The critical care nurse’s role in End-of-Life care: issues and challenges

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ABSTRACT
Aim: The purpose of this article is to discuss the challenges critical care nurses face when looking after patients needing End-of-Life (EoL) care in critical care environments.

Background: Critical care nurses frequently provide care to patients who fail to respond to treatments offered to support and prolong life. The dying phase for individuals in critical care settings, commonly after withholding/withdrawing treatment, is very short posing great demands on critical care nurses to provide physical and emotional support to both patients and their families. Despite the existence of recognized care planning frameworks that may help nurses in providing EoL care, these are not used by all units and many nurses rely on experience to inform practice. A number of aspects such as communication, patient/family-centred decision-making, continuity of care, emotional/spiritual support and support for health professionals have been indicated as contributing factors towards the provision of effective EoL care. These are considered from the perspective of critical care nursing.

Conclusion: Skills development in key aspects of care provision may improve the provision of EoL care for critical care patients and their families.

Relevance to clinical practice: Critical care nurses have an essential role in the provision of effective EoL care; however, this dimension of their role needs further exploration. It is noted that educational opportunities need to be provided for critical care nurses to increase the knowledge on planning and delivering EoL care. To inform this evaluation of current EoL care provision in critical care is necessary to address a knowledge deficit of the needs of nurses who seek to support patients and their families at a critical time.

Key words: Care professionals • Critical care nursing • Family care in critical care • Withholding/withdrawing treatment

INTRODUCTION
Seriously ill patients are admitted to critical care units to take advantage of advanced technology and intensive nursing care with a primary emphasis on recovery and surviving. An admission to critical care creates a crisis to both patients and families as in most cases there is no previous severe condition to suggest the need for such an admission (Stayt, 2007; ICNARC, 2010). Despite advances in technology and medicine that support and prolong life, many patients deteriorate and fail to survive. As a result, in addition to the initial crisis leading to admission to critical care, health care professionals and the families have to deal with the management and negotiation of death which is regarded as highly stressful and emotionally distressing (Stayt, 2009). Mortality rates in adult critical care units stand at approximately 17% (ICNARC, 2010), thus care of the dying patient is an important and frequent part of critical care. The purpose of this article is to raise some of the key issues that may impact on the quality of such care and stimulate discussion about the challenges critical care nurses face when they provide End-of-Life (EoL) care.

Recent reports demonstrate dissatisfaction with the care surrounding patients’ death in the National Health System (Healthcare Commission, 2007; Department of Health, 2008), implying that the care of the dying patients and their families in hospitals may be a poor experience. Given that a high percentage of these deaths happen in critical care, factors that may
contribute to dissatisfaction with the management of the death in critical care such as unnecessary suffering, pain and lack of communication need to be considered (Clarke et al., 2003).

Unnecessary suffering and ineffective communication at the end of life in critical care is frequently attributed to the difficulty of identifying the perfect timing to shift from cure to comfort orientated care. In addition, the provision of EoL care in critical care is further complicated because of the short duration of the dying phase. Most deaths in critical care occur after withdrawal of treatment, creating a short dying phase of usually up to 4 h (Hall and Rocker, 2000; Wunsch et al., 2005). The risk of sudden imminent death does not allow for ‘preparation for death’ prompted in ideal palliative care and it places enormous demands on the nurses who are expected to provide high-quality palliative care for both the dying and the bereaved in such a short time (Neuberger, 2003; Morgan, 2008). Health professionals frequently express discomfort about speaking with families and a dying patient about death (Lloyd-Williams et al., 2009). Critical care nurses specifically tend to distance themselves from families and dying patients by engaging in practical tasks and avoiding discussing sensitive issues (Shorter and Stayt, 2010). In addition, the provision of effective EoL care can be further compromised because of a lack of essential palliative care skills and staff shortages within critical care units (Costello, 2006).

Current critical care policy does not explicitly support non-technical, non-beneficial or palliative care within critical care (Pattison, 2006; Morgan, 2008), leaving critical care nurses without clear guidance on the care of dying patients. However, the Department of Health (2008) has placed great emphasis on the EoL agenda and the NHS EoL care programme, initially directed at the primary care, is gradually transferring to secondary care. In the UK, the specific ways in which critical care nurses contribute to EoL care remain poorly defined and described. Despite this lack of research in critical care EoL in UK, there is a wealth of literature in North America that has led to the development of seven domains and associated quality indicators for EoL care in critical care (Table 1). Clarke et al. (2003) developed the domains and associated quality indicators through a consensus process that aimed to encapsulate all the variables that could provide measurements for determining the quality of EoL care. It is expected that using these quality indicators to inform care giving and evaluation, critical care nurses will be able to provide better quality EoL care.

In order to analyse the challenges critical care nurses face when caring for dying critically ill patients and identify good practices or areas requiring further research, Clarke et al.’s (2003) domains were used as a framework to structure the discussion in this analysis paper. The seven domains provided also keywords to identify the most relevant and updated evidence on databases such as CINAHL and MEDLINE. A breadth of literature was identified relevant to each domain, thus we do not claim to have exhausted all the available evidence as it would happen on a systematic literature review (Cronin et al., 2008). Every effort was made to use the most updated information to raise and discuss the issues and challenges critical care nurses face when they provide EoL care, however, we did not exclude highly regarded older publications.

### Communication

The Department of Health (2003) regards communication as an essential skill for health care professionals in order to be able to provide high-quality, effective and compassionate care to dying patients and their families. Lautrette et al. (2007) suggest that effective communication in critical care can improve outcomes, especially for the bereaved family. Although nurses working in critical care consider communication with dying patients and their relatives an effective therapeutic resource, they also view themselves ill-prepared for the task (Trovo De Araujo and Paes Da Silva, 2004). McCaughan and Parahoo’s (2000) study revealed that communication occupies a high place among the areas demanding greater knowledge by nurses in the care of dying patients. The lack of communication skills in this particular aspect of care has led practitioners in many cases missing opportunities to facilitate family interactions (Curtis et al., 2005).

As family satisfaction and ratings of the quality of palliative and EoL care are linked with good communication, a shared decision model is advised as appropriate to improve communication, with collaboration between physicians and nurses and ultimately between health care professionals and the patient/family. Collaboration would facilitate a patient and family-centred decision-making approach (Latour et al., 2009). Other

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Source: Clarke et al. (2003).
interventions that may help improving communication could include brochures and allowing more time for family members to talk. Lautrette et al.'s (2007) randomized control trial found that the provision of a brochure on bereavement and providing more time for family members to talk can improve communication and reduce the burden of bereavement for families. However, the trial was conducted in France where the authors acknowledge that paternalism is more evident in the patient-physician relationship, thus similar studies should be contacted in UK to identify the effectiveness of such interventions.

Patient and family-centred decision-making
In the context of EoL care in critical care, decision-making in most cases refers to treatment withholding or withdrawal (Lautrette et al., 2006). Although the competent patient has a right to choose, after provision of full information, whether to undergo any aspect of treatment that is offered, critically ill patients are commonly unable to think and participate in decisions, as they may be unconscious, sedated, intubated and ventilated (Bailly et al., 2003; Bell, 2007). Therefore, much of the discussion about what is happening to the patient and decisions about treatment take place between the patient's family and the critical care physicians and nurses.

Under UK law, the ultimate authority for medical care of the incompetent adult rests with the treating physicians rather than the next-of-kin, nurses or the courts (Bell, 2007). Although the legislation seems to adopt a paternalistic approach, the physicians have to act in the ‘best interests’ of the patient, which include best medical interests, the patients’ wishes and beliefs when competent, their general well-being and their spiritual and religious welfare (Department of Health, 2001). The critical care nurse’s role in decision-making is not well defined. Coombs and Long (2008) report that nurses’ views on withholding or withdrawing life-supporting treatment may not always be elicited, despite spending more direct time with the patients and their families. On the other hand, Latour et al.’s (2009) European study demonstrates that the majority of critical care nurses are involved ‘actively’ in the decision-making process to withhold or withdraw life-supporting treatment. However, the nature of this ‘active involvement’ is not clarified in their study, adding little new evidence on the nurse’s role in decision-making. Regardless of how actively critical care nurses participate in decision-making to withhold or withdraw life-supporting treatment, it is important that they promote patient and family-centred decision-making, as this approach sees patients embedded within a social structure and web of relationships and is seen as a comprehensive ideal for EoL care in critical care (Truog et al., 2008). Recently, attention has also been drawn to promoting patient and family-centred decision-making with non-English-speaking patients and families. Thornton et al. (2009) suggest that non-English-speaking members may be at increased risk of receiving less information about their patient’s critical illness from health care professionals because of the language and cultural barriers. Given this, future studies should consider ways to promote patient and family-centred decision-making from a multi-cultural perspective with families of critically ill patients.

Continuity of care
The organization of critical care services creates several challenges in the care of dying patients. The rapid turnover of staff, resulting in a great number of staff caring for a single patient, creates the potential for discontinuity of care and conflicting goals of care among the health care professionals (Danis et al., 1999). The family may also hear various and divergent information and opinions, both formal and informal, regarding the patient’s condition from numerous health care professionals, creating further confusion and raising obstacles for providing effective EoL care (Beckstrand and Kirchhoff, 2005).

As the health care professionals spending most time with patients and their families, critical care nurses may feel anxiety when they have to face the challenge of bringing varied perspectives together and identifying a plan of care that each party believes would accommodate the patient’s needs. Puntillo and McAdam (2006) suggest that multi-professional discussions have to take place to allow reflection about the aims of care and explorations to what EoL care means to different health professionals. An aid for efficient continuity of care at the end of life could be the use of an established and evidence-based care plan such as the Liverpool Care Pathway (LCP) which is an integrated care pathway for the dying. The LCP for critical care aims to improve care of the dying in the last hours/days of life by providing clear goals in the management of physical, psycho-social and spiritual symptoms (Ellershaw, 2007). By facilitating comprehensive documentation of symptoms, care provided and problems during the dying process, the LCP contributes to structuring care and proactively managing the comfort of the patient (Veerbeek et al., 2008).

Emotional and practical support for patients and relatives
As the majority of dying critically ill patients is not able to communicate, emotional and practical support has been mainly focussed on the patients’ family. Studies
have shown high levels of anxiety and depression among family members of critically ill patients because of the absence of regular health care professionals-family discussions and the lack of a private space for family meetings (Pochard et al., 2001). In addition, Simpson (1997) found that the critical care environment separates dying patients from their families with technological barriers such as machines, tubes and wires, and the constant sound of alarms going off, creating further anxiety.

Bach et al. (2009) suggest that one of the most fundamental roles nurses play in providing emotional support to families of critically ill patients is being present at the bedside, providing comfort, a caring touch and a listening ear. Ciccarello (2003) also describes nursing presence within EoL care as a simple but powerful intervention. Fridh et al. (2009) suggest that nurses should attempt to overcome the dehumanizing aspects of dying in a technological environment by ‘reconnecting’ the patients with their family. The strategy advised to achieve this is the development of trust between nurses, doctors and the patient’s family, by accepting the inevitability of death (Simpson, 1997). Although further interventions are suggested by Simpson (1997) for reconnecting the family and the patient such as therapeutic manipulation, environmental manipulation and emotional support for the family, the author does not provide clear advice on how these can be achieved. Further research is required to explore the concept of presence and how to reconnect patients during their last stages of life and their families in the highly technological environment of critical care.

### Symptom management and comfort care

According to Puntillo et al. (2004), pain is one of the most prevalent symptoms in critical care as it is usually associated with procedures such as suctioning, turning, wound care and the presence of endotracheal tubes – procedures that patients dying in critical care are subjected to as nurses aim to keep them comfortable. The management of pain in dying critically ill patients may pose difficulties as the common pain assessment tools may be of little value in assessing the semi-conscious patient’s pain (Cosgrove et al., 2006). However, the use of behavioural pain assessment tools based on physiologic variables and behavioural observations, such as the Behavioral Pain Scale (Payeh et al., 2001) or the Critical-Care Pain Observation Tool (Gelinas et al., 2006), may assist critical care nurses in objectively assessing dying patients’ pain. For the relief of pain, discomfort, anxiety and distress opioids and sedatives are commonly used. A Delphi study of critical care experts conducted in Canada (Hawryluck et al., 2002) concluded that the use of analgesia and sedatives for dying critical care patients should be individualized, suggesting also that there should not be a maximum dose because of the individual response to analgesia and sedation. However, Toscani et al. (2003) caution that suffering can have a profound redemptive meaning for some patients, emphasizing further the importance of individualized approaches in the management of pain, anxiety and distress.

Other common symptoms for dying patients in critical care apart from pain include respiratory distress, nausea and increased respiratory tract secretions (Nelson et al., 2001; Cosgrove et al., 2006; Solano et al., 2006). Extensive literature exists with regards the pharmacological management of distressing symptoms and comfort care to guide health care professionals (Toscani et al., 2003; Cosgrove et al., 2006; Hugel et al., 2006; Truog et al., 2008). Despite the existence of a wide pharmacological range for the relief of symptoms at the end of life, critical care nurses are faced with limitations, such as prescribing and consequently delivering medication timely. Non-pharmacological interventions used within palliative care to relieve symptoms and provide comfort, such as massage therapy and music therapy (Demmer, 2004), could possibly be used in the care of dying patients in critical care. A systematic review (Bradt and Dileo, 2010) has shown that the evidence with regards the effectiveness of music therapy at relieving symptoms at the end of life is inconclusive; however, therapeutic massage has been found to provide pain relief in a randomized control trial of advanced cancer patients receiving palliative care (Kutner et al., 2008).

### Spiritual support

According to Carr (2008), at the core of a dying person’s and family’s experience there is often an overpowering sense of personal loss, with associated spiritual suffering that requires appropriate nursing intervention in critical care. Kruse et al. (2007), after studying spirituality and coping at the end of life, have concluded that spirituality is an essential element in creating a peaceful death. As the acknowledgement of the patient’s and families’ spiritual needs in end of life is associated with greater satisfaction (Gries et al., 2008) and a peaceful death (Kruse et al., 2007), it is suggested that health care professionals should routinely ask patients and families whether spiritual needs are being met and, if not, how the hospital’s resources might be more helpful (Faber-Langendoen and Lanken, 2000). Timmins and Kelly (2008) advise the use of simple assessment tools that will facilitate the gathering of objective information to help in providing holistic critical care. However, as spirituality lacks clear definition, critical care nurses may feel anxiety with regards the most effective means...
of addressing the spiritual needs of patients and families. Burkhart and Hogan (2008) have identified the need for further research to explore initially what techniques accurately recognize spiritual needs and what interventions may promote spiritual well-being.

**Emotional and organizational support for clinicians**

Calvin et al. (2007) reveal that critical care nurses regard the provision of EoL care to dying patients as a privilege. However, the provision of care to patients who are not likely to recover is usually associated with moderated levels of moral distress which can lead to emotional exhaustion (Meltzer and Huckabay, 2004; Elpren et al., 2005). Delays in decision-making may also result in unnecessary suffering for the patient and the family, creating more disappointment to nurses (Hov et al., 2007). Furthermore, after a patient dies, nurses may grieve and if the grief is concealed or suppressed it may lead to further stress (Brosche, 2003; Calvin et al., 2009). It is suggested by Rushton (1992) that the unrecognized health care professionals’ suffering and grief may also undermine the effectiveness and quality of care offered.

Truog et al. (2008) acknowledge that health care professionals have important bereavement needs. Strategies to support critical care nurses as they provide terminal care have to be considered by all critical care units. Cosgrove et al. (2006) suggest formal or informal briefings as a strategy to cope with EoL situations. The briefings could take the format of clinical supervision which is regarded as an effective way to provide peer support and stress relief for nurses (Brunero and Stein-Parbury, 2008). In addition, Ellershaw (2010) advises mandatory training and education with courses tailored to the health care professional’s needs and the development of specialist palliative care teams in every acute hospital as another form of organizational support for nurses. As a result of the range and large number of individuals involved in the delivery of EoL care, innovative models of education are advised, such as e-learning for reaching a large workforce (Department of Health, 2008).

**DISCUSSION AND CONCLUSION**

In critical care units, the usually short phase of patients’ dying pose great demands on nurses creating challenges in providing effective EoL care to patients and their families. Arising from the analysis of the literature, the areas of communication, continuity of care, education and integration of palliative care principles in critical care appear to require immediate attention. For effective and compassionate provision of EoL care, nurses need to promote patient and family-centred decision-making through effective communication with all involved in the patient’s care. It is acknowledged that provision of clear information in a variety of forms to the dying patient’s family will help. This will be enhanced by the availability of health professionals for the discussions needed to improve the provision of effective EoL care.

Linked with this, critical care nurses should consider how care plans help ensure continuity on the delivery of appropriate care for people who are in the dying phase of their illness and after death. One of the frameworks the Department of Health (2008) has identified as effective in planning EoL care is the LCP. The indications are that the critical care specific LCP (LCP-ICU) provides an evidence-based multi-disciplinary resolution to most of the domains discussed in this article, including continuity of care, symptom management, spirituality and communication (Morgan, 2008). However, a number of reports suggest that education and adequate support are essential for the successful implementation of the LCP-ICU (Walker and Read, 2010) and that the length of the LCP-ICU document may not suit the speed of death in critical care (Morgan, 2010). It is evident that in order to implement such care pathways successfully, training of health and social care professionals is required. Furthermore, the extent to which this tool applies to the critical care units needs further consideration and evaluation.

Overall, good knowledge of palliative care principles is required to relieve physical, emotional and spiritual distressing symptoms for both patients and their relatives. Although EoL care has been integrated into pre-registration nursing education, there are still concerns that students are not adequately prepared to provide terminal care (Dickinson et al., 2008). Until recently EoL was not considered as a component of education for critical care nurses with much of the attention in role development being given to life-sustaining care giving in formal education programmes (Walker, 2001; EfCCNa, 2004). More recently Coombs and Long (2008) have highlighted the need to enhance the education of the existing workforce, targeting especially novice critical care nurses, in order to develop good EoL care in practice. This reflects the Department of Health (2008) priority action to improve the skills of people working with dying people and their families. Appreciating the challenges of time, they suggest a key element is establishing online courses for health care professionals which enable flexible learning to occur. From this, perspective critical care nurses may find useful the e-ELCA (End of Life Care for All), a course focussing on the core elements of EoL care (www.e-lfh.org.uk, 2009). Although such courses will fill an educational gap,
there is a need to evaluate the impact and effectiveness of such programmes in supporting care delivery in critical care practice.

In response to identified need, there is a desire to integrate the good principles of palliative care into critical care. However, much work needs to be carried out to determine the optimal ways of doing this in an environment where it is acknowledged that what is commonly recognized as good practice in caring for the dying does not lend itself to situations in which the dying phase is radically curtailed. The principles of good EoL care indicated above need to be adapted to provide the best care for those who are unfortunate to die as a result of acute life-threatening situations in a critical care environment and their families and loved ones left behind. To support these developments the critical care nurse’s role in providing EoL care needs to be explored further. The domains outlined here could help structure and inform the development of future research studies.

WHAT IS KNOWN ABOUT THIS TOPIC

- A considerable time of critical care nurses’ work consists of caring for dying patients and their families.
- The dying phase of patients in critical care, usually after withholding or withdrawing treatment, is very short.
- There are high demands on critical care nurses to provide effective and compassionate EoL care within a short time.
- Little guidance exists with regards how best critical care nurses can fulfil their role in providing EoL care.

WHAT THIS PAPER ADDS

- This paper raises key issues in the context of EoL care in critical care.
- Aspects of EoL care in critical care such as communication, patient and family-centred decision-making, continuity of care, emotional and practical support for relatives, symptom management and spiritual support for patients and emotional and organizational support for critical care clinicians have provided a starting point to identify knowledge gaps and areas for further research in the pursuit of effective EoL care in critical care.

REFERENCES


