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ANNIVERSARY SERIES: THE STATE OF THE SCIENCE

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