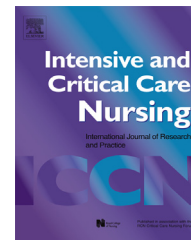




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‘Something normal in a very, very abnormal environment’ – Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia



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Summary The majority of deaths of children and infants occur in paediatric and neonatal intensive care settings. For nurses, managing an infant/child’s deterioration and death can be very challenging. Nurses play a vital role in how the death occurs, how families are supported leading up to and after the infant/child’s death. This paper describes the nurses’ endeavours to create normality amidst the sadness and grief of the death of a child in paediatric and neonatal ICU. Focus groups and individual interviews with registered nurses from NICU and PICU settings gathered data on how neonatal and paediatric intensive care nurses care for families when a child dies and how they perceived their ability and preparedness to provide family care.

Four themes emerged from thematic analysis: (1) respecting the child as a person; (2) creating opportunities for family involvement/connection; (3) collecting mementos; and (4) planning for death.

Many of the activities described in this study empowered parents to participate in the care of their child as death approached. Further work is required to ensure these principles are translated into practice.

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Implications for Clinical Practice

- Pediatric and neonatal intensive care nurses need specialist skills to be able to support families and honour the dying child.
- Creating opportunities for families to interact with the dying child, and inform the death are essential.
- There is scope for neonatal and pediatric intensive care nurses to go beyond the 'routine' collection of mementos as a way of supporting grieving families.

Introduction

The primary goal of therapy in intensive care units (ICUs) is to assist the recovery of seriously ill patients through technologically sophisticated care (Copnell, 2005; Hamric and Blackhall, 2007). Despite this goal, the mortality rate is higher in ICU than most other health care settings (Yu and Chan, 2010); this is no less for paediatric and neonatal intensive care (PICU and NICU), as the majority of in-hospital deaths of children and infants take place in these settings (Chang et al., 2013; Stark et al., 2008; Yorke, 2011).

For parents, the death of an infant or child is regarded as one of the most devastating events endured (Davies, 2004). Not only is parental grief intense, but it can also be overwhelming because they lose a part of themselves and the hopes and dreams they had for the child (Davies, 2001, 2004). Given that the majority of children who die are hospitalised at the time of their death (Chang et al., 2013), the experience and grief of parents associated with the loss of their child is influenced by interactions with, and actions of, various clinicians involved in their child's care (Butler et al., 2015; Meert et al., 2001).

Deterioration in a child's condition and/or their death can also result in personal grief and a sense of failure for nurses, especially if they are primary carer/nurse within the care team (Hamric & Blackhall, 2007; Yam et al., 2001). Consequently, nurses often attempt to rationalise a death as a way of coping. But rationalising the death of an infant or child is significantly harder than an adult because society regards the death of a young person as an 'undeserved death' (O'Connor et al., 2010).

When death occurs in NICU and PICU, nursing care of the family is equally as challenging as caring for the dying infant or child in the time leading up to and after death. Nurses play a role in what happens as death approaches, how the death occurs and how the family are engaged after death. Nurses express concerns about knowing what to say to parents, how to prepare them for imminent death and how to support parental grief (Ahern, 2013).

Numerous studies have identified other factors that impact upon the parental experience. Caring actions, sensitive and caring staff and understandable explanations were cited in one study as being most helpful to parents (Brooten et al., 2012). Similarly, other studies have stressed the importance of communication between clinicians and parents (Darbyshire et al., 2013; Meert et al., 2001; Yorke, 2011), with another paper stating that families relied more heavily of nursing professionals than other family members (Beckstrand et al., 2009). Importantly however, when clinicians demonstrate caring in other ways, which go above

and beyond the professional role (Meyer et al., 2006), the parental experience is also improved. A recent PICU study found that measures such as making the PICU environment more comfortable and welcoming, minimising the imposing nature of the technology and facilitating parents' time at the bedside by giving them access to a telephone and hospital meals were identified by bereaved parents as strategies to improve their experience (Yorke, 2011).

Parents also appreciate the rituals and practices designed to mark the death of an infant or child and used to create memories (Butler et al., 2015). The making of memories is increasingly recognised as an aid in parental coping and grieving (Schott et al., 2007). Often nurse initiated, they include keepsakes such as a lock of hair, hand and foot prints, memory boxes and hospital identity bands (Abib El Halal et al., 2013; Brooten et al., 2012; Meert et al., 2009; Meyer et al., 2006). These keepsakes, also referred to in the literature as mementos, were described as helpful for parents in their grief (Brooten et al., 2012). Photographs of the infant or child before and after death are also common and are said to provide both memory and meaning to the parents' experience of their child after the death (Heartfelt, n.d.; Michelson et al., 2013; Yorke, 2011).

Other studies report that rather than physical keepsakes, parents and families instead appreciated other actions or gestures by clinicians that demonstrated respect of the parents' and family's needs and acknowledged that the child was important and special (McGuinness et al., 2014; Meert et al., 2009). This included having time alone with the child and being encouraged and supported to provide care to the child leading up to the death (Brooten et al., 2012; Meert et al., 2009; Yorke, 2011).

Some studies of parental experiences indicated that activities which they valued were not universally performed, for reasons which are unclear. Parents reported not being allowed to be with their child either during or after death (Neidig and Dalgas-Pelish, 1991), a lack of privacy while their child was dying (Abib El Halal et al., 2013), and not receiving desired mementos, an outcome justified against miscommunication between families and clinicians (Widger and Picot, 2008).

This paper reports on one aspect of a larger study that examined nurses' experiences of caring for families when a child dies, and their preparedness to provide family centred end-of-life care (Bloomer et al., 2015). We describe the nurses' endeavours to create memories for families and facilitating families' interactions with the dying infant/child amidst the sadness and grief of the death of a child in paediatric and neonatal ICU.

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