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Caring Intensely Until the End: The Lived Experiences of Intensive Care Unit Nurses

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Abstract

Nurses are essential members of the health care team and work alongside doctors, pharmacists, respiratory therapists, and other crucial health care persons to utilize a multidisciplinary approach to patient-centered care. In the intensive care unit, this includes being a patient advocate when end-of-life care measures are being implemented. Providing care for patients who are at the end of life can be distressing to intensive care unit nurses, who are often the ones that spend most of their time alongside patients and their families. Due to the typical nurse-to-patient ratio, which is generally one to two patients per nurse, intensive care unit nurses are continuously exposed to dying patients and their surrounding support systems. By looking at the lived experiences of intensive care unit nurses when caring for the critically ill, improvements can be identified to address issues nurses encounter and concerns nurses have when providing end-of-life care to critically ill patients.

Introduction

Critical care nurses are essential members of the multidisciplinary health care team who ensure patient-centered care is provided for those who are critically ill. In the intensive care unit, this includes being a patient advocate when end-of-life care measures are being implemented. According to the National Institute on Aging, end-of-life care is the term "used to describe the support and medical care given during the time surrounding death" (2017, para. 2). However, end-of-life care does not happen only in the moments before a patient dies. Instead, one should think of end-of-life care being the care provided days, weeks, or even months before a patient's death (National Institute on Aging, 2017). Research shows that approximately 95% of patients in intensive care units are unable to make informed decisions regarding their health because of various medical factors, such as present illness, condition, or sedation (Holms, Milligan, & Kydd, 2014). Providing care for patients who are at the end of life can be distressing to intensive care unit nurses, who are often the ones that spend most of their time alongside patients and their families. Due to the typical nurse-to-patient ratio in intensive care units, which is generally one to two patients per nurse, intensive care unit nurses spend more one-on-one time with dying patients and their surrounding support systems. Although death is inevitable, intensive care unit nurses have the ability and power to help patients experience good deaths. According to the Institute of Medicine, a good death is classified as one that is "free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards" (Meier et al., 2016).

Although intensive care unit nurses possess the ability to empower their patients who are receiving end-of-life care and their families, there are barriers present in intensive care units that

are preventing nurses from providing high quality care in these last days. Factors that affect the ability of intensive care unit nurses to provide end-of-life care include poor communication and decision-making, informal end-of-life care education and training sessions, distress levels among staff members, and the stressful, chaotic work environment of an intensive care unit (Holms, Milligan, & Kydd, 2014). In addition, the patients that nurses care for in intensive care units are critically ill and unstable. "Despite such progress…mortality rates remain high, with up to 50% of hospital deaths taking place in these units" (Velarde-Garcia et al., 2016, p. 1). Due to high mortality rates, intensive care unit nurses are continuously being exposed to patient suffering and grief, which can lead to increasing levels of anxiety, emotional distress, and nurse burnout (Kisorio & Langley, 2015).

The instability of critically ill patients means that there is a significant potential for a rapid decline in the health status of these patients. During this time, patients are typically switched from a curative treatment approach to end-of-life care. End-of-life care is not only difficult for patients and their families, but to the nurses, who are the ones that spend most of their shift at the bedside caring for them. Once barriers that intensive care unit nurses encounter when providing care at the end of life are recognized, improvements can be identified and potentially implemented in the future to offer intensive care unit nurses the necessary support needed when caring for those who are dying and their families. By offering further support to intensive care unit nurses providing end-of-life care, it is expected that nurses will feel more confident and comfortable when caring for those who are dying, which will indirectly assist patients in experiencing good deaths.

Methods

A qualitative literature review was conducted of the lived experiences of intensive care unit nurses when providing end-of-life care to patients. Twenty-one articles were identified that presented research on the topic. However, eight were chosen for review. Article criteria included articles that were qualitative, peer reviewed, accepted for publication no earlier than the year 2014, and written in English only. The databases utilized were Proquest Nursing & Allied Health Database, CINAHL, and Academic Search Ultimate. When searching for applicable articles, examples of key words used include the following: end-of-life care, intensive care unit nurses, intensive care units, emotional distress, physical distress, education in intensive care units, effective communication in intensive care units, and intensive care unit working environment.

Review of Literature

There is limited research on factors that restrict intensive care unit nurses from providing high quality end-of-life care to patients and what measures can be taken to support nurses when providing care at the end of life. A large percentage of the scholarship that does involve factors that impede intensive care unit nurses' abilities to provide end-of-life care is published over five years ago and is considered outdated, which means that the research and sources may not be relevant to current hospital protocols and intensive care unit environments and available services. In addition, there is minimal scholarship that addresses supportive measures and interventions that can be implemented to decrease the severity or overall presence of the identified factors that impact providing care at the end of life. Most of the supportive measures found among present research is recommended at the end of research studies, when more studies need to be conducted that test implementing recommended interventions. When performing the literature review, the following themes were noted: emotional and physical staff distress, barriers in communication

and decision making, improper education and end-of-life training, and the work environment of intensive care units.

Emotional and physical staff distress

Given the high stress environment of intensive care units and need for health care professionals to have heightened levels of awareness, research supports that intensive care unit nurses experience increased levels of distress. Holms, Milligan, and Kyadd (2014) specifically researched how providing end-of-life care to patients in intensive care units causes increased levels of distress among nurses. In intensive care units, patient health statuses tend to decline rapidly, causing the transition from maintaining or preserving life to change quickly to providing end-of-life care. Some nurses and their medical colleagues view end-of-life as a failure and focus on the importance of keeping patients alive. For nurses, even those who do not hold this viewpoint, providing end-of-life care can cause increased levels of distress. The study found that providing end-of-life care to patients who are dying and their families "has been portrayed as one of the potentially most distressing components of the ICU nurse's workload" and "can impinge on the professional and personal wellbeing of…nursing staff" (Holms, Milligan, & Kyadd, 2014, p. 555). Furthermore, researchers found that accumulated amounts of stress related to caring for those receiving end-of-life care can lower job satisfaction levels, cause nurse burnout, and eventually lead to nurses leaving their positions in intensive care units.

End-of-life care can be difficult for health care professionals to implement due to the ethical dilemma associated with withdrawing patients from curative treatments. Jordan, Clifford, and Williams (2014) discussed how caring for patients receiving end-of-life care in intensive care units can cause conflicting emotions among nurses. A factor identified in the study that often causes conflicting feelings amongst nurses is the removal of life-sustaining treatment. Some

nurses in the study "felt as though they were killing the patient by performing instructions given by…doctors to withdraw treatment" (2014, p. 78). When end-of-life care was being implemented, nurses reported feeling helpless because there was only so much that they could do for their patients. In addition, nurses "expressed mixed emotions of sadness, grief, and anger when caring for patients who presented with end-of-life issues" (2014, p. 78). Findings also indicated that nurses experienced increased levels of distress and grief, which is also supported in the following study.

Velarde-Garcia et al. (2016) discussed and identified that there are several factors that place nurses at a higher risk of experiencing distress in their work environment, such as how emotionally attached intensive care unit nurses are to their patients receiving end-of-life care and the age of their patients receiving end-of-life care, that place nurses at a higher risk of experiencing distress in their work environment. Factors identified that contributed to high levels of emotional attachment and which then linked to increased levels of distress among intensive care unit nurses included: Patients' lengths of stay in the hospital, the rapport that patients and their families established with nurses, and the degree in which nurses personally identified with their patients were all major factors that contributed to high levels of emotional attachment. Ultimately when nurses are emotionally attached to their patients, it can cause their professional and personal lives to intertwine with one another, which "in turn causes a major and excessive emotional burden" (Velarde-Garcia et al., 2016, p. 8). The age at which a patient dies also impacts the experience that intensive care unit nurses have when caring for patients receiving end-of-life care. It was found that there is a difference when caring for younger patients versus older adults. Nurses caring for younger patients who they did not expect to die reported more

traumatic experiences and higher levels of distress. However, nurses caring for older adults receiving end-of-life care did still experience elevated levels of distress in the work environment.

Communication and decision making

Poor communication and decision-making were identified as a serious issue among intensive care unit nurses and other health care workers when caring for dying patients. Holms, Milligan, and Kyadd (2014) found in their study that one of the main consequences of poor communication was due to inconsistencies when providing end-of-life care to patients. When communication is unclear, members of the health care team receive mixed messages, which causes their patients to receive differing levels of care throughout the course of their hospital stay. Differing levels of care was evident throughout various treatment plans, especially when decisions were made to either withhold or withdraw life-sustaining treatment. Within the study, some nurses felt conflicted due to the focus on curative, life-saving efforts in the intensive care unit. This led to nurses feeling uncomfortable and not ready to discuss end-of-life care with their colleagues or patients and their families. Nurses believed that communication was a key factor of success when providing end-of-life care to critically ill patients and that they had more positive experiences when there was open communication among medical colleagues.

Another study conducted by Brooks, Manias, and Nicholson (2017) similarly explained the importance of communication between the members of the health care team, patients, and patient family members in intensive care units. One factor impacting communication identified in the study was poor timing with initiating discussions about end-of-life care. It is vital to discuss patient wishes at an earlier time in their hospital stay, or perhaps even earlier while patients are seeking care in the community, public health setting, or even before there is illness or treatment sought. This would allow patients more time to think about their wishes regarding care at the end

of life, as well as give family members more time to understand and digest what their loved ones' wishes are. Poor timing was associated with distress and discomfort amongst nurses and other medical professionals in the intensive care unit setting. In addition, when these conversations were not brought up in a timely manner, it decreased the amount of trust the family had towards members of the health care team. Nurses were also sometimes excluded from participating in end-of-life care discussions with physicians, patients, and patient family members. Exclusion resulted in nurses feeling inadequately prepared to discuss end-of-life care with patients and their families. In addition, nurses felt like they did not know pertinent information about their patients' treatment plans when they were excluded from meetings with patients and their families.

Literature has also suggested that nurses experience exclusion during end-of-life care discussions with physicians. Kisorio and Langley (2015) specifically researched the impact of intensive care unit nurses not being involved in end-of-life care discussions among physicians. Most of the nurses in the study stated they were not regularly involved in the decision-making process about their patients' treatment plans. Often nurses were only asked for their opinions in instances where physicians had already made decisions about the patient's care. The main issue with this was that excluding health care team members prevented everyone from being on the same page about the patient's treatment plan. Nurses felt strongly about being included in these discussions because they "spent the longest time with the patient and…believed that they should contribute towards decisions regarding patient care" (Kisorio & Langely, 2015, p. 33).

Although having open communication among the health care team is important, it is also imperative to include patient family members in end-of-life care discussions. Kisorio and Langley (2016) focused on the importance of effective communication with patients' family

members. The study found that once patients' treatment plans were switched from a curative approach to an end-of-life approach, physicians only met with families once before the patients' deaths. In addition to this, in order to gain information about their family members' health statuses, families had to seek out nurses and physicians to get patient updates, rather than the health care providers regularly including families and the patient when formulating or discussing treatment plans. Although the health care providers in the study did not communicate effectively with the family members, the researchers noted the importance of including the family members in end-of-life care discussions to help them understand what was happening with their loved ones and what they should expect from the dying process. It is important to recognize that studies have found there is poor communication not only among healthcare colleagues, but with the patients receiving end-of-life care and their family members.

Education and end-of-life care training

Informal end-of-life care education and a lack of training sessions were also found to be barriers preventing intensive care unit nurses from providing end-of-life care to their patients. Holms, Milligan, and Kydd (2014) discussed the consequences of not receiving formal education and training on end-of-life care and its impact on intensive care unit nurses. Most of the nurses in the study stated there is a minimal amount of formal training provided by facilities on this topic. Instead nurses in intensive care units mostly learn what-to-do and what not-to-do from observing fellow nurses and through trial and error when they themselves are providing end-of-life care. Education that facilities offer on end-of-life care is limited, with some not requiring it at all. With this, nurses feel pressured and expected to be able to provide remarkable, high quality end-of-life care without much guidance from colleagues and supervisors. In addition to feeling expected to provide care with minimal education, nurses were also expected to deal with the stressful

challenges that accompany providing end-of-life care. They explained often feeling distressed, which included frustration, anger, and sadness. End-of-life care is not recognized as being as important as other educational topics, such as caring for a patient receiving ventilation or dialysis. Consequences of not receiving enough formal end-of-life care training and education results in nurses inadequately providing holistic nursing care for patients during the dying process. Nurses in the study believed that receiving education on different ethical issues surrounding end-of-life care, as well as how to appropriately console family members and dying patients, would be beneficial and allow them to provide better care for their patients.

Environmental factors

In addition, the work environment in intensive care units was also found to be a barrier preventing nurses from providing quality end-of-life care to their patients. Holms, Milligan, and Kyadd (2014) discussed the environmental factors that impact the quality of care that patients are receiving from nurses when at the end of life in intensive care units. The working environment and general atmosphere of an intensive care unit is fast-paced, busy, and often far from being peaceful. Nurses believed that the "lack of peace, privacy, and space" (Holms, Milligan, & Kyadd, 2014, p. 552) were crucial challenges when providing optimal end-of-life care to patients. Due to this, some healthcare persons argue that patients in the intensive care unit should be relocated to another unit once their treatment plan switches from utilizing a curative approach to one that is focused on end-of-life. Although this may seem beneficial, patients who are receiving end-of-life care are generally unstable, require closer monitoring, and may be utilizing life-sustaining technologies that require care from specially trained health care providers, such as assisted breathing devices like mechanical ventilators. Instead the literature review identified numerous modifications that can be made to the chaotic intensive care unit environment to help

decrease the overall amount of stress that nurses, patients, and patient family members are going through. Some of the modifications discussed in the article include establishing a more peaceful atmosphere within patient rooms and common areas for families around the unit, raising awareness that some patients may be receiving end-of-life care in nearby rooms, and treating others with respect during difficult times at the end-of-life (2014). By decreasing the amount of stress that both patients and their families are going through, nurses in intensive care units will feel as though they are better able to adequately provide for their patients and their family members, which will decrease levels of emotional distress in intensive care unit nurses.

Another environmental barrier is the need for additional resources in intensive care units. Henrich et al. (2016) discussed how the lack of resources in an intensive care unit environment causes increased amounts of moral distress. Nurses and other health care professionals agreed that there is an inadequate amount of resources in intensive care units. This lack of resources causes significant amounts of moral distress in nurses because the ability to provide the highest quality of care possible to patients who are at the end of life is impeded. Resources found to be lacking in the intensive care unit that effect nurses include "lack of appropriate equipment…and the absence of a nurse educator" (2016, p. 60). Not having equipment appropriate for patient care or a nurse educator as a liaison and unit resource not only affects members of the heath care team, but also the patients that are being taken care of.

Recommendations

Current research does include some recommendations for interventions to implement in the intensive care unit setting to help improve the quality of end-of-life care that nurses provide to patients. Brooks, Manias, and Nicholson (2017) suggested that utilizing end-of-life care plans can improve communication barriers among the health care team, which was identified as a

barrier. The end-of-life care plan is a documented plan for a patient's end-of-life care and contains information including patient orders and consults to different departments, such as palliative care. Although this was not discussed in the article, it may be beneficial to include the health care providers that the patient typically has so that nurses assigned to a specific patient are familiar with their plan of care and have been with them during the course of their hospitalization.

The literature used in this study touches on the importance and need for end-of-life care to be included in hospital curriculum, as well as continued education for experienced nurses. The End-of-Life Nursing Education Consortium (ELNEC) created a program for nursing students, nurse educators, and practicing nurses on how to properly and confidently care for dying patients. The developed program includes eight modules: "Ethical/Legal Issues; Cultural Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement; and Preparation for and Care at the Time of Death" (Barrere & Durkin, 2014). Although the program was designed for specialties such as oncology and critical care, there has not been any research about the implementation of the program in intensive care unit nurse education. Given that the program provides topics within the realm of end-of-life care, future research could test its effectiveness in improving the quality of patient care and competence of nurses providing end-of-life care in intensive care units.

In addition to working to ensure that staff have the training and education necessary to provide compassionate and comprehensive end-of-life care, it is also necessary to explore opportunities for the staff themselves to feel supported and encouraged to emotionally process their experiences. While many hospitals and health care settings have employee assistance programs available to staff, there may be a stigma tied to participation and/or staff may feel that

it is not feasible with their work schedule. Looking at ways to further encourage participation in these types of programs, perhaps by speaking about them more openly, making both group and individual support available, and eliciting input from staff regarding what services would be most of use to them, may encourage increased participation. In a fast-paced environment such as an intensive care setting, situations and patients change quickly and there may be a tendency to move from one task to another expeditiously. However, the loss of a patient is significant, and as discussed earlier, certain losses tend to be particularly difficult for nursing staff. Working to develop and implement regular memorials or rituals may help to encourage staff to process their feelings, both individually and with one another, and acknowledge the significance of their relationship with the patient and their family. Certainly what these programs would look like would likely vary significantly depending on the specific setting but having staff participate in their development would further help to empower them in providing end-of-life care.

Conclusion

Being a nurse in an intensive care unit is a job often fraught with stress and a wide variety of challenges. Many of these are magnified while providing end-of-life care, and frequently, a number of barriers exist that negatively affect the provision of this care. As there is up to a 50% mortality rate among patients in intensive care units, it is imperative that efforts are made to better understand and address this need. Patients, particularly those in need of and receiving end-of-life care, and their families, are in especially vulnerable positions and nurses are uniquely positioned to be effective advocates and provide compassionate care that comforts and empowers the patient. However, in order to do this effectively, nurses and other staff need to be better educated and comfortable having end-of-life conversations with patients and their families while providing end-of-life care. Indeed, research suggests that nurses recognize the significance of

this type of care and in many situations, are eager to feel better equipped to provide it. There is no doubt that providing end-of-life care is an inherently emotional and often physically demanding endeavor but with proper education, communication and supports put into place, it can and should also be a rewarding and positive experience, for the nurses as well as all staff involved, and most importantly, for the patients and their families.

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