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Intensive care nurses' experiences with withdrawal of life-sustaining treatments for intensive care patients: A qualitative study

Abstract

Objective: To explore the experience of intensive care nurses when participating in the withdrawal of life-sustaining treatments from intensive care unit patients.

Design and methods: A qualitative descriptive and explorative design. Data were collected in 2017 and 2018 by interviewing nine intensive care nurses. The data were analysed by using systematic text condensation.

Setting: The nine intensive care nurses interviewed worked in four different intensive care units located in one university hospital and one local hospital.

Main outcome measures: Experiences when participating in the process of withdrawing life-sustaining treatments.

Findings: Three categories emerged from the data analysis: ICU nurses' experiences of stress in the process of treatment withdrawal; a requirement for interdisciplinary support and cooperation; and elements to achieve a dignified treatment withdrawal process.

Conclusion: The intensive care nurses experienced challenges and emotional reactions when patients were overtreated or when they had to participate in treatments they did not agree with. They considered debriefings to be helpful in dealing with emotions. Thorough planning, good communication, pain relief, and the creation of a peaceful environment were perceived as important elements in achieving a dignified treatment withdrawal process.

Keywords: end-of-life care, ICU nurses' role, intensive care nurses, withdrawal of life-sustaining treatment, withdrawal of life support, withdrawal of treatment

Implications for clinical practice

- Leaders of intensive care units (ICU) should be aware that ICU nurses with limited work experience may find undignified treatment withdrawals more stressful than more experienced ICU nurses.
- Regular interdisciplinary meetings, in which all parties are involved in discussions on treatment withdrawal, could improve the experience of ICU nurses when participating in the withdrawal of life-sustaining treatment.
- The ICU nurses considered the use of a thorough plan for the process of treatment withdrawal to be essential if a dignified treatment withdrawal process was to be made possible.

INTRODUCTION

An intensive care unit (ICU) patient is defined as ‘a patient where it exists threatening or manifest, acute deficiency in one or more organ functions, and where the deficiency is supposed to be fully or partly reversible’ (Buanes and Kvåle, 2017). ICU patients, therefore, are critically ill and face the possibility of death. Ongoing advances in technology and medicine allow an increasing number of ICU patients with severe illnesses to receive complex treatments. However, the treatments ICU patients receive are not always successful (Noome et al., 2016), and it may be necessary to withdraw life-sustaining treatment (WLST) to release a patient from prolonged suffering. Data from the Norwegian ICU population in 2017 indicates that ICU mortality was around 10% (Buanes and Kvåle, 2017). The process of WLST is defined as actively stopping life-sustaining interventions and treatments, such as ventilator support or vasoactive medications on which the patient’s survival depends (Hoel et al., 2014, p. 329). It is primarily ICU nurses who care for patients during the last phase of life once a WLST decision has been made. ICU nurses carry the responsibility of being actively involved in end-of-life care, they participate in decisions regarding WLST, and provide interventions to relieve symptoms in the dying patient (Lykke, 2017).

Previous studies have explored the care that ICU nurses provide to patients and their families during and after WLST, and they describe the importance of honouring the patient’s wishes, while also providing information and communicating about the treatment withdrawal process (Arbour and Wiegand, 2014; Efstathiou and Walker, 2014; Noome et al., 2016; Ranse et al., 2016). Informing and educating patients’ families on the WLST process, providing them with emotional support, and meeting their needs have all been emphasised as important by ICU nurses (Arbour and Wiegand, 2014; Noome et al., 2016). Other studies have investigated teamwork, collaboration, and communication between ICU nurses and physicians regarding WLST decision-making and have found that nurses feel

underrepresented in end-of-life decisions (Efstathiou and Walker, 2014; Flannery et al., 2016; Kisorio and Langley, 2016). Flannery et al. (2016) described how ICU nurses experience communication problems and underrepresentation in discussions on end-of-life care, even though they are the patient's main health care provider, and how this leads to their experiencing anger and frustration. Kisorio and Langley (2016) found that, in the experience of ICU nurses, their involvement in end-of-life decisions can enhance teamwork and contribute necessary information regarding the patient's care. However, the nurses frequently experience insufficient support with a lack of debriefings following end-of-life care, and they find that teamwork is lacking in the units.

In a mixed method study conducted by Coombs et al. (2015), 78% of ICU nurses stated that withholding treatment was ethically more acceptable than treatment withdrawal. Furthermore, data from focus group interviews revealed that ICU nurses have varying views on the use of intravenous fluids, nutrition, and passive limb exercise once the decision to withdraw life-sustaining treatment has been made. However, the majority of ICU nurses view patient comfort as paramount (Coombs et al., 2015). Teixeira et al. (2014) found a positive relationship between ethical decision-making and burnout in nurses, although this did not apply to physicians. According to Jakimowicz et al. (2017), when ICU nurses experience conflicts, ethical dilemmas, moral distress, and detachment from patient care situations it can limit their ability to provide nursing care.

Knowledge regarding ICU nurses' experiences of participating in the WLST process is limited. Such knowledge could provide evidence for increased support for ICU nurses engaged in this process as well as a higher standard of practice, possibly resulting in a more dignified WLST process for patients and their families. Therefore, the current study aims to explore the experiences of ICU nurses when participating in the process of WLST with ICU patients.

METHODS

Research design

The study adopted a descriptive and explorative qualitative design using semi-structured interviews with ICU nurses. Such a design is relevant for describing and obtaining an understanding of ICU nurses' experiences during the process of WLST. The data collection method is suitable for exploring the experiences of participants and the meanings they attribute to them. Semi-structured interviews were used to capture each ICU nurse's individual experience, while also providing the participants with more time for reflecting and speaking openly than would be possible in focus groups (Polit and Beck, 2017).

Setting, sampling, and sample

Wards managers recruited ICU nurses from four different adult ICU units (general, surgical, medical, and trauma) located in one university hospital and one local hospital in the south-east of Norway. Purposeful sampling was carried out so that the participants recruited could provide rich data about a range of experiences when participating in the process of WLST with ICU patients. The following criteria were applied: nurses with more than two years of work experience in an adult ICU, participated in more than two WLST cases, and from different ICU units. In purposeful sampling, the participants are selected because they are 'information rich' and have extensive knowledge of the phenomenon of interest. The sampling is aimed at gaining insight into the phenomenon and not an empirical generalization from a sample to a population (Patton, 2015). A total of nine ICU nurses agreed to participate in the study, two males and seven females. The average age of the participants was 45 years, while the average length of experience of working in an ICU was 13 years (range 2–28 years). Two participants had only two years' experience of working in an ICU.

Ethical approval

The Norwegian Centre for Research Data approved the study (reference number 56405), and the hospitals involved approved the study. Prior to the interviews, the participants received written and oral information about the study, which underlined that their participation was voluntary, that they had the right to withdraw at any time during the study, and that anonymity and confidentiality were safeguarded. Written informed consent was obtained from all participants before the interviews.

Data collection

Nine individual interviews were conducted between November 2017 and February 2018. An interview guide with open-ended questions and follow-up questions was used. The interview guide covered the following topics: dignified and undesirable experiences, emotional impact of the treatment withdrawal process, training and guidance, ethical challenges, and other challenges. Participants were encouraged to give examples from their own experience and their own views on WLST. The interview guide was piloted prior to the interviews and no changes were deemed necessary. The interviews were performed at the participants' workplaces and lasted about 60 minutes, except for two, which lasted approximately 30 minutes. The interviews were audiotaped and transcribed verbatim by the first author.

Data analysis

The transcripts were analysed inductively using systematic text condensation (STC) (Malterud, 2012). STC was used because the participants' own descriptions and perspectives were emphasised. The data were analysed as a whole by identifying patterns of similarities and differences in the ICU nurses' experiences of WLST across the different ICU units. In

step one, the transcripts were read several times to get an overview of the material as a whole, and seven preliminary themes were identified, guided by the aim of the study. In step two, meaning units relevant to the preliminary themes were identified, coded, and organised into three code groups. In step three, the meaning units within each code group were condensed and marked with codes to sort meaning units into subgroups. The meaning units in each subgroup were condensed and abstracted (Table 1). The fourth and final step in the analysis was conducted by abstracting the subgroups in a code group to a category (Table 2) and then developing an analytical text from the condensate for each subgroup, which formed the findings of the study.

Trustworthiness

Both the first and third authors work as ICU nurses. Reflexivity was enhanced by using the first author's written notes regarding subjective knowledge and preconceptions regarding ICU nurses' experiences of treatment withdrawal. These notes raised awareness throughout the research process and ensured that the method and results would not be affected by these previous preconceptions. The data analysis was an iterative process in which the first author analysed the data while the last author read five of the interviews and asked questions during the data analysis process to expand understanding and provide competing interpretations (Granheim and Lundman, 2004). All the authors participated in the interpretation of the results, facilitating alternative interpretations due to their different clinical and research expertise. Transferability was enhanced through a detailed description of the method, the data analysis, and the results supported by quotations. This affords the reader an opportunity to judge whether the findings are transferable to their own setting (Graneheim and Lundman, 2004).

FINDINGS

Three categories emerged from the data analysis: ICU nurses' experiences of stress in the process of treatment withdrawal; a requirement for interdisciplinary support and cooperation; and elements to achieve a dignified treatment withdrawal process.

ICU nurses' experiences of stress in the process of treatment withdrawal

All participants described having experienced an undesirable WLST process. During hectic shifts, ICU nurses and physicians could treat patients without having sufficient time to properly assess the patient's case. It was perceived as challenging to be caring for patients who had undergone surgery and were being treated without realistic consideration of their excessive age or poor prognosis, particularly when the treatment contributed to prolonging and possibly even increasing their suffering. Participants described how disagreements within the medical team or with the family about treatment decisions could delay the decision to withdraw life support, resulting in overtreatment and the overall experience of suboptimal care. Even though most of the participants wanted WLST to commence earlier, two participants stated that they did understand the difficulties experienced by physicians in deciding on WLST due to all the treatment options that exist today.

A young patient was severely injured and subsequently operated on numerous times, which was for me, as a nurse, horrible to watch, and it was hard to imagine any quality of life afterwards. That was a situation that has stuck in my mind ever since as undignified. In my opinion, the patient should have been allowed to die much earlier.
(Participant 5)

In the experience of participants, extubating could lead to obstructed airways and dyspnoea, yet patients were often in obvious discomfort with non-invasive ventilation (NIV) treatment. According to these participants, this was distressing for both the family and the ICU nurse to witness.

I find it hard when you have removed the endotracheal tube and the patient doesn't want the NIV-mask and then dies as a consequence of the extubation. (Participant 2)

However, some participants stated that extubation in the WLST process provides dignity and a natural and aesthetic death.

Conflicts with or within the patient's family were particularly difficult for the participants when attempting to conduct WLST in a dignified manner. Family members could be angry and frustrated when they lacked information about the WLST decision. Participants regarded it as particularly stressful when family members disagreed among themselves about whether to initiate WLST. Participants perceived that the family could disregard the patient's wishes, such as having no ventilator treatment or the use of pain relief and sedation, due to their fears about hastening death. Nurses experienced such situations as contradicting basic palliative care and considered them stressful.

When presiding over the WLST process, participants often felt alone, isolated, and emotionally affected. They experienced the need to be in control of the patient, the family, and the whole treatment withdrawal process to enable them to respond to unexpected events. Participants perceived it as important that they were not too affected and emotionally involved as that could lead to their being powerless to act. However, participants experienced that they could respond with tears both during and after difficult and sad WLST situations, often due to their empathy with the patient and the family. Unforeseen circumstances that

arose could easily leave the participants feeling alone, as mere bystanders, alongside the terrified families. Furthermore, participants described the stress and distress they experienced when trying to comfort families after witnessing undignified WLST processes. The participants with limited work experience found the undignified WLST situations particularly stressful and they would often continue to think about them at home. The more experienced participants were less disturbed by these situations.

All treatment withdrawals are challenging, and I count the minutes until my shift is over. I find it tough to count the minutes until I can go home. When I come home, I keep thinking about the situation, what we could have done better for the patient and the family. (Participant 4)

Caring for a patient for weeks and seeing only deterioration created the sense of being forced to participate in treatments they disagreed with, and this could lead to feelings of meaninglessness and distress. Participants expressed that, over time, they lost the will and the courage to participate in treatments they perceived as undignified. They sometimes found the withdrawal of treatment to be a relief because it was hard to see patients suffering daily with little hope of survival.

A requirement for interdisciplinary support and cooperation

Participants felt that cooperation and support from an interdisciplinary team, consisting of nursing colleagues and physicians, was an important aspect of coping with participation in WLST. Regular interdisciplinary meetings where the patient's case was discussed, the treatment withdrawal process was carefully planned, and a strategy for handling unforeseen events was put in place were regarded as crucial in achieving an appropriate WLST process.

Having a calm and cooperative physician present during WLST contributed to its being a positive experience and provided the participants with a sense of security. Most of the participants stated that they were usually heard and supported by the interdisciplinary team after tough withdrawal situations. Physicians often participated in debriefings, which allowed the participants to discuss their particular struggles in these difficult situations. However, some participants felt that debriefings happened only rarely. They wanted more time allocated for debriefings, that involved both the physicians and the nurses, to discuss their feelings and overall experience and to prepare them for the next WLST situation. This is illustrated in the following:

I think we should be better at debriefing right after the treatment withdrawal. Just a short conversation before we go home. Maybe that is what we do when we talk amongst us colleagues, but it's not systemised in any way. (Participant 8)

Participants experienced challenges when there was a lack of communication and irregular interdisciplinary meetings regarding the WLST process. Members of the interdisciplinary team did not always acknowledge the ICU nurses' views or assessment of patient cases, which led to difficulties in their coping and preparing for treatment withdrawal. Participants often wanted to talk about their bad WLST experiences. However, it was reported that debriefings were often difficult to organise because of hectic shifts and patient turnover. Participants mentioned how the lack of debriefings or conversations about withdrawals could lead to the suppression of feelings and unresolved insecurities concerning the WLST process.

Some of the participants commented on episodes when the physician had commenced the treatment withdrawal process without a thorough plan and without including or clearly communicating this to the ICU nurses or to the patient's family. However, the majority noted

that they generally realised the need for treatment withdrawal before the physicians. Physicians often wanted to continue with treatment, while the participants felt that patients should be released from their suffering earlier.

I have experienced cases where WLST was decided on and commenced by the team, but another physician told the nurses to resume treatment. That is terribly wrong.

(Participant 2)

Elements to achieve a dignified treatment withdrawal process

All the participants experienced playing an important role in patient and family care in ensuring a peaceful WLST process. Elements that contributed to achieving a dignified treatment withdrawal process for the patient included a thorough plan for the WLST process, communication with the family, administration of relief and an aesthetic death, and creating a peaceful environment.

A thorough plan for the WLST process. Participants emphasised the importance of having a plan in order to provide a death that was dignified for both the patient and the family and to make it possible to prepare the family. They further described the responsibilities they carried for withdrawal of life-sustaining medications and for phasing out the ventilator treatment, either independently or in conjunction with the physician.

Communication with the family. Participants emphasised the responsibility they carried for informing both the patient and the family about all aspects of WLST. They highlighted the active role they played in ensuring that patients, whenever possible, and all family caregivers understood the reason for the withdrawal of treatment before it commenced. Furthermore, preparing the family early was regarded as a prerequisite in helping them to accept that their loved one would not survive. Additionally, the participants underlined the significance of the

families feeling empowered, of their being involved in the decision-making, and of their having the opportunity to say farewell. Participants felt that providing empathy, support, and accommodation of the family's wishes were all important, since the family were the ones left with the sorrow after the patient's death.

So we inform, we help to inform with the physician, we support them, hold them, and answer more questions. We're caring, we give them the time they need, and bring them into the patient's room where we continue to provide them with care and support at the same time that we are tending to the patient. (Participant 1)

Furthermore, some of the participants explained the importance of talking with the family after the patient's death. In these conversations, the family often provided the nurse with their own perspectives on the positives and negatives of the WLST process. This was seen as very beneficial in terms of helping the family through the mourning process.

Administration of relief and an aesthetic death. Participants emphasised that a peaceful process meant a death without dyspnoea, pain, or discomfort. Managing the patient's comfort, administering the medications necessary for pain relief, in addition to extubation for a natural and aesthetic death, were all seen as priorities. Aesthetics included the patient looking clean and presentable to the family without too much evidence of equipment and technical devices connected to them.

She was deeply sedated, which she was still allowed to be. Then we reduced the ventilator settings, and in the end, we disconnected it. So that was actually quite dignified. (Participant 8)

Creating a peaceful environment. In the final moments, when death was imminent, participants described how they re-focused the family's attention away from the dropping vitals on the monitoring machines and towards the patient. In addition, the machines were turned off timeously so as to avoid noises from the technical equipment and to facilitate a peaceful WLST process.

That is maybe why I've become more determined to explain that we have tried everything, but treatment withdrawal is now occurring. It can quickly be forgotten, when there is so much equipment, that there is a person lying in the bed. (Participant 9)

DISCUSSION

The current study aimed to explore the experiences of ICU nurses when participating in WLST. The findings provide insights into ICU nurses' experiences of stress in the process of treatment withdrawal, their need for interdisciplinary support and cooperation, and the elements that combine to achieve a dignified treatment withdrawal process.

Participants in the current study said that WLST usually occurred in a peaceful and dignified manner, but they also appeared to have been emotionally affected by undignified WLST situations. These included situations where patients were overtreated or experienced discomfort and where conflicts occurred within the family or in the interdisciplinary team. These situations all affected the care of the patient. Similar to previous studies (deBoer et al., 2013; Kisorio and Langley, 2016), the current study showed that WLST processes are experienced as particularly emotional when the participants have established a particular connection with the patient or family. Emotional reactions can be related to the ICU nurse's perceptions of the quality of life of the patient, to feeling a sense of connection with the patient and relatives, and to the ICU nurse's personal experience with WLST decision-making

(McAndrew and Leske, 2015). The emotional reactions of the participants in the current study seemed to be related to experiences of empathy with the patient and the family, and deeper emotional reactions typically occurred after caring for a patient for an extended period.

Following an undignified WLST process, the participants described the following reactions: feeling powerless to act, loss of will, meaninglessness, stress, and the loss of courage to participate in new WLST situations. Nurses working in intensive care units often experience higher levels of occupational stress than nurses working in other units. Stress during participation in the WLST process can threaten a nurse's physical and mental well-being (Babanataj et al., 2019). Furthermore, ICU nurses may be more prone to occupational stress when there is a lack of continuity in the WLST plan, a lack of competencies, and a lack of emotional support (Gelinas et al., 2012). Limited work experience can lead to feelings of being inadequately prepared to provide a dignified WLST process for the patient and their family (Holms et al., 2014). The current study suggests that participants with limited work experience seem to be more affected and more readily become stressed in undignified situations than more experienced participants. Inexperienced ICU nurses may lack the confidence to communicate their concerns about patient care to the treating team during a difficult process such as WLST. Furthermore, stress is found to be a potential barrier to providing quality care for a patient during WLST; it also diminishes job satisfaction and can lead to burnout (Holms et al., 2014; Zomorodi and Lynn, 2010). Pereira et al. (2016) identified that as many as 31% of professionals working in ICUs have high levels of burnout. Caring for dying patients has been reported to be painful, traumatic, exhausting, draining, and depressing, and ICU nurses have been reported to feel powerless in these situations (deBoer et al., 2013; Kisorio and Langley, 2016; Vanderspank-Wright et al., 2018). ICU nurses who carry lingering emotions of stress due to previous undesirable experiences may remove themselves from potentially stressful situations and spend less time with the patient and their

family, leading to poorer patient care (Mealer and Moss, 2016). In the current study, after participating in challenging WLST procedures, participants reacted with tears, counting the minutes until the workday ended and continuing to think about the WLST situation at home. It is evident that this could contribute to stress, burnout, and diminished job satisfaction, contributing to the risk of experienced ICU nurses leaving their demanding work environment (Holms et al., 2014).

In the current study, the participants' roles included organising and planning interdisciplinary meetings with all parties involved in a patient's treatment to discuss a preliminary plan for the WLST process. Flannery et al. (2016) suggest that ICU nurses play an informal role in suggesting to a physician that WLST should be discussed. McAndrew and Leske (2015) state that ICU nurses perceive their role as bringing all the parties involved in the patient's care together to decide whether WLST should be considered. However, participants in the current study felt that they were sometimes not heard nor were they informed by the physicians about a plan for WLST. There is additional evidence that suggests that ICU nurses appear dissatisfied with their communication with physicians during WLST, and that they experience this lack of communication as a barrier to providing appropriate care in these situations (Noome et al. 2016; Zomorodi and Lynn, 2010). The involvement of ICU nurses in WLST has been described by Flannery et al. (2016) as being decided by the physicians, and it appears to lack formal documentation.

Participants in the current study valued debriefings with the interdisciplinary team for discussing difficulties and their general feelings relating to the WLST situation; such meetings are recommended following difficult WLST situations (Downar et al., 2016). Debriefing is designed to deal with a situation by recognising reactions and it is considered beneficial in helping nurses to cope with emotional distress and to learn something from the situations they have been exposed to (Pender and Anderton, 2015; Vanderspank-Wright et al.,

2018). However, debriefings are sometimes difficult to organise because of hectic workdays, and this can result in ICU nurses suppressing their concerns about WLST. Insufficient time because of paperwork and new patients to be admitted may be a barrier to debriefing (Vanderspank-Wright et al., 2018). Leaders of ICU wards need to establish routines for systematic debriefings after difficult WLST situations. ICU nurses should receive support and have access to psychosocial resources if they experience distress or burnout, and they should also get some relief from their responsibilities after participating in WLST (Attia et al., 2012).

Participants in the current study considered that managing the patients' comfort, withdrawing life-preserving medications and equipment, and presenting the patient aesthetically without too much apparatus being visible were all important elements in achieving a dignified treatment withdrawal process. Previous research suggests that managing the patient's physical symptoms during the WLST process while minimising technology are important nursing responsibilities (Arbour and Wiegand, 2014; Vanderspank-Wright et al., 2018). Similar to our findings, Downar et al. (2016) suggest that all monitoring machines should be discontinued unless their purpose is to provide comfort. The removal of distracting technical apparatus can contribute to compassionate care for the patient and their family (Efstathiou and Ives, 2017). However, ICU nurses may be uncertain about removing the monitoring equipment because paying attention to the patient's vitals could provide the family with reassurance that the patient is still being looked after (Efstathiou and Walker, 2014). Zomorodi and Lynn (2010) suggest that the family should decide whether the technical equipment should be removed because watching the monitor could be a source of comfort for them.

Several of the participants in the current study described experiences with situations where a patient was overtreated and the decision to implement WLST was delayed. Similar findings have been described in previous studies (Flannery et al., 2016; Teixeira et al., 2014;

O'Neill et al., 2016). As the main care providers, ICU nurses may recognise earlier than physicians that a treatment is futile (Flannery et al., 2016). Consequently, at times, the ICU nurse may value the commencement of WLST and terminal care (Teixeira et al., 2014) and may find aggressive treatment of dying patients more inappropriate than the physicians do (O'Neill et al., 2016). Participants in the current study expressed the challenges they experienced when caring for patients who were being overtreated, because they perceived that increased suffering and discomfort were inflicted on these patients. Conflicts can arise when physicians decide to continue with treatment, but the ICU nurses feel that it is offering false hope to the patients (Jakimowicz et al., 2017). Even though a patient's suffering may appear to be unnecessarily prolonged by an aggressive treatment, the ICU nurse may be conflicted about arguing to withdraw treatment because of cases in the past where patients have survived long and aggressive treatments. However, Nieminen et al. (2011) recommend that ICU nurses should initiate consultations with physicians and then cooperate in ensuring the patient's safety.

Finally, some participants in the current study found it challenging to witness patients receiving NIV in the last stages of life due to the obvious discomfort they experienced. NIV can inflict mask pressure and distress on a patient and fail to relieve the patient's symptoms, whereas just withdrawing ventilator support allows a natural and aesthetic death. Nonetheless, obstructed airways are a possibility that can expose patients to dyspnoea and respiratory distress, and in such cases, ventilator support is considered effective and symptom relieving (Rochweg et al., 2017). Most of the participants in the current study considered removal of the tube to be optimal. However, it is important to highlight that there is no way of predicting whether a patient's airways will remain open until the tube is removed, so this action needs to be considered carefully in each individual patient's case. In one study, the ICU nurses agreed that an endotracheal tube should only be removed if the patient can maintain open airways

(Langley et al., 2013). If they are to provide comfort, ICU nurses need to make advanced level clinical judgments and evaluate and improve their nursing activities, such as assessing whether the patient can maintain open airways (Nieminen et al., 2011). It is also noteworthy that decisions regarding the initiation of WLST must involve medical expertise and thorough discussion, where personal preferences should be of minimal importance compared to evidence-based guidelines.

Strengths and limitations

Individual interviews were utilised, which provided room for deeper reflection and resulted in different data than that which focus group interviews would have provided. The range in the participants' demographics and workplaces contributed to rich variations and distinctions in the ICU nurses' experiences. Limitations of this study could be its small sample size and the inclusion of a few participants from each ICU unit. There may be experiences and nuances of experience that we were not able to identify. However, based on the narrow aim of the study, the participants' expertise in the area, and their willingness to share their experiences, the sample size was considered to have generated sufficient information power and a rich variety in its descriptions (Malterud et al., 2016). Graneheim et al. (2017) claim that it is not certain that the richness of data increases with the number of participants or pages of text. During the data analysis, patterns of similarities and differences in the ICU nurses' experiences were identified across the different ICU units, and the data material was analysed as a whole. Our aim was not to compare the experiences of ICU nurses across different units. Another possible limitation is that the participants were all recruited from urban hospitals. Since the ICU cultures might be different, participants from rural hospitals could have different experiences. In order to determine whether the findings of a study can be applied in other settings depends on how the findings are read. In qualitative research, findings can be applied

to other settings if the reader is able to determine for which other situations the findings might provide valid information (Malterud 2001).

CONCLUSION

The ICU nurses interviewed perceived that they play an important role in WLST. Furthermore, they viewed their responsibilities as being oriented around providing a comfortable and dignified death for their patients. The ICU nurses often felt alone and isolated in the WLST process, and those ICU nurses who had limited work experience found the WLST situation more stressful than the experienced ICU nurses. It was considered particularly challenging to participate in WLST when the patient was overtreated or when the ICU nurses had to participate in treatments they did not agree with and when they felt that they were inflicting additional discomfort on the patient. The ICU nurses were all emotionally affected by difficult WLST situations, and they experienced stress and loss of will to participate in similar situations. The need for debriefings was discussed, and debriefings were considered beneficial in helping ICU nurses to deal with their emotions. However, debriefings were considered difficult to organise because the ICU nurses had to get on with their workdays. Finally, thorough planning, good communication, pain relief, and the creation of a peaceful environment were perceived as important elements in achieving a dignified treatment withdrawal process.

References

- Arbour, R. B., Wiegand, D. L., 2014. Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study. *Intensive Crit Care Nurs.* 30(4), 211-218. doi.org/10.1016/j.iccn.2013.12.002
- Attia, A. K., Abd-Elaziz, W. W., Kandeel, N. A., 2012. Critical care nurses' perception of barriers and supportive behaviors in end-of-life care. *Am J Hosp Palliat Care.* 30(3), 297-304. doi: 10.1177/1049909112450067.
- Babanataj, R., Mazdarani, S., Hesamzadeh, A., Gorji, M. H, Cherati, J. Y., 2019. Resilience training: Effects on occupational stress and resilience of critical care nurses. *Int J Nurs Pract.* 25(1), e12697. doi.org/10.1111/ijn.12697
- Buanes, E. A., Kvåle, R., 2017. *Norsk intensivregister: Arsrappport for 2017 med plan for forbedringstiltak (Norwegian Intensive Care Registry: Annual report for 2017 with plans for improvement)*. <https://helse-bergen.no/norsk-intensivregister-nir> (accessed 18.05.19).
- Coombs, M., Fulbrook, P., Donovan, S., Tester, R., deVries, K., 2015. Certainty and uncertainty about end of life care nursing practices in New Zealand intensive care units: A mixed methods study. *Aust Crit Care.* 28, 82-86. doi.org/10.1016/j.aucc.2015.03.002.
- deBoer, J., van Rikxoort, S., Bakker, A. B., Smit, B. J., 2013. Critical incidents among intensive care unit nurses and their need for support: Explorative interviews. *Nurs Crit Care.* 19(4), 166-174. doi: 10.1111/nicc.12020
- Downar, J., Delaney, J., Hawryluck, L., Kenny, L., 2016. Guidelines for the withdrawal of life-sustaining measures. *Intensive Care Med.* 42(6), 1003-1017. doi:10.1007/s00134-016-4330-7
- Efstathiou, N., Ives, J., 2017. Compassionate care during withdrawal of treatment: A secondary analysis of ICU nurses' experiences. *Nurs Ethics.* 1-12. doi: 10.1177/0969733016687159

- Efstathiou, N., Walker, W., 2014. Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: A qualitative study. *J Clin Nurs.* 23, 3188-3196.
doi:10.1111/jocn.12565
- Flannery, L., Ramjan, L. M., Peters, K., 2016. End-of-life decisions in the intensive care unit (ICU) – Exploring the experiences of ICU nurses and doctors: A critical literature review. *Aust Crit Care.* 29(2), 97-103. doi.org/10.1016/j.aucc.2015.07.004
- Gelinas, C., Fillion, L., Robitaille, M. A., & Truchon, M., 2012. Stressors experienced by nurses providing end-of-life palliative care in the intensive care unit. *Canadian Journal of Nursing Research*, 44(1), 18-39.
- Graneheim, U. H., Lindgren, B. M., & Lundman, B. 2017. Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Educ Today*, 56, 29-34.
doi.org/10.1016/j.nedt.2017.06.002
- Graneheim, U. H., Lundman, B., 2004. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today.* 4, 105-112. doi: 10.1016/j.nedt.2003.10.001
- Hoel, H., Skjaker, S. A., Haagensen, R., Stavem, K., 2014. Decisions to withhold or withdraw life-sustaining treatment in a Norwegian intensive care unit. *Acta Anaesthesiologica Scandinavica.* 58(3), 329-336. doi:10.1111/aas.12246
- Holms, N., Milligan, S., Kydd, A., 2014. A study of the lived experience of registered nurses who have provided end-of-life care within an intensive care unit. *Int J Palliat Nurs.* 20(11), 549-556.
- Jakimowicz, S., Perry, L., Joanne, L., 2017. An integrative review of supports, facilitators and barriers to patient-centred nursing in the intensive care unit. *J Clin Nurs.* 26, 4153-4171. doi: 10.1111/jocn.13957

- Kisorio, L. C., Langley, G. C., 2016. Intensive care nurses' experiences of end-of-life care. *Intensive Crit Care Nurs.* 33, 30-38. doi.org/10.1016/j.iccn.2015.11.002
- Langley, G., Schmollgruber, S., Fulbrook, P., Albarran, J. W., Latour, J. M., 2013. South African critical care nurses' views on end-of-life decision-making and practices. *Nursing in Critical Care.* 19(1), 9-17. doi: 10.1111/nicc.12026
- Lykke, P. M. E., 2017. Funksjons- og ansvarsbeskrivelse for intensivsykepleier (Description of function and responsibilities for Intensive Care Nurses). <https://www.nsf.no/vis-artikkel/3637056/10504> (accessed 18.05.19).
- Malterud, K., 2001. Qualitative research: standards, challenges, and guidelines. *Lancet* 358, 483–488.
- Malterud, K., 2012. Systematic text condensation: A strategy for qualitative analysis. *Scand J Soc Med.* 40, 795–805.
- Malterud, K., Siersma, V. D., Guassora, A. D., 2016. Sample size in qualitative interview studies: guided by information power. *Qual. Health Res.* 26(13), 1753-1760.
- McAndrew, N. S., Leske, J. S., 2015. A balancing act: Experiences of nurses and physicians when making end-of-life decisions in intensive care units. *Clin Nurs Res.* 24(4), 357-374. doi: 10.1177/1054773814533791
- Mealer, M., Moss, M., 2016. Moral distress in ICU nurses. *Intensive Care Med.* 42, 1615. doi.org/10.1007/s00134-016-4441-1
- Nieminen, A.-L., Mannevaara, B., Fagerström, L., 2011. Advanced practice nurses' scope of practice: A qualitative study of advanced clinical competencies. *Scand J Caring Sci.* 25(4), 661-670.
- Noome, M., Dijkstra, B. M., van Leeuwen, E., Vloet, L. C. M., 2016. The perspectives of intensive care unit nurses about the current and ideal nursing end-of-life care. *J Hospice Palliat Nurs.* 18(3), 212-218. doi:10.1097/njh.0000000000000221

- O'Neill, C. S., Yaqoob, M., Faraj, S., O'Neill, C., 2016. Nurses' care practices at the end of life in intensive care units in Bahrain. *Nurs Ethics*. 24(8), 950-961. doi: 10.1177/0969733016629771
- Patton, M. Q., 2015. *Qualitative research and evaluation methods*. London: Sage.
- Pender, D. A., Anderton, C., 2016. Exploring the process: A narrative analysis of group facilitators' reports on critical incident stress debriefing, *The Journal for Specialists in Group Work*. 41:1, 19-43, DOI: 10.1080/01933922.2015.1111485
- Pereira, S. M., Teixeira, C. M., Carvalho, A. S., Hernández-Marrero, P., 2016. Compared to palliative care, working in intensive care more than doubles the chances of burnout: Results from a nationwide comparative study. *PLOS One*. 1-21.
- Polit, D. F., Beck, C. T, 2017. *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia: Wolters Kluwer.
- Ranse, K., Bloomer, M., Coombs, M., Endacott, R., 2016. Family centered care before and during life-sustaining treatment withdrawal in intensive care: A survey of information provided to families by Australasian critical care nurses. *Aust Crit Care*. 29, 210-216. doi.org/10.1016/j.aucc.2016.08.006
- Rochweg, B., Brochard, L., Elliott, M. W., Hess, D., Hill, N. S., Nava, S., Raof, S., 2017. Official ERS/ATS clinical practice guidelines: Noninvasive ventilation for acute respiratory failure. *Eur Respir J*. 50(2), 1-20. doi:10.1183/13993003.02426-2016
- Teixeira, C., Ribeiro, O., Fonseca, A. M., Carvalho, A. S., 2014. Ethical decision making in intensive care units: A burnout risk factor? Results from a multicentre study conducted with physicians and nurses. *J Med Ethics*. 40(2), 97-103. doi.org/10.1136/medethics-2012-100619

- Vanderspank-Wright, B., Efstathiou, N., Vandyk, A. D., 2018. Critical care nurses' experiences of withdrawal of treatment: A systematic review of qualitative evidence. *Int J Nurs Stud.* 77, 15-26. doi.org/10.1016/j.ijnurstu.2017.09.012
- Zomorodi, M., Lynn, M. R., 2010. Critical care nurses' values and behaviors with end-of-life care: Perceptions and challenges. *J Hospice Palliat Nurs.* 12(2), 89-96.

Table 1. Illustration of the analysis process.

<p>Category ICU nurses' experiences of stress in the process of treatment withdrawal</p>	
<p>Subcategory b. How ICU nurses are affected in undignified withdrawal situations</p>	
Meaning units	Condensate
When you feel like you're doing a good job, but things are just flowing, and you get nowhere, and they keep continuing treatment. Then I lose motivation to work and that's not right. (Participant 3)	Motivation to work is lost when the patient is overtreated
It's important to have interdisciplinary meetings so we can guide those nurses bedside with the patient. I feel that with us nurses quite often the level of stress becomes so big leading to emotional exhaustion, and then we don't manage to see the whole picture or other perspectives. (Participant 1)	The stress can become so big that it leads to emotional exhaustion, and we can't manage to see other perspectives
To find a balance is challenging. You might think: if I give this dose of pain relief will that be what triggers death? (Participant 7)	Fear of causing death by relieving the patient's symptoms
I had a patient that was so extensively overtreated and us nurses cried our eyes out every day because it was so terrible undignified. (Participant 8)	Nurses were emotionally affected when the patient was overtreated
If I had a patient from day one where I had a lot of contact with the family, I would personally feel a defeat if things didn't end well. I would really feel that. (Pilot participant)	If I had the patient since admission and contact with the family, I could feel a defeat if things don't end well
If they (withdrawals) are very close in time, I would just feel exhausted. I just have to go home and lay down. Then I feel like I just have to endure the day. (Participant 4)	When withdrawals occur in quick succession, I feel exhausted and just need to endure the day
It is not always easy because there is pressure for you to act quickly and effectively, so it can feel like a defeat if you stop and say now I need some space. (Participant 6)	The work pressure can lead to feelings of defeat if you need a break/space

Table 2. Overview of categories and subcategories

Categories	Subcategories
ICU nurses' experiences of stress in the process of treatment withdrawal	ICU nurses experience of undignified withdrawal process How ICU nurses are affected in undignified withdrawal situations
A requirement for interdisciplinary support and cooperation	The significance of interdisciplinary and collegial care in withdrawal situations Experienced challenging interdisciplinary and collegial situations
Elements to achieve a dignified treatment withdrawal process	ICU nurses' perceptions of their role in the withdrawal process Perception of ICU nurses' role in the interdisciplinary team