

Guest Editorial and Call for Papers

Spotlight on Bereavement Care in the ICU

Intensive care units (ICUs) are dedicated to supporting and saving lives; yet, despite medical advances, a significant number of critically ill patients die in this setting. International mortality rates in adult ICUs in North America (Canadian Institute for Health Information, 2016; Society of Critical Care Medicine, 2018), the UK (Intensive Care National Audit and Research Centre, 2018) and Australasia (Australian and New Zealand Intensive Care Society, 2017) have been reported to range between 7.9% and 29%, and are generally lower for paediatric ICU (PICU) patients (Australian and New Zealand Intensive Care Society, 2017; Paediatric Intensive Care Audit Network, 2017; Society of Critical Care Medicine, 2018). Between April 2016 and March 2017, 255 National Health Service adult critical care units in England, Wales and Northern Ireland participated in an audit of patient outcomes. The reported 13.7% mortality rate was equivalent to 23 142 non-survivors (Intensive Care National Audit and Research Centre, 2018). Hence, bereavement; ‘the situation of having recently lost a significant other’ (Buckley *et al.*, 2015, p.64) is an inherent feature of ICU practice and nursing in critical care.

The theorists Parkes and Weiss (1983) describe bereavement as the entire experience of anticipating a death, the death itself, and the subsequent adjustment to living. The concept of anticipatory grief has been identified as relevant to understanding ICU family needs (Coombs, 2010), and once patient death has occurred, the family member status changes from anticipatory to bereaved (Warren, 1997). Schut *et al.* (2001, cited in Stephen *et al.*, 2006, p.4) suggest the purpose of bereavement care is ‘to benefit the bereaved individual, to help him or her to deal with the emotional and practical problems following the loss of a loved one’. This signifies bereavement care for families at the time of patient death, and post ICU. It leads us to consider a classification of pre- and post-death family care in the contexts of end-of-life care and bereavement care respectively. At the same time, it is important to be mindful of the efficacy of pre-death interventions on post-death bereavement outcomes. A recent study by Suttle *et al.* (2017) suggests that attending to the needs of grieving parents in PICU may influence their recovery from bereavement and similar conclusions can be drawn from relatives’ experiences of caring in adult ICU (Fridh *et al.*, 2009). Intimation of an association between the quality of pre-death care and a healthy

bereavement is exemplified in the words of a family member who reminisced; ‘... Because my husband died well, I live well’ (Office of the Ombudsman, 2014, p.2).

The importance of bereavement care for families of ICU decedents cannot be underestimated. Changes in physical and mental health are not uncommon, and the nature of sudden death and bereavement in ICU can add to the complexity of families’ grief. A prospective study by Kentish-Barnes *et al.* (2015) identified symptoms of complicated grief in 52% of relatives who experienced the death of a loved one in ICU and the findings draw our attention to end-of-life care practices and communication amenable to improvement. Identifying bereaved families’ needs and understanding care interventions that either helped or hindered their grief is pivotal to developing an evidence-base of effective care practices. Parents in PICU (Yorke, 2011) and relatives of adult patients (van der Klink *et al.*, 2010) have identified the need for follow-up care and support, and the literature contains many praiseworthy examples of local ICU enterprise. Downar *et al.* (2014) found that most clinicians (ICU nurses and physicians) at two teaching hospitals in Toronto, Canada, were willing to support or participate in an ICU-based bereavement screening and support program, as desired by family members bereaved in ICU, regardless of their mental health status. Emotional support and a meeting to review the events prior to patient death were the types of support most desired by bereaved family members who participated in this study. Researchers have also uncovered the emotional impact of nurses’ exposure to dying, death and bereavement in ICU (Shorter and Stayt, 2010; Bloomer *et al.*, 2015; Lima *et al.*, 2018), and nurses’ need for peer support, and reflective debriefing to give closure to events (Walker and Deacon, 2016).

The allocation of resources to support bereavement care will require sound reasoning at a time of increased demand for specialist intensive care and the rising costs of ICU provision. Demonstrating the merit of post-ICU bereavement care is likely to play an increasingly important part in shaping the provision of follow-up care; situated, co-ordinated and delivered within ICU or the outsourcing of bereavement care and the signposting of families to community-based charitable bereavement organisations. Stayt (2007) identified perceptions of role ambiguity and conflict in meeting ICU families’ needs and a decade on, barriers to achieving holistic nursing care persist. Pressure to provide high-quality care for a growing number of patients and families invites us to consider ICU nurses’ role in bereavement care; should this be limited to care in the immediate aftermath of patient

death in the ICU or encompass continuing support for the grieving family in the short and/or longer-term? Is there a role for a specialist nurse in bereavement care or is bereavement care a generic responsibility of all ICU nurses? Clinical experience and competing workload demands also require consideration as these factors may impact the provision and quality of bereavement care (Raymond *et al.*, 2016).

Kurian *et al.* (2014) studied the practice and beliefs of registered nurses (RNs) working in four adult ICUs at a hospital in the USA. The majority of RNs felt that support to bereaved families should be part of their routine work (68%, n=75), and that ICU nurses have an important role to play in helping bereaved families come to terms with their grief (73%, n=80). However, almost half (46%, n=51) felt they had not received sufficient education, training and experience – a recurrent theme in the literature that has implications for the wellbeing of both the recipients and providers of care. Conceptual clarification of the meaning of bereavement care in ICU should be used to define the requisites of competent care and inform ICU nurses' education and practice-based learning needs. We suggest local and national research to define the nature and boundaries of culturally-sensitive bereavement care, when it should be delivered, by whom and with what qualifications. However, opportunities for international collaboration should be embraced, as this can facilitate cultural awareness of the beliefs and practices of self and others. An internationally renowned end-of-life care nursing education training programme incorporating loss, grief, and bereavement, and directed to acute and critical care nurses (Grant *et al.*, 2013) serves as an example of curricula designed to develop nurses' confidence and competence as a provider of bereavement care. Then again, the impact of global austerity measures affecting continuing education may lead to in-house and hands-on training in bereavement care. Opportunities for experiential learning in practice must be embraced as a method of helping less experienced colleagues to develop their skills in family bereavement care through excellent role modelling, professional mentorship and clinical supervision.

ICU nurses will encounter a multiplicity of family needs as the patient transitions from living, to dying and death. The reporting of bereavement care practices mostly focuses on patient and family care prior to death (Coombs *et al.* 2016); a state of knowledge which may be attributed to proactive palliative and end-of-life care quality improvement agendas. However, examples of innovation in ICU bereavement care can be found in the literature such as the focus group study of ambient music during after-death care by Holm *et al.*

(2012). Specific components of post-death bereavement care have been identified through national surveys in the USA (McAdam and Erikson, 2016), England (Berry *et al.*, 2017), Denmark (Egerod *et al.*, 2018) and across Australia and New Zealand (Coombs *et al.*, 2016; Mitchell *et al.*, 2017). Care practices at the time of patient death in ICU included viewing of the deceased, and providing information about 'what to do' following a death and available avenues of support. Continuing care for families in the weeks or months after a patient's death was provided through a range of follow-up support practices, and access to an ICU bereavement service. However, there was a notable lack of consensus on the nature, organisation, delivery, and availability of bereavement care and service provisions. International researchers concluded that most ICUs in the USA do not provide a bereavement follow-up service (McAdam and Erikson, 2016); bereavement care in English ICUs is underdeveloped (Berry *et al.* 2017); the provision of ICU bereavement follow-up services in Australia has fallen slightly in the past decade (Mitchell *et al.*, 2017) and comprehensive bereavement care has not yet been fully integrated in Danish ICUs (Egerod *et al.*, 2018). Bereavement in ICU is a complex phenomenon of global interest, yet in pressing need of research investment for improved culturally-competent care.

The critical issues highlighted in this editorial signify opportunities for quality improvements in bereavement care through ICU practice development, post-ICU follow-up and continuing education and support for nurses. Evaluation, audit, and research are essential activities for evidence-informed care practices, to measure the quality and impacts of existing and new interventions, and in shaping the future provision of bereavement care for grieving families in ICU.

A call for papers

We will place the spotlight on bereavement care in the ICU by dedicating a Special Issue of *Nursing in Critical Care* to this topic. We invite the submission of papers reporting original research, literature reviews, case studies, quality initiatives and service evaluations of relevance and importance to nurses who are at the forefront of providing bereavement care in adult and PICUs. We welcome papers reporting on: the nature and provision of bereavement care in the ICU; education and training initiatives; evidence-based care practices; the experiences and impacts of bereavement care interventions; provider and/or recipients' perspectives. Guidelines for Authors can be found at: <https://onlinelibrary.>

wiley.com/page/journal/14785153/homepage/forauthors.html Papers should be submitted using the journal's online Submission Site: <http://mc.manuscriptcentral.com/ncr> The cover letter should specify that the paper is being put forward for the forthcoming Special Issue: 'Bereavement Care in the ICU'. The closing date for the submission of manuscripts for this Special Issue is: **30 November 2018**.

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