



## Research paper

# Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and sources of discomfort. A mixed methods study



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## ARTICLE INFORMATION

## Article history:

Received 13 August 2014

Received in revised form

28 November 2014

Accepted 8 January 2015

## Keywords:

Neonatal intensive care unit (NICU)

Paediatric intensive care unit (PICU)

End of life care

Death

Dying

Linguistic Inquiry

Emotional talk

## ABSTRACT

**Background:** The majority of in-hospital deaths of children occur in paediatric and neonatal intensive care units. For nurses working in these settings, this can be a source of significant anxiety, discomfort and sense of failure.

**Objectives:** The objectives of this study were to explore how NICU/PICU nurses care for families before and after death; to explore the nurses' perspectives on their preparedness/ability to provide family care; and to determine the emotional content of language used by nurse participants.

**Methods:** Focus group and individual interviews were conducted with 22 registered nurses from neonatal and paediatric intensive care units of two major metropolitan hospitals in Australia. All data were audio recorded and transcribed verbatim. Transcripts were then analysed thematically and using Linguistic Inquiry to examine emotional content.

**Results:** Four core themes were identified: preparing for death; communication challenges; the nurse–family relationship and resilience of nurses. Findings suggested that continuing to provide aggressive treatment to a dying child/infant whilst simultaneously caring for the family caused discomfort and frustration for nurses. Nurses sometimes delayed death to allow families to prepare, as evidenced in the Linguistic Inquiry analysis, which enabled differentiation between types of emotional talk such as anger talk, anxiety talk and sadness talk. PICU nurses had significantly more anxiety talk ( $p = 0.018$ ) than NICU nurses.

**Conclusion:** This study provided rich insights into the experiences of nurses who are caring for dying children including the nurses' need to balance the often aggressive treatments with preparation of the family for the possibility of their child's death. There is some room for improvement in nurses' provision of anticipatory guidance, which encompasses effective and open communication, focussed on preparing families for the child's death.

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## 1. Background

Intensive care units (ICUs) are places where the critically ill receive technologically sophisticated care<sup>1,2</sup> and where the primary goal of therapy is to help patients, irrespective of their age, survive and recover from acute threats to their health.<sup>3</sup>

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Nevertheless, the mortality rate among patients in the ICU, including paediatric and neonatal intensive care (PICU and NICU), is higher than most other health care settings.<sup>4</sup> The majority of in-hospital deaths of children and infants take place in the ICU.<sup>5</sup>

For NICU and PICU nurses who are a constant presence at the bedside<sup>2</sup> the death of a child/infant is a critical event that is particularly challenging<sup>6</sup> and can be a source of significant anxiety, discomfort and sense of failure.<sup>7</sup> Nurses experience personal grief when a child or infant dies, and the bereavement experience can be long-lasting, painful and stressful.<sup>7</sup> This can be intensified if there is a lack of clarity around their role and responsibilities, or a sense that optimal end of life care was not provided.<sup>8</sup>

Nurses provide care for families of the child in the time leading up to the death and after the death; in adult ICU settings this is sometimes perceived as a burden due to competing priorities and demands.<sup>9</sup> Caring for families is an important component of clinicians' work; the relationships between staff and parents have been shown to impact on parental satisfaction with end of life care and to positively contribute to short and long term grieving in parents and family members.<sup>10</sup> For nurses, knowing what to say to parents, how to prepare them for an imminent death and supporting parents in their grief are important concerns.<sup>11</sup> Evidence from neonatal settings has shown that nurses can, however, feel inadequately prepared, educationally and emotionally, for their role.<sup>11,12</sup>

In other care settings, nurses have been found to use a number of coping mechanisms, including maintaining a professional distance and avoiding intimacy with the patient and family<sup>13</sup>; using euphemistic language such as 'passed away'<sup>14</sup>; and rationalising the death.<sup>15,16</sup> Nurses can make value judgements based on the social loss associated with the patient death. For example, an elderly patient's death can be justified in terms of their long life lived, or their having had a 'good innings'.<sup>14,16,17</sup> However, when a younger person, an infant or child dies, rationalising the death may be significantly harder and is regarded as an 'undeserved death'.<sup>17</sup>

Few studies have examined PICU and NICU nurses' experiences of death of an infant/child. What is known is that a nurse's attitude to death is constantly evolving with each new experience of death<sup>18</sup> and, while nurses accept that caring for dying patients is an inescapable part of their role, the death of a patient can lead to feelings of professional failure<sup>19</sup> and death anxiety<sup>20</sup> for nurses in a variety of settings. Death anxiety is a multi-dimensional construct related to fear of death and dying.<sup>20</sup> Previous studies in which healthcare workers reported their experiences with patients have revealed that different emotions are narrated when talking about different types of events.<sup>21,22</sup> For example, when discussing the care of dying patients in an acute hospital ward, nurses expressed frustration in needing to rely on subtly influencing doctors towards recognising a patient's likely dying, rather than feeling free to express their own opinion.<sup>21</sup> In another study, medical students used anger talk when narrating patient dignity and safety breaches by clinical teachers and sadness talk when narrating student abuse stories.<sup>22</sup> This paper reports on a study which examined how nurses talked about their experiences of caring for families when a child dies, and their preparedness to provide family centred end-of-life care.

## 2. Objectives

The objectives of this study were to explore how NICU/PICU nurses care for families before and after death; to explore the nurses' perspectives on their preparedness/ability to provide

family care; and to determine the emotional content of language used by nurse participants.

## 3. Method

This mixed methods study utilised focus groups and individual interviews to gather data on how NICU and PICU nurses care for families when a child/infant dies and how they perceive their ability and preparedness to provide family care. Where participants were willing to participate, but were not available at the times focus groups were scheduled, one-to-one interviews were conducted. All focus groups and interviews were audio recorded and transcribed verbatim.

## 4. Ethical considerations

Human Research Ethics Committee approval was obtained from each clinical site and Monash University.

## 5. Setting and sample

Twenty-two registered nurses from NICU ( $N=9$ ) and PICU ( $N=13$ ) settings in two Australian metropolitan hospitals participated in this study. Nurses were eligible to participate if they were employed as a Registered Nurse (RN), had at least one year of nursing experience in either NICU and/or PICU and had cared for at least one child/infant who had died in the NICU/PICU.

Initial contact was made with the Nurse Unit Managers from the 4 units, who then forwarded details of the study to their staff via Nursing staff were asked to determine their own suitability to participate in this study according to the inclusion criteria and make contact with the researchers to register their interest. Interview times and locations were negotiated via the Nurse Unit Managers following dissemination of an Explanatory Statement. At the time of meeting with the potential participants, the research and the Explanatory Statement were discussed and all questions answered. Written consent was then gained prior to commencement of the interviews.

## 6. Data collection

The focus group interviews utilised a semi-structured conversational approach, facilitated by the researcher to encourage communication and interaction amongst participants<sup>23</sup> about each nurse's preparedness, perception of their ability and experiences in providing care for the family before and after the death of a child. From the four participating units, 19 nurses participated in focus groups (of between 2 and 4 participants), and four were interviewed individually between November 2012 and January 2013 by one member of the research team who had experience with conducting focus group and individual interviews. The individual interviews were conducted utilising the same semi-structured conversational approach used in the focus group interviews.

In order to protect the anonymity of participants, once eligibility of individuals was determined prior to commencement of the interviews, no other demographic data was collected. The intent was to explore the experience and emotion as reflected by the participants at that time, irrespective of these other factors.

All interviews were conducted in a private, quiet space located within the health service workplace of participants, at a mutually agreeable time. Interviews lasted for between 17 min and 50 min. They were audio-taped and professionally transcribed for analysis.

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