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Caring for the dying patient in the ICU — The past, the present and the future

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Summary The aim of this paper is to present the state of the science concerning issues in end-of-life (EOL) care which have an impact on intensive care nurses possibilities to provide nursing care for dying patients and their families. The perspective of families is also illuminated and finally ethical challenges in the present and for the future are discussed.

The literature review revealed that the problem areas nurses report concerning EOL care have been the same over three decades. Most problems are related to inter-disciplinary collaboration and communication with the medical profession about the transition from cure to comfort care. Nurses need enhanced communication skills in their role as the patient's advocate. Education in EOL care and a supportive environment are prerequisites for providing EOL care. Losing a loved one in the ICU is a stressful experience for close relatives and nursing care has a profound impact on families' memories of the EOL care given to their loved ones. It is therefore important that ICU nurses are aware of families' needs when a loved one is dying and that follow-up services are appreciated by bereaved family members. Ethical challenges are related to changed sedation practices, organ donation, globalisation and cultural sensitivity.

Implications for Clinical Practice

- Since communication is shown to be the factor that mostly influences families' opinions on EOL care quality improved communication between the nursing and medical profession is crucial for the future.
- ICU nurses need to enhance their role in the decision-making process by being more prominent in their role as the patient's advocate.
- Dying patients and their close relatives need proximity and privacy in the ICU.
- Follow-up services are appreciated and requested by bereaved family members.
- Nurses need education in EOL care and support from superiors, especially when patients die in conjunction with ethical challenging situations.

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Introduction

Intensive care nursing implies being confronted with existential questions such as the meaning of suffering and death (Hov et al., 2007). For nurses, who are the professionals most close to the patients, death is a reality. Patients die in the intensive care unit (ICU) despite the medical imperative of intensive care is to save lives and that ICUs are regarded as hosting a death-denying culture (Nelson, 2006). This paper presents some main areas concerning end-of-life (EOL) care which engage the profession of ICU nurses. Additionally, the perspective of family members is illuminated and finally some challenges in the present and for the future are discussed.

A short lock back

Since the first establishment of intensive care units in the 1950s, caring for dying patients has been an integrated part of intensive care nursing. A brief search in the database of this journal showed that death and dying is a topic that has engaged clinicians and scholars since the first issues of intensive care nursing was published. It is interesting to note that one of the first articles published in intensive care nursing that dealt with death, was published in the section of the journal called ''problem pages'' (Webster, 1985). In that paper a nurse reported on problems she meet in her daily work with dying patients in a coronary care unit (CCU). She disputes the conception that the death of a patient in the CCU is seen as a failure that could have been prevented. As a result when death occurs, it leads to feelings of guilt among the clinical staff. Further she described the design of the unit, with no privacy, neither for the dying patient nor for the fellow-patients. The need for openness when talking about death with patients and family members was also paid attention to. Another topic this nurse discussed was the conflict when medical interventions hamper the patient's right to a peaceful and dignified death. Accordingly, questions and dilemmas regarding end-of-life decisions were early recognised by ICU nurses. In 1988, a clinical teacher from England (Dunaway, 1988) described how she travelled to the United States to conduct a survey concerning approaches to decision-making at seven hospitals. Her aim was also to examine how these decisions affected ICU nurses. Thus, this issue was a growing problem at this time, acknowledged by ICU nurses but perhaps not yet on the agenda among most ICU physicians in Europe. However, today all ICU health care professionals report that the transition from curative medical care to EOL care is the most problematic stage in providing EOL care (Coombs et al., 2012; McAndrew and Leske, 2014).

ICU nurses' perspectives on EOL care

The limited review above mirrored some issues concerning end-of-life care that were discussed among ICU nurses in the eighties and in the early days of this journal. It is therefore interesting to ascertain that the problem areas nurses faced and discussed then still exist and that author's articles have continued to explore these questions over three decades. Several studies have focused on what nurses' experience as problems or obstacles when caring for dying patients (Espinosa et al., 2008). The most common problems ICU nurses report are lack of involvement in the care planning and in EOL decisions, disagreement among physicians and other healthcare team members, unrealistic expectations from families, lack of experience and education, lack of support from superiors, too low staffing levels and an environment not designed for EOL care (Espinosa et al., 2010; Zomorodi and Lynn, 2010).

Studies investigating moral stress among critical care nurses have revealed that the majority of clinical situations resulting in moral distress were related to EOL care and included such issues as: medical futility, families who wished to continue life support against the best interest of the patient, organ donation and over- or under administration of pain relief (De Villers and DeVon, 2013; Wiegand and Funk, 2012). In the study of De Villers and DeVon (2013) the item with the highest total score for moral distress intensity was, ''Initiate extensive life-saving actions when I think it only prolongs death''. The notion that nurses consider the patient as dying despite all life-saving actions has been described by Coombs et al. (2012). Nurses, more often than physicians connected the concept of futility of treatment to the concept of dying whereas the medical profession seemed to separate these concepts. To overcome the interdisciplinary tensions between the nursing and medical professions the authors stress that this discrepancy must be respected and they suggest that a diagnosis of dying would facilitate the transition from curative intervention to end-of-life care (Coombs et al., 2012). In conclusion, the major problems ICU nurses report concerning EOL care are related to issues about when to stop futile medical care and to the insufficient dialogue with the medical profession about end-of-life decisions. To move forward there is a need for more research to evaluate interventions that can improve communication between health care providers in the ICU (Kryworuchko et al., 2013).

The need for education and support

Improving the interdisciplinary dialogue about EOL care is important but difficulties in communication are also related to the nursing profession itself (Trovo de Araujo and Paes da Silva, 2004). Nearly three decades ago, Thomson (1988) noticed that nurses used subtle avoidance in conversations about death and that they felt ill-equipped to deal with dying patients. For the future, she asks for more supervised caring for nursing students and training in interpersonal relationships. Furthermore, she asks for additional specialist nurses in acute hospitals, who should be better educated in the care of the dying and the bereaved. In recent studies, nurses still report on insecurity and lack of education in EOL care (Crump et al., 2010; Espinosa et al., 2010) Nursing education differs among countries and so does education in intensive care nursing. Kirchhoff et al. (2003) observed in 2003 that text books in intensive care nursing lacked descriptions of EOL care. This area has improved and in addition to text books, guidelines for holistic EOL care and symptom alleviation are available (Ellershaw and Ward, 2003; Puntillo et al., 2014). Education in EOL care must be mandatory in all nursing education and at all levels. As a complement

to regular education, the implementation of EOL courses exclusively directed to acute and critical care nurses have been reported as successful (Grant et al., 2013). However, the only way to gain experience is to not avoid taking care of dying patients. Junior nurses need support from more experienced colleagues who can act as role models for new colleagues. Furthermore, support from managers and an ICU environment that give room for both cure and EOL care is necessary for nurses' possibilities to provide excellent EOL care.

Communication and quality of EOL care

Communication issues also involve the dying patients' family and good communication has been shown to be the most important predictor of the quality of EOL care given to family members. The importance of nurses' engagement and involvement in conversations with families cannot be overestimated (Gutierrez, 2012; Nelson et al., 2010; van Mol et al., 2014). A Norwegian study (Lind et al., 2012) including 27 relatives of 21 deceased patients, revealed that family members experienced nurses as vague and evasive in their communication with families about the patient's condition and few family members experienced that nurses participated in meetings with physicians and family members. The authors argue that nurses have to take more responsibility in, and be more honest in their communication with family members about EOL care issues. Sorensen and Iedema (2007) stress that nurses have unique insights in the dying patients' situation and therefore nurses need to enhance their role in the decision-making process by being more prominent in their role as the patient's advocate. Sorensen and Iedema (2007) emphasise that the barriers to nursing advocacy for dying patients in the ICU do not solely lie with the medical profession but also in the nursing profession's own attitudes and practices.

However, more positive findings have been published, indicating that there is a change even if it is going slowly. For example Adams et al. (2011) report that many ICU nurses are now more proactive in discussions concerning EOL decision making. Another positive side is the number of studies that demonstrates that holistic compassionate caring for dying patients and families has become embedded into usual practice (Fridh et al., 2009a; Gerritsen et al., 2013; Wall et al., 2007; van der Klink et al., 2010). Since ICU patients often are too ill to present themselves as individuals nurses rarely know the dying patient as a person (Fridh et al., 2009b). Therefore the patient becomes a person through the relatives' narratives about their loved ones and the relation nurses create with the dying patients' family members is perhaps unique (Popejoy et al., 2009; Ranse et al., 2012). EOL care in the ICU has similarities with EOL care in other settings but there are also differences. ICUs have high nurse—patient ratio compared to general wards, which implies possibilities for good comfort care and lower risk for the patient to die alone if no next-of-kin is at the bedside when death occurs. To be cared for in the ICU at the EOL offer possibilities for good alleviation of symptoms such as pain, anxiety and respiratory distress. ICU nurses are educated and experienced in handling the drugs as well as the technology needed for this purpose.

Losing a loved one in the ICU

Losing a loved one in the ICU is one of the most stressful events that a person can experience. It is a ''life-changing'' event and it will be remembered by the close relatives forever. According to Schmidt and Azoulay (2012) up to 40% of bereaved family members had symptoms of general anxiety, major depressive disorders or complicated grief one year after the loss of a loved one in the ICU. The authors emphasise the importance of improved communication strategies to prevent ''post-ICU'' burden in close relatives. This is surely a wise conclusion and as reported above, good communication is crucial, but another important issue to discuss is what impact good EOL care performed by nurses can have on close relatives' post-ICU burden from a long-term perspective.

Family members' need for privacy and proximity

When family members of critically ill patients are asked to rank their needs, the best possible care for their loved one is usually the most prioritised need. The need for information is often the second ranked need (Al-Mutair et al., 2013). However, if these needs are met, studies have revealed that the needs of proximity to the loved one and the need for privacy are important issues for family members and not always recognised by the ICU staff (Nelson et al., 2010). Foss and Tenholder (1993) found that ICU patients' families have more needs for privacy than family members in general and Buchman et al. (2003) found that family members of dying patients have a greater need for privacy in the ICU than families of survivors.

Historically, the ICU environment has not been designed for family-oriented care and the lack of private rooms when providing end-of-life care is a recurrent problem reported by nurses (Espinosa et al., 2008). Patients frequently die in open ICU areas with no privacy for the patient or the family involved (Fridh et al., 2007). The advantages of private rooms are often discussed in relation to patient safety and infection control (Kesecioglu et al., 2012) but privacy for dying patients and their families is an important argument which should be emphasised when designing new intensive care units.

Concerning families' need for closeness, improvements have been made concerning visiting times and in letting family members in to the intensive care unit, at least if the patient is dying. But proximity also implies not to separate the dying person from his/her family during the last hours of life by e.g. letting family members spend hours in the waiting room during lifesaving activities. Accepting the family's presence during CPR is now promoted by several professional societies including the European federation of critical care nurses association (EfCCna) (Fulbrook et al., 2007; Lippert et al., 2010). To what extent those guidelines are practiced, warrants further investigation.

Follow-up services for bereaved families

Follow-up meetings after a loved one's death in an ICU are requested and wished for by bereaved families (Downar et al., 2014; van der Klink et al., 2010; Williams et al.,

2003). To come back and visit the ICU and having a conversation with the staff that cared for the patient is an important service to improve family satisfaction with EOL care. When such services are offered, they are highly appreciated by bereaved family members (Engström et al., 2008; Fridh et al., 2009a). A follow-up meeting offers an opportunity for the involved staff to help the family to sort out the causes and events that led to the death of the patient. Such conversations can relieve guilt from the family members and help them to become reconciled with their loss. Furthermore, a follow-up meeting gives room for the involved staff and the families to take farewell with peace of mind (Fridh et al., 2009b; King and Thomas, 2013).

Challenges in the present and for the future

The future is rarely as you expect it, thus speculating about what issues will have the main impact on EOL care in the ICU in the future is difficult. Some changes are already here and need attention. Ever since the polio epidemics in the 1950s, lifesaving technology has characterised intensive care units. The ongoing development of technology has led to the success of intensive care, and today lives can be saved to an extent that probably nobody could have predicted in the early stages of intensive care medicine. This evolvement will continue, but it also raises important ethical questions; is all use of new technology lifesaving or when is it solely death prolonging and a misuse of ICU resources (Kompanje et al., 2013)?

Sedation practices have changed in intensive care and nowadays patients are lighter sedated during their stay in the ICU than previously (Barr et al., 2013). This implies that the patients probably are more aware of their own condition and presumably also about their imminent death. This means new ethical challenges about patient involvement in the decision-making process. How and when should the patient be informed and how should patient's ability to make adequate decisions be assessed?

The specialty of transplantation has made great progress, something that again raises ethical questions (Monforte-Royo and Roque, 2012). ICU nurses already care for brain dead patients while waiting for organ donation and in some countries for patients who will become donors after cardiac death (Everidge, 2012). Developments in transplantation medicine indicate that even patients suffering from cardiac arrest outside the ICU can be considered as organ donors. For these patients it is suggested that consent to donation from the family can be retrieved after the cardiac arrest. In the meantime the organs requested for donation will be oxygenated with help from advanced technology. Where and how these patients should be cared for is an issue that needs to be highlighted by the nursing profession and by hospital managers (Melia, 2014).

In the last decade, awareness of the threat from both multi-resistant bacteria and global epidemics has become a reality in health care and in intensive care (Sprung et al., 2010). Whether we have the resources to give both a high-technological and human care in the ICU for patients dying in a pandemic is a question that should engage also the nursing profession.

Globalisation also includes that most of us live in multi-cultural societies. As availability of intensive care is increasing world-wide the interest of what constitutes a dignified death and a good EOL care are questions for the nursing profession globally. This means that we need to broaden our horizons about what constitutes a good death for the individual person and the family members involved (Ford, 2012; Niimura, 2013). Presently, most studies describing EOL in the ICU have a European or western-world ethnocentric perspective on what good EOL care includes (Wiegand, 2006). However, an increasing number of studies examining EOL care from different cultural perspectives can now be seen (Bloomer and Al-Mutair, 2013; Kongsuwan et al., 2010).

We also live in a violent world. Both victims and perpetrators lives are saved by intensive care and nurses are expected to give compassionate EOL care for both parties if they die. These situations are ethical demanding for all staff involved, but nurses are the professionals closest to the patient (Eisenberg and Benbenishty, 2013). All human beings have the right to a dignified death and even the most harden criminal or terrorist may have a grieving family at the bedside. All the situations discussed above raises the need for ethical forums that have to be implemented as a resource for supporting ICU clinical staff in demanding situations.

Issues for further research

Altogether, findings from qualitative research demonstrate that close relatives mostly experience that nurses provide holistic and compassionate EOL care in the ICU (Adams et al., 2014; Fridh et al., 2009a). However, an important question still remains and that is to show what significance ICU nurses have on EOL care quality. It is rarely possible to ascertain dying patients' opinions about the care given in the ICU. Therefore we have to rely on how the close relatives experience the care. One important question is what impact nursing care have on the relatives' health and recovery in the long-term after losing a loved one in the ICU. This question raises related but unexplored issues i.e. what impact have staffing levels, the nurse/patient ratio, and the level of nurse education on the quality of EOL care in the ICU. These are examples of important questions that have to be addressed in future research in the field.

Conclusion

ICU nurses' perceptions of EOL care have historically been and are still often described in the literature as a problem area. The problems nurses report are mostly related to interprofessional collaboration with the medical profession and to divergent opinions about when the patient should be considered as dying. Since communication is shown to be the factor that mostly influences families' opinions on EOL care quality, enhanced communication between the nursing and medical professions is crucial for the future.

When good communication across the ICU staff is a reality and when family members are involved in EOL conversations, decisions to limit medical care can be made timely and without prolonging the suffering for the dying patient. Nursing care has a profound impact on families' memories

of the EOL care provided for their loved ones. It is therefore important that nurses are aware of the relatives' needs for proximity and privacy when a loved one is dying in an ICU and that follow-up services are appreciated by bereaved family members. The literature reveals that despite the obstacles ICU nurses face in the transition from cure to comfort care, nurses host ethical sensitivity and have capability to provide excellent EOL care for dying patients and their families. For the future and in times of limited resources and global challenges it is necessary for the nursing profession to prove that excellent nursing EOL care can make a difference for the dying patient and the bereaved family.

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