



Original Article

'No second chance' – Junior neonatal nurses experiences of caring for an infant at the end-of-life and their family



Sharon Nurse, Msc., Bsc., RCNT, RM, RN, ENB704, Senior Lecturer (Midwifery)^{a,*}, Jayne Price, PhD, MSc. RSCN, RN, Associate Professor (Faculty of Health, Social Care and Education)^{b,1}

^a School of Nursing & Midwifery, Queen's University Belfast, Medical Biology Centre, 97 Lisburn Road, Belfast BT9 7BL, United Kingdom

^b Kingston University and St George's University London, Kingston upon Thames, Surrey, KT2 7LB, United Kingdom

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KEYWORDS

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Abstract Death of an infant is acutely stressful for parents and professionals. Little is known about junior nurses' experiences providing end-of-life care in Neonatal units (NNU). This study aimed to better understand junior nurses' experiences providing end-of-life care in NNU. Neonatal nurses (n = 12) with less than 3 years experience participated in a focus group. Nominal Group Technique (NGT) was used to build consensus around the challenges faced, alongside suggested developments in improving future care provision. Primary analysis involved successive rounds of ranking and decision-making whilst secondary analysis involved thematic analysis. All issues, whether environmental, professional or social appeared driven by an awareness on the part of nurses, that there was no 'second chance' which created a huge pressure to 'get it right' for the infants and families. Regarding future care 2

Abbreviations: E-o-l, End-of-life; NNU, Neonatal Unit; NICU, Neonatal Intensive Care Unit; NGT, Nominal group technique; PICU, Paediatric Intensive Care Unit.

* Corresponding author. Tel.: +1 2890 975836.

E-mail address: s.nurse@qub.ac.uk (S. Nurse).

¹ Tel.: +44 020 8417 5703, 07770536923 (mobile).

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areas of improvement identified were 'Education and Training' and Support. This paper unpacks these findings making recommendations for practice.
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Introduction

Estimates indicate over 80,000 babies in the UK are admitted to neonatal units each year ([Together for Short Lives \(TfSL\), 2013](#)). Whilst historically neonatal care has primarily focused on treatment, and survival, neonatal palliative care has evolved as an emerging speciality amidst a widening presence of life-limiting and life-threatening conditions in neonatal population ([Mancini et al., 2013](#)). Palliative care places emphasis on quality of life for babies with complex life-threatening and limiting conditions and their families prior to, during and after death, whenever or wherever that death may occur. Enhanced technology and care has attributed to a reduction of 20% in the number of babies who die in the neonatal period between 2000 and 2010 ([SANDS, 2012](#)). However, it still remains the case that approximately one in 300 babies dies in the first four weeks of life (write reference in full [CMACE, 2011](#)). Given the stress and difficulty associated with death of a baby ([Brosig et al., 2007](#); [Gold, 2007](#); [Kain, 2007, 2013](#)), Association for Children's Palliative Care [ACT \(2009\)](#) (now called Together for Short Lives (TfSL)) devised an integrated care pathway to support professionals caring for infants who have life-threatening or life-limiting conditions including end-of-life care. How much this is used is unclear.

Literature review

Across the literature it is evident that palliative and end-of-life care (e-o-l care) in the NNU remains a relatively new concept in neonatology. Much of the literature around neonatal palliative care focused on decision-making, ethical issues, parental involvement and nurses' attitudes with only a few studies exploring the actual anxieties of nursing staff and their education needs. [Zhang and Lane \(2013\)](#) support the theory that nursing and midwifery curricula are currently lacking in education on e-o-l care; these findings are supported by [Peng et al. \(2013\)](#) who state that current education provision to neonatal nurses does not meet their distinctive needs and indicate that the main areas requiring greater educational support. Numerous studies confirm inadequate educational and professional preparation for carrying out e-o-l

care ([Engler et al., 2004](#); [Contros et al., 2004](#); [Thompson and Hall, 2007](#); [Robertson et al., 2011](#)). The literature currently reinforces that caring for dying babies is a stressful and anxiety-provoking part of neonatal nursing ([Kain, 2013](#)). Evidence regarding professionals' experiences suggests lack of confidence in caring for infants at the e-o-l ([De Lisle-Porter and Podruchny, 2009](#); [Parker et al., 2013](#)). However, few studies depth, the challenges and reasons behind such challenges experienced by neonatal nurses involved in e-o-l care, particularly junior nurses. In order to redress such gaps in knowledge, the objectives of this study were to unpick experiences of junior neonatal nurses providing e-o-l care to babies, with the overall aim to provide suggestions as to how to improve their experiences and address their needs, thus improving care.

Method

Design

Since the study sought to explore junior neonatal nurses' experiences of providing e-o-l care for infants, qualitative methodology was considered appropriate ([Silverman, 2013](#)).

Data collection

Focus groups ($n = 2$), adopting the nominal group technique (NGT), were used to collect data from a purposive sample of neonatal nurses from a class of 17 neonatal nursing students enrolled on Short Course in Neonatal Studies within a Higher Education Institute (HEI) in part of the United Kingdom (UK). Representing 7 neonatal units, 12 students with less than 3-years experience within the specialism participated. Each focus group consisted of 6 participants with 2 facilitators. Ethical approval was granted from the relevant organisations.

NGT is 'a structured meeting which seeks to provide an orderly procedure for obtaining qualitative information from target groups most closely associated with a problem area' ([Van de Ven and Delbecq, 1972](#), p. 338). NGT can generate a high volume of ideas and solutions instantly, making it efficient and cost effective. It tends to avoid disproportionate contribution a common drawback

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