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'I cried too' Allowing ICU nurses to grieve when patients die

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Final approved version

Caring for dying patients and their families has always been part of what we do in intensive care. It is encouraging that, despite an increase in severity of disease, the odds of intensive care unit (ICU) mortality have reduced (Vincent et al 2018). For those patients who are unlikely to survive, there is also increasing evidence of more open discussions about priorities of care, as reflected in scientific and conceptual papers (Coombs et al 2015, Van del Bulcke et al, 2018). Despite this progress towards more explicit communication about death and dying with patients and families in ICU, studies conducted by Jang & colleagues (2019) and Betriana & colleagues (2019) illustrate that this open-ness stops short of acknowledging the impact of a patient's death on health care professionals.

Early work in ICU defined a good death as: "*free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards*" (Field and Cassel 1997, p4). Since that time, there has been exploration of many aspects of end-of-life care e.g. decision-making processes, but little exploration about the effect on nurses when caring for dying patients of in the ICU.

More recent work has demonstrated that the quality of the patient's death, their suffering and loss of dignity, have been significantly associated with emotional distress in nurses (Lief, et al., 2018). Hence, in order to minimise nurses' distress, we need to identify the specific challenges for nurses and focus on improving these aspects of care; and there is some evidence to inform our understanding here. The CONFLICUS study, conducted over a decade ago, examined the prevalence, characteristics and risk factors for perceived conflicts in 323 ICUs across 24 countries (Azoulay et al 2009). The authors identified eight sources of conflict related to end-of-life care, including sub-optimal decision-making processes. Multivariate analysis showed an association between higher prevalence of conflicts and caring for at least one dying patient over the previous week (OR 1.17, 95%CI 1.02–1.34, $p= 0.0270$), and providing care before and after death for at least one patient who died within the previous week (OR 1.53, 95% CI 1.33–1.76, $p < 10^{-4}$).

Although the CONFLICUS study remains a highly cited and well-disseminated study, care provided for patients at the end of life continues to be a source of conflict between ICU health care professionals (Archambault-Grenier et al 2018) with little acknowledgment of the impact on nurses from frequently caring for those at end of life, and few strategies to minimise this impact. This area is clearly raised in a study exploring perceptions of a 'good death' with 55 ICU nurses in the UK and Israel. A major findings to come from this work was achieving closure for nurses (as well as for

families). Participants spoke of the impact left by a patient's death using phrases such as 'all of us are not really over it' and highlighted the lack of opportunity to demonstrate grief through comments such as 'it's like "that's it, your shift's over. Done, Dusted. Off you go"' (Endacott et al 2016).

Acknowledging that nurses do grieve for patients would be an important step forward. In this issue of the journal, Betriana and colleagues present findings from an in-depth exploration of the lived experiences of Muslim nurses who have cared for a dying patient in ICU. They have used a creative approach – graphic representation – to encourage the nurses to illustrate their grief, and the potential impact of grief on nurses' well-being is powerfully presented. Findings of the qualitative study undertaken by Jang and colleagues, also published in this issue, show that caring for dying patients prompts nurses to consider their own mortality and emphasises the need for better preparation of nurses.

Nurses will grieve for patients even if the death has been a 'good' death. We should look to provide support during and following all patient deaths; not just the most difficult ones. Death touches us all in different, and sometimes surprising, ways. Kisorio and Langley (2016) conclude from their focus group study exploring end of life care with ICU nurses in South Africa that ICU nurses need care to enable them to provide "the best possible end-of-life care". Potential solutions exist such as use of simulation to develop conflict resolution skills (Kim et al 2018), better use of inter-disciplinary rounds (Ten Have & Nap 2014), and approaches to assess the ethical decision-making in ICU (Van den Bulcke et al 2018). There are also more 'immediate' and practical strategies of being aware of the workloads of clinical team members who have recently cared for multiple patients at end of life, of providing more junior staff with close support or buddying up with a nearby staff member, and of allowing the nurse to solely care for a dying patient and their family, rather than undertake other responsibilities on shift.

Attendance to staff wellbeing may engender nursing resilience when coping with stressful circumstance, such as death in ICU. Indeed, interventions using mindfulness in ICU have received a higher profile in recent years. Mindfulness encourages an individual to observe emotions from a detached view. This may result in greater acceptance of one's experiences (Lamothe et al 2016) and a higher awareness of emotion, when it occurs (Jimenez et al 2010). Whilst mindfulness may be perceived as somewhat of a current buzz-word, initial studies using mindfulness with ICU staff have reported reduction in stress (Gauthier et al 2015), decreased burnout (Cohen-Katz et al 2005), decreased post-traumatic stress disorder symptom scores (Mealer et al 2014), and an improvement in anxiety and depression scores (Lan et al 2014). However, any long-term impact is currently

difficult to assess given the range of interventions e.g., meditation, mindfulness-based Cognitive Therapy and the diverse outcomes measures used.

It is a privilege and responsibility to care for someone at the end of life, but we also have an obligation to acknowledge grief in our colleagues, to look out for each other, to provide open and honest preparation for new staff, and to provide support not just for the patient and their family, but also all caregivers during end-of-life care in ICU.

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