 'dying process' in the ICU often begins once it is clear that: 1) patients will not recover from their illness; 2) life-sustaining measures are no longer of benefit (for the aim of recovery) and 3) goals

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of care are re-evaluated through formal dialogue between the healthcare team and the family/substitute decision maker(s) and within the context of patients' wishes should they be known (Bach et al., 2009; Coombs et al., 2012). Intensive care unit nurses have a continuous bedside presence and spend complete shifts with patients and families during the dying process (Adams et al., 2011). Their presence facilitates the development of therapeutic and trusting relationships with patients and families. Literature reveals that ICU nurses support patients and families throughout the dying process and help them achieve their goals of care by working collaboratively with the healthcare team (Bach et al., 2009; Peden-McAlpine et al., 2015).

Once a decision is made to transition from curative to comfort measures, ICU nurses are often the healthcare providers who carry out the withdrawal process (Hov et al., 2007; Vanderspank-Wright et al., 2011b). Nurses ensure patient dignity and comfort by removing unnecessary technology and providing symptom management through pharmacological and non-pharmacological measures (Long-Sutehall et al., 2011). Nurses use their knowledge and skills to manipulate technologies and medications during the withdrawal process (i.e. keeping the patient fully oxygenated and/or continuing with the vasopressors to maintain a blood pressure) to provide more time for family and friends to arrive at the bedside and say their final goodbyes (Fridh et al., 2009). Literature has emphasised the challenges nurses experience while aiming to provide 'good' EOLC within the critical care environment (Attia et al., 2012; Beckstrand et al., 2006; Kirchoff and Kowalkowski, 2010; Ranse et al., 2012). These challenges include: 1) poor communication between physicians and families and also between physicians and nurses, which can lead to patients not having their wishes or goals of care respected and/or carried out at the end-of-life; 2) the lack of structured support in dealing with distressing situations via debriefing with the interdisciplinary team, counselling or managerial support; 3) lack of time to engage with families, which can hinder nurse-family relationships; 4) lack of formal education and training in EOLC whereby nurses may feel underprepared and 5) the technological mandate of the ICU with its focus on treatments that can cause prolonged suffering, discomfort, and prevent a dignified death for patients (Attia et al., 2012; Beckstrand et al., 2006; Kirchoff and Kowalkowski 2010; Ranse et al., 2012). Despite these challenges, research has captured the stories of nurses providing EOLC in the ICU and revealed sentiments of feeling privileged and rewarded (Vanderspank-Wright et al., 2011b). As a result, we know from the extant literature on the topic, that there is meaning to be found in the experiences of ICU nurses who care for patients and families at the end-of-life. Therefore, the aim of this qualitative research study was to explore what nurses describe as meaningful within the context of providing EOLC in the ICU.

## Methods

A phenomenological study using Van Manen (1997) was designed. The constructivist underpinnings of phenomenology (both ontological and epistemic) enabled the researchers to acquire a deeper understanding of the phenomenon of interest. According to Van Manen (2017), "experiencing meaningful moments" in phenomenological inquiry makes the endeavour "worth the effort" (p. 779). As is consistent with this methodological approach, the primary researcher (first author), carefully positioned herself within the research design, considered her past experiences as an ICU nurse and documented her assumptions about the phenomenon.

### Setting

The study setting was a 32-bed medical/surgical ICU in a tertiary care teaching hospital in Canada. At the time of recruitment,

the staffing compliment of clinical nurses was 140+ full-time and approximately 15 part-time nurses. The patient population included those with cancer related illness, sepsis, burns and patients admitted post-operatively following extensive thoracic surgery.

### Sample

The nurses in the unit were all RNs who had received specialised training in critical care from the hospital. Participants were included in this study on a first come, first serve basis assuming they met the inclusion criteria. Inclusion criteria were: 1) RNs who were working part-time or full-time in the ICU; 2) who had provided end-of-life care to a patient/family in the ICU; 3) who were English or French speaking and 4) who had a minimum of six months experience in the ICU. Previous dialogue with the unit's nurse educator suggested that nurses who had been present in the unit for six months had sufficient exposure to EOLC in the ICU in order to have experiences to share. Recruitment continued until patterns of responses were emerging in the data and this was evident after the sixth interview. Six ICU nurses, with a range of experience of four to 23 years in ICU participated.

### Data collection

Data collection occurred over a period of four months. Data was collected through face-to-face, unstructured interviews. Interviews were scheduled at a mutually agreed time between the primary researcher and the participant. Prior to beginning the interviews, each participant completed a demographic questionnaire. Interviews were 45–60 minutes in length; all were audio-recorded. Each interview began with a broad question "Tell me about a meaningful experience where you provided end-of-life care for a patient and family in the ICU?" Probing questions (e.g. 'tell me more about' or 'can you give me an example of') were used to generate more in-depth responses when required. A second interview for member checking was conducted with the participants once the data analysis was completed.

### Data analysis

All interviews were transcribed and verified against the original recording for accuracy. The data were analysed using Van Manen's (1997) three-step approach (the holistic approach, the selective approach, and the detailed (line by line) approach). The first step was the holistic approach where the first-author attempted to capture the meaning of the text as a whole (Van Manen, 1997). The first author read and re-read the data until becoming very familiar with it. During the second step (the selective approach) the first author identified significant statements and phrases that were important to the study (Van Manen, 1997). These were coded in an effort to organise and categorise the data. The third step as per Van Manen (1997) was the detailed approach whereby multiple readings were undertaken and every sentence of the interview data was examined. The significant statements from step two were extracted, re-examined, and organised into themes and subcategories. The relationship both within and between themes was analysed to bring forth the experience of the participants. Data analysis was completed in collaboration with the second and third authors who read all the transcripts and assisted with the analysis. They were experts in both critical care nursing and qualitative research methods. The fourth author assisted with the analysis and was an expert in qualitative methods.

### Methodological rigour

Efforts to ensure methodological rigour included credibility, dependability, confirmability and transferability as articulated by Lincoln and Guba (1985). To ensure credibility (truth-value), the first author, met regularly with the research team. Member checking was conducted to obtain the participants' comments on the developed themes. For dependability (reliability of the data), a decision trail was maintained by documenting decisions made throughout the study as well as decisions related to the data analysis, such as how the findings were interpreted and the results reported (Noble and Smith, 2015). To ensure confirmability, the first author's presuppositions were made explicit before beginning data collection in an effort to demonstrate that the findings came from the participants' narratives and not personal assumptions. Transferability was facilitated through a description of the study setting and participant characteristics (Lincoln and Guba, 1985).

### Ethical considerations

Approval was received from the institution and university research ethics boards (approval number: AO1-15-04). Written informed consent was obtained prior to each interview. Participation was voluntary and participants could withdraw from the study at any time. Pseudonyms were assigned to each participant to ensure anonymity.

### Findings

#### *The essence: being able to make a difference*

The essence of ICU nurses' meaningful experiences of providing EOLC was interpreted as 'Being Able to Make a Difference'. 'Being able to make a difference' reflected participants' efforts to contribute towards a good death for dying patients and their families in the ICU. Knowing they could make a difference in the care they provided to patients and families helped them find meaning in their work. Margo described:

*'As long as you feel that you've made a difference and you've made things a little bit easier in such a hard situation... you feel like you've done your job, you've done the best that you can both as a nurse and as a person.'*

Three main themes related to being able to make a difference emerged from the data: *Creating a Good Death*, *Navigating the Challenges*, and *Making it Work*.

#### *Theme 1: Creating a Good Death*

The participants described their efforts towards the creation of a good death by *respecting wishes*, *facilitating comfort*, *being there*, *preserving dignity and peacefulness* and *connecting with families*.

#### *Respecting wishes*

All participants emphasised that respecting patients' wishes was an important aspect of creating a good death in the ICU. In what was considered the most ideal end-of-life circumstances, patients could make their physical and/or emotional needs known to their care providers (their family as well as the ICU nurses and physicians). In this instance, goals of care and EOLC decision-making became less complicated because patients' wishes were clear. Even though it was easiest when patient's wishes were known, it was still difficult for families. Tracey reflected:

*'I mean it's so wonderful when a patient can provide their family with enough information to make the decision... when the family*

*knows that they're doing the patient's wishes no matter how hard the decision is, it's easier for them and that in itself makes our job easier.'*

Coming to know and then ultimately respecting patients' wishes required good communication and teamwork between the family and the healthcare team.

As part of their role, nurses facilitated the planning and execution of family meetings. Participants described these meetings as spaces where open dialogue between the family and health care team could occur which facilitated: 1) getting to know what patients' wishes were or might be and 2) structuring goals of care in ways in which patients' wishes were respected. Amy elaborated:

*'Teamwork ... good communication... understanding among the teams, the ICU team, the nursing team, the doctors, the palliative care [team]... everybody that's involved... that's the way to make the patients comfortable... die with dignity and respect their wishes.'*

Margo, added: *'If we can abide by people's wishes and do what honours them and how they would have liked to live their life... is the biggest compliment you can show them.'*

#### *Facilitating comfort*

Participants described the provision of comfort as an essential aspect of providing a good death for patients and their families. The provision of comfort care included pain and symptom management through both pharmacological and non-pharmacological means. Amy described:

*'A good death for me in the ICU... is when you make the patient comfortable... from the beginning of the process till the end... no suffering, comfortable.'*

In the study setting, a comfort care protocol provided the parameters for analgesia, sedation and for withdrawal of life-sustaining measures (i.e. titration of vasopressors and weaning from mechanical ventilation). However, the participants also reflected on using their judgement, particularly with respect to terminal weaning of mechanical ventilation. Tracey explained:

*'Sometimes we take the ventilator off, sometimes we don't. It really depends on how involved the lungs are... I find that always difficult because [extubating] can cause some... discomfort. I find when we take the breathing tube out or even sometimes take them off the vent they can gasp a lot... whereas you don't notice that on the vent... I find they don't really gasp and we can control that better.'*

Participants also emphasised that non-pharmacological measures such as repositioning, providing mouth care and bathing patients, demonstrated to family members that they (the nurses) were still caring for the patient. Sherri reflected:

*'Knowing that I'm there to provide symptom management and make sure that the drips don't run out and you know that sort of stuff... we still provide... mouth care and you know checking, providing that little bit of care to make the family not just believe but that I actually am caring for their loved one'* [emphasis added].

#### *Being there*

Participants described being there for patients and families as meaningful and part of providing a good death. They were explicit in their beliefs that nobody should die alone and that family presence at the bedside was important. In situations where family could not be there in time, or the patient did not have family, they also felt it was imperative that they, as ICU nurses, be there for the dying patient. Sherri recalled an experience where family members

were in transit but were unlikely to make it to the hospital before the patient died. She described:

*'I went in the room and sat down next to her and held her hand. . . I don't like anybody to die alone. I don't care if they have family or not . . . nobody should go alone as far as I'm concerned. . . so I was there for her last moments, her last breaths but it left me with a very heavy heart because I knew her family was coming in and they weren't going to be there.'*

Similarly, Kathy recalled 'being there' for a patient without family:

*'I was there for two days with the patient. . . holding the patient's hand . . . very meaningful and I don't think I'm ever going to forget that. . . I've done what I was supposed to do that day. . . I was supposed to be in that room and supposed to hold that patient's hand when he took his last breath.'*

#### Preserving dignity and peacefulness

Participants ascribed meaning to their efforts in preserving human dignity. For some, spirituality and religion were connected to peacefulness and were described as important aspects of a good death. Participants referred to the 'little things' they did to preserve dignity and demonstrate to the family that their loved one was cared for. Tracey described *'whether that be combing their hair, putting their hands on the top of their sheets so family members can feel like they can hold them, making sure their face is washed and they're clean. . . it shows care'*. Sherri spoke of efforts to preserve dignity, by removing unnecessary technology and equipment, *'I want them to be able to focus on knowing their loved one. . . so I really try to get rid of as much as I can.'*

#### Connecting with families

Families were integral to participants' experiences in providing EOLC to patients in the ICU. Participants described connecting with families as fundamental to creating a good death and required two essential elements: *making time to build relationships* and *creating a space for family* within the ICU.

*Making time to build relationships.* Participants explained that time spent with families was about getting to know them and getting to know the patient through them. Time spent with families also facilitated keeping the family informed and involved in the patient's care. Margo explained: *'Time allows you to be there for the family and explain things. . . [but] mostly to be there. . . It makes you feel good and makes you feel you've done your job and it makes them feel understood.'* Participants also expressed that not having enough time to spend with patients and families made it more difficult for the nurses to build relationships with families.

*Creating space for family.* Aside from efforts to remove technology and equipment, the participants reflected on how they manipulated the ICU environment in an effort to create an intimate and personalised space for families. Personalised spaces made the ICU more home like. Patients and families could experience comfort, memories and final moments and have a space in which to grieve. Kathy reflected:

*'He brought his guitar in and they sang. . . while she died. . . they knew that she loved it when he played guitar, it was really wonderful. . . we just closed the door. . . they. . . played guitar, and talked and reminisced. It was really lovely.'*

#### Theme 2: Navigating the Challenges

The participants reflected on the challenges they experienced that ultimately affected the creation of meaningful experiences

wherein a 'good death' was possible. They identified these challenges as being multifactorial and they described how they attempted to navigate their way through them. Subthemes included *Coming in Cold*, *Not Connecting*, and *Not Being on the Same Page*.

**Coming in Cold** was described by participants as experiences where they would provide EOLC to a patient and family they hadn't met previously. They found these experiences uncomfortable and difficult. Sherri elaborated on the challenges of coming on shift and having to quickly find ways to establish a level of trust with the family. She explained:

*'Often times I come in and it's a family and a patient I don't know. I get report and then I have to say 'Hi my name is and I'm going to be with you this evening or this day' and you know it's sort of like the elephant [i.e. unspoken] in the room that your loved one is dying. . . I'm here to help everybody sort of cope with it and watch what's happening. . . The hardest is when you don't know the family, you don't know the situation, you're coming in cold.'*

However, the participants worked towards establishing a relationship with the family as quickly as possible. Sherri described that she would *'feel it out with the families'* by finding out where they were in the EOL process and then provide them with information they needed.

**Not Connecting** involved situations where participants felt unable to connect or establish a relationship with the family. Participants explained that some families were more difficult to build a connection with, particularly if there was discord either within the family or between the family and the healthcare team. Participants also reflected that some families were more 'closed off' but did not explain how or why this occurred. Margo elaborated:

*'Sometimes you just don't feel that connection with the person and sometimes there's no reason, sometimes you know it's just a vibe that they don't get along with you or you don't get along with them. Sometimes it just doesn't click. . . sometimes it just doesn't come together.'*

Participants also added that when the unit was particularly busy (i.e. high acuity and multiple admissions) it had a potentially negative impact on building relationships with patients and families. Unit busyness could result in nurses who were assigned to patients at EOL being pulled away to help their colleagues. The latter took away from the time they have to know the family. Margo added, *'if it's really busy in the unit and someone's critically ill and we can potentially save them, sometimes it does take away from the time where we can sit there and have time to deal with the family.'*

**Not Being on the Same Page** was described as three different scenarios that contributed to discord and lack of consensus/agreement about the plan of care. These included: 1) when the family and physicians were not on the same page; 2) when the health team members were not on the same page with each other and 3) when the family was not respecting the patient's wishes. The common contributing factor across all scenarios appeared to be a lack of communication and teamwork. Kathy summarised:

*'The biggest thing is when the family and the doctors and the team, and the patient are not all on the same page. . . I've had a situation where a doctor may have given them undue hope. . . that I felt they shouldn't have and I felt like the family was asking to stop doing this, cause the son was saying he wouldn't want all this, why should we keep doing this. And the doctor said, "well I think we should keep going, we should give it a few more days you know, see where he's going" and it just went downhill from there.'*

Kathy also reflected:

*'It was probably one of the hardest family meetings because the patient had input... The patient speaking for himself and you don't see that very often here... but this time... the patient speaking and telling us that he didn't agree with what the physician was saying.'*

### Theme 3: Making it Work

Despite the identified challenges, participants described how they navigated their way through them to be able to provide a good death and to find meaning in their work. Subthemes identified included *Building Relationships Quickly*, *Taking Care of Yourself* and *Recognising It's a Privilege*.

#### *Building Relationships Quickly*

While described as a challenge when “coming in cold”, building relationships quickly was considered to be both a necessary and important aspect of providing end-of-life care. Sherri reflected:

*'You have to build that relationship very quickly and whether they know my name doesn't matter. All they know is that there was a nurse there that provided care and made them feel safe, that's all that matters to me at the end of the day.'*

#### *Taking Care of Oneself*

Participants described engaging in self-care in order to continue to work in, and through, difficult situations. Participants reflected that as ICU nurses, seeing patients die occurred on a daily basis and that support was essential and necessary in being able to navigate the challenges they experienced. Self-care varied across participants. Amy reflected:

*'In order to take all this stuff from all these challenges, nurses need to take care of themselves and if it's necessary we can ask for counselling, we can talk to the clinical manager, and outside the job we can meditate. We can have a good life, we can read books, we can forget that we are nurses for a certain period of time until we come back and then it's easier or take stretches and not work overtime... we need mental health. We can do whatever it takes outside of work not to think about our patients and the challenges we have and [when] we have stretches, days in between our shifts, then it's easier to come back and take care of... a dying patient.'*

#### *Recognising It's a Privilege*

Ultimately, participants reflected how being able to provide a good death and work with patients and families, despite the challenges they experienced, was seen as rewarding and a privilege. Tracey stated: *'I feel... privileged to be a part of it. It's a pretty intimate part of somebody's life, their death... for the patient and the family... a really big part of that is a privilege.'* Sherri added:

*'These are moments you never forget, when the daughters... just lost their mother and they come to the nurse and they will hug the nurse and say thank you for the care you gave and my mum died peacefully and we are happy. These are sad moments and you have tears in your eyes and they are happy that their mum is in a better place.'*

## Discussion

In this current study, when participants were asked to share their meaningful experiences, they spoke of what they perceived to be a ‘good death’. As a result, this study makes explicit that what is meaningful in nurses’ work within the context of EOLC, is to con-

tribute towards the creation of a ‘good death’ in the ICU through optimal communication and team work, ensuring patient comfort, spending time with families, being there for patients/families and making a space for families.

Good communication was required in all aspects of nurses’ practise with respect to the provision of EOLC: building relationships with families, patients’ wishes being respected, being there for patients and providing comfort for patients. These findings echoed similar results in a study conducted by Cook and Rocker (2014) and a literature review by Efstathiou and Clifford (2011) where good communication during the provision of EOLC was associated with family satisfaction. In this current study, nurses often mentioned initiating family meetings and EOLC discussions but this is not consistently reported in the literature and across ICU/critical care contexts. For example, nurses often initiate communication regarding EOLC including initiating family meetings; however, they are not always included by physicians in the family meetings or end-of-life discussions thus resulting in fragmentation (Baliza et al., 2015; Weinberg et al., 2009). As such, an elaboration of the role that ICU nurses ought to play within the context of the interprofessional team with respect to decision-making and establishing goals of care is merited.

Facilitating comfort for the patient was imperative in creating a good death. In this current study, the nurses described the comfort care protocol as providing them with the necessary tools to evaluate symptom management strategies and help make decisions to provide patient comfort and alleviate distress. Jensen et al.'s (2013) study found that protocols and guidelines improved EOLC by enabling quicker decision making by nurses with the provision of comfort measures such as analgesia. Given the complexity of treatment withdrawal in the ICU, an emphasis on the use of guidelines and protocols has been advocated by key stakeholders including the Canadian Critical Care Society and the Canadian Association of Critical Care Nurses. In recently published guidelines, Downar et al., (2016) recommend that all ICUs should use protocols for the withdrawal of life-sustaining therapies because they can increase the quality of EOLC provided to patients and families. Importantly, however, guidelines do not preclude the provision of individualised care (Downar et al., 2016) and it is evident that, in an effort to provide quality EOLC care in the ICU, the need for clinical assessment and judgement is paramount.

In this study, participants also described the time spent establishing trusting relationships with families as a necessary component of a good death. Relationships with families were central to their provision of EOLC. Many studies have found that nurses establishing a trusting relationship with family can lead to good patient outcomes in the ICU including EOLC (Efstathiou and Walker, 2014; Fridh, 2014). When nurses had the time to connect with families, they did so by listening, talking and simply being present at the bedside. Kirchoff and Kowalkowski (2010) suggested that unit staffing should be arranged to accommodate nurses so they have only one patient when they are providing EOLC and this would allow nurses more quality time to spend with patients and families. Studies have also highlighted how continuity of care during EOLC contributes to relationship building between nurses and families (Efstathiou and Clifford, 2011; Truog et al., 2008). The latter could be facilitated by assigning a nurse to the same patient over several consecutive days/nights.

For participants in this study, being present with patients and families was an important contributing factor in the creation of a good death. Some participants described ‘being there’ as a sense of obligation and duty to patients while they were dying. Finfgeld-Connett (2006) described presence as “an interpersonal process that is characterised by sensitivity, holism, vulnerability, and adaptation to unique circumstances” (p. 710–711). In this current study, participants used explicit actions such as holding the patient’s hand,

talking to them about everyday matters and providing them with reassurance. The use of touch in EOLC was a major finding in Hov et al.'s (2007) study. They described in detail how nurses used non-verbal communication (with their hands-on patients' bodies) to demonstrate safety, dignity, comfort, and compassion.

Finally, by manipulating the ICU environment to allow for spaces where families could grieve and have private moments with their loved one, was important to the participants in this study. Several research studies have supported the intervention of nurses modifying the ICU environment to create spaces that generate comfort and peace for the family/patient and one that foster positive memory making (Arbour and Wiegand, 2013; Bratcher, 2010; Efstathiou and Ives, 2017; Pattison et al., 2013; Ranse et al., 2012). Ranse et al.'s (2012) suggested that altering the ICU environment can help "facilitate meaningful end-of-life experiences for patients and their families" (p. 10). Efstathiou and Ives (2017) suggested that when extraneous equipment was removed from the room, it allowed a more 'natural' death to occur. Almost two decades ago, Johnson et al. (2000) found that removing the technology promoted a more natural death and one that was "more dignified and aesthetically pleasing" (p. 284). More research is needed to explore how ICU nurses create an environment that unites the patient and family in an effort to facilitate meaningful end-of-life experiences.

### Limitations

Findings from this study are potentially limited by the specialised nature of ICU settings and may not be readily transferable to other critical care environments. Nurses who were very comfortable and confident with the provision of EOLC may be overrepresented in this study sample. The small sample size is a limitation of this study. Additionally, the sample may not adequately reflect the experience of novice nurses given the demographics of the nurses who participated.

### Conclusion

This phenomenological study has given voice to the role of ICU nurses in providing meaningful experiences in EOLC for patients and families. The essence of nurses' meaningful experiences was 'being able to make a difference' which reflected nurses' efforts to contribute to a good death for patients and families. The participants' stories went beyond simply listing what they perceived as a good death to describing how they created good deaths and provided good EOLC despite identified challenges. Providing EOLC is considered a rewarding and privileged experience of the ICU nurse.

### Conflict of interest

We have no conflicts of interest to declare.

### Funding sources

There are no funding sources to report.

### Ethical statement

Research ethics approval was received from the University of Ottawa REB and the REB of the study site.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.iccn.2019.03.010>.

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