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The mourning after: the potential for critical care nurses to improve family outcome and experience in end of life care

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Thirty years ago you would have been hard pushed to see Critical Care and Palliative Care mentioned in the same journal, let alone in the same sentence. However the world has moved a long way since the 1980’s and it is now recognised that end of life care is an important and intrinsic part of everyday practice in critical care. Indeed during the 2013 Australia and New Zealand Intensive Care Society Scientific Meeting in Hobart, the significant number of papers and posters focussing on delivery of care at end of life gives evidence to this sea change.

However, the profile of end of life in critical care has advanced more than just a modest increase in the number of conference presentations. Clinical and academic staff have been developing an evidence base to inform critical care practice when recovery from critical illness is not achievable and treatment withdrawal becomes the focus of the clinical management plan. This emerging body of literature is helping us understand what the end of life trajectory in critical care looks like; who is involved in the care and what happens at this time; and the impact that end of life has on those involved.

From international data we know that considerable numbers of patients die in critical care (Angus et al 2004, Harrison et al 2004) often as a result of withholding or withdrawing
treatments (Frick 2003). The transition to end of life care is usually instituted where survival is unlikely or there is an expected poor quality of life post critical illness for the patient (Sprung et al 2003). Once such a consensus is reached amongst all staff, families and patients, treatment withdrawal begins (Coombs et al 2011) with death occurring rapidly for those requiring high levels of life supporting therapies (Wunch 2005).

The medical literature in this area often focuses on the transition from curative to palliative interventions in critical care. Given medicines’ central role in making clinical management decisions, studies have explored the prognostic uncertainty of identifying patients at high risk of dying (Barnato and Angus 2004) and principles of best communication practices at end of life (Scheunemann et al 2011). The importance of family conferences (Curtis et al 2007) and information brochures (Lautrette et al 2007) are specific communication strategies explored to date.

How information about critical illness and treatment decisions is shared with families is important. We know this from empirical work that demonstrates the impact of how bereaved families experience communication with health care staff and the impact of this on family health outcomes (Anderson et al 2008) and satisfaction with care (Wall et al 2007). The central tenet of these studies is that good communication improves bereaved family satisfaction with care and reduces the incidence of anxiety, depression, post-traumatic stress and complex grief in the bereaved. This body of work helps us understand
that what we do for families during end of life care in critical care has short and longer term impact.

Nurses also have an important role within the delivery of end of life care including offering bedside support to families (Efstathiou and Clifford 2011) and working between medical staff and families to inform clinical decision making (Jensen et al 2013). Nurses are key in managing the processes of care at the very end of life in critical care (Long Sutehall et al 2011). All these essential aspects of the nurses’ role in end of life care are underpinned and enabled by communication. So drawing on our understanding of the importance of interactions with families from the work above, how could this influence and inform nursing practice?

I would suggest that from the moment a nurse meets the family of a critically ill patient, the importance of the ‘how, what, when and where’ of communication should be considered. And these should be taken into account across the end of life care trajectory. Think about how you manage the first meeting with a family: how do you introduce yourself, where do you share sensitive clinical information, when do you establish what the family understanding of the situation is and how do you establish what the family’s needs are? In thinking about supporting and talking with families at the bedside, what skills do you use to establish rapport with families and how do you ascertain patient and family preferences about care at end of life? We know that nurses are pivotal in managing the actual process of
treatment withdrawal, so at this time, what do you say to understand what families want and how do you talk with families about what death and dying looks like in intensive care?

Critical care nurses interact with families of critically ill patients every day. And yet it is clear that we are only just starting to understand the importance of communication for family members in critical care. Speaking with families includes activities that range from the simple answering of the unit buzzer to talking with families about literally life and death changing moments. This beholds us all to consider the impact of every interaction with family members, cognisant of how each of us holds the potential to impact on family outcome and satisfaction for bereaved family members in critical care.
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