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

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 if right' for the infants and families. Regarding future care 2 areas of improvement identified were 'Education and Training' and Support. This paper unpacks these findings making recommendations for practice.

150 words

Key words:
End-of-life, infants, neonatal unit (NNU), anxieties, junior nurses

Abbreviations

E-o-l   End-of-life

NNU   Neonatal Unit

NICU   Neonatal Intensive Care Unit

NGT   Nominal group technique

PICU   Paediatric Intensive Care Unit

Acknowledgements

Introduction

Estimates indicate over 80,000 babies in the UK are admitted to neonatal units each year (Together for Short Lives (TfSL, 2015). 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, 2014). 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 – 2010 (SANDS, 2012). However, it still remains the case that approximately one in 300 babies dies in the first four weeks of life (CMACE, 2011). Given the stress and difficulty associated with death of a baby (Brosig et al, 2007; Gold, 2007; Kain, 2008; Kain, 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 & 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, 2009; Parker et al, 2013). However, few studies have explored in 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 of regular focus groups where, for example a group member dominates (Price et al., 2013). Therefore the NGT seemed highly appropriate for examining problems experienced by junior nurses providing EOL care in NNU. Two questions aligned with study aims were posed (see table 1). The same 5-stage NGT process (Lennon et al, 2012) (Table 2) was adopted in both focus groups. Initially, participants generated independently issues they considered significant in relation to caring for infants at the end-of-life and their families. These issues were then discussed in successive rounds of decision-making within an overall process of developing a professional consensus concerning priorities for care development (Price et al., 2013).

Table 1: Questions used in Focus Groups

Question 1	Question 2
Consider the challenges regarding your practice in relation to e-o-l care in the NNU?	In light of the challenges, consider opportunities for future development of this aspect of care?

Table 2: Focus group overview (Adapted from Lennon et al., 2012)

- Brief overview of Study/Aim. Introduction of nominal group process – written consent from those wishing to proceed
- Silent Generation: Participants to consider issues regarding their practice in relation to EOL.
- Round Robin: listing ideas
- Clarification Feedback and discussion of ideas (flip chart)
- Ranking Statements: ordering ideas (using stickers)
- Focus Group Reflection: Discussion final rankings
- Silent Generation: participants to consider in light of the challenges, opportunities for future development
- Round Robin: listing ideas
- Clarification Feedback and discussion of ideas on to a flip chart
- Ranking Statements: ordering ideas (using stickers)
- Focus Group Reflection: Discussion final rankings
- Conclusion, consensus and summing up

Data Analysis

Focus Group discussions were recorded (with consent) using a digi-recorder.

Primary data analysis focused on the issues and subsequent priorities for care

development as these were identified consensually according to rankings assigned by group participants. A further stream of analysis focused on discussions

accompanying prioritisation reached within each group. Such secondary analysis provided insight into the rationale underpinning issues identified and subsequent consensus.

Thematic analysis is frequently used in qualitative research (Green and Thorogood, 2009) and was performed by identifying commonalities through comparison of transcripts and outputs of both focus groups with one another. As a means of enhancing analytical rigour, analysis was undertaken by one researcher (SN), who subsequently discussed emerging analytical concepts with another (JP). Modifications were made as necessary based on their discussions.

Findings

Challenges caring for dying infants

A total of 13 challenges were identified, encompassing environmental, personal and professional issues (See table 3).

Whilst all 13 were classed as challenges, 3 top joint rankings across groupings emerged. Each challenge although distinct was interrelated. The highest ranking challenge related to nurses' concerns about lack of experience and confidence in caring for an infant at the EOL. Such a concern referenced the lack of opportunity often to provide this particular type of care and lack of experience in being able to identify when an infant's condition worsened, in turn impacted confidence. Whilst there was a palpable anxiety about caring for a dying infant and their family, most

nurses appeared willing to take on the challenge with suitable support and guidance, the fear escalated as many discussed the absence of the required support. Lack of experience seemed to feed into the joint 2nd ranked issues firstly the worry relating to their ability or lack of ability as they perceived it, to show empathy in a way that did not over step professional boundaries and also being able to involve families in an appropriate and meaningful way in care, which nurses recognised as important for bonding but also relating to memory making for the future. As well as concerns about lack of experience/confidence the third highest joint rank issue related to anxiety caused for the nurses by what they perceived as their own lack of knowledge regarding care and their need for support to combat this. Support identified included guidance from more senior staff or from for example a care pathway that would give them triggers to follow. Such guidance was seen a potent means of decreasing their anxiety and increasing confidence, a combination of which were viewed by these junior nurses as integral to quality e-o-l care.

Further professionally related challenges included navigating their way through the documentation, knowing what to say to parents, saying the wrong thing and the potential damage that could cause for parents both in the short and longer term. Whilst the junior nurses felt they lacked confidence they also believed that parents recognised this and veered towards the experienced nurses, which was recounted in the focus groups as further impacted their feelings of inadequacy. Interestingly, it was regularly discussed that within different units there were a few very experienced neonatal nurses that always took care of the infants who were e-o-l; this meant that no-one else got experience and staffing levels often meant that junior staff were unable to shadow senior colleagues and learn from their expertise. The longer a

junior nurse worked in NNU they felt more was expected of them, and their concomitant fear intensified as they felt the expectations on them was greater, but they still had not any experience in this as they viewed it, highly skilled, extremely important aspect of care. In addition, issues akin to the environment served as triggers for anxiety in terms of the noise and lack of privacy within a very clinical environment. On a personal level a fear existed about how to deal with their own emotional responses whilst remaining professional at all times.

Table 3: Combined group responses – Challenges

Comments:	Number of votes	Ranking
Lack of confidence and experience eg. identifying when the baby gets worse and what to do	11	1st
Scared of not providing the right kind of comfort measures for the dying baby and the baby suffering pain or other symptoms	9	=3rd
Being able to involve the family appropriately including making memories	10	=2nd
Being able to show empathy	10	=2nd
Parents may look more to senior staff in providing care	3	=6th
Managing own emotional responses	7	4th
Communicating with parents and letting them know what to expect	1	=8th
Lack of knowledge needing guidance the first time by senior staff or pathway	9	=3rd
Same staff always provide e-o-l care in NNU	1	=8th
Location of the dying baby within NNU – privacy lacking other options	2	7th
Saying the wrong thing	6	5th
Dealing with angry parents	No votes	

Lack of experience reporting and recording events- documentation	3	=6th

Taken as a whole from the challenges raised and discussion within groups, 3 key themes which were interrelated and one overarching theme arose. Junior nurses had real concerns about their perceived lack of experience, the associated competence and the underpinning knowledge. What appeared to link all three themes and challenges raised (overarching theme) was the overwhelming pressure and urgency associated with the awareness on the part of the nurses that there was no rehearsal or second chances with a baby at the end-of- life. For themes see table 4.

Table 4: Theme exploration

Theme	Explanation	Evidence from quotes
1. **Lack of knowledge**	This theme encompassed the very real fear of the junior nurses that they did not have the required knowledge to deliver EOL care, causing worry and anxiety. The lack of knowledge included aspects such as pain/symptom management for the baby, knowledge regarding signs of deterioration, documentation and after death care.	*"My priority is making sure the baby is comfortable but I'm not sure I would have the knowledge or confidence to do this properly."* *"I need to know what to do for the baby."* *"I'm not sure I would know how to involve parents in making memories of their baby."*
2. **Lack of experience**	These themes reflected a professional/ personal struggle in that junior nurses wanted experience of caring for dying babies but were fearful they would be left unsupported. There was a sense of that experienced nurses nearly had a monopoly on this aspect of care. Junior staff desired opportunities to learn about what they perceived as very 'specialised' neonatal care, however they would avoid it in case support was absent.	*"Parents pick up on our lack of experience and may want someone more senior to take over baby's care."* *"I have a fear of being upset in front of parents."* *'We don't get the opportunities to care for dying babies- senior nurses always get to do it in our unit."*

3. **Lack of Competence**	The perceived lack of competence in junior nurses was centrally linked to missed opportunities to gain experience working with babies at the end of life. Competence included meeting the babies' physical needs and also competence around sensitive and complex communication. Junior nurses feared that only with experience and the associated essential support would they develop the necessary competence to ensure best care.	*"I'm scared of missing any details in the documentation."* *"I'm afraid of seeming disconnected from the parents – not acting appropriately or saying the wrong thing at the wrong time."* *"I would want to balance 'being there' with not giving enough support."*

Future developments for care

Collectively, 9 initiatives for future development were identified across the focus groups (Table 5). Whilst each identified strategy was viewed as holding merit, 3 top ranked strategies were highlighted. Multiple opportunities for training and education, both externally and in-house held importance for junior nurses as well as crucially professional support. Viewed jointly as the most potentially valuable strategy was the belief that further in house training was required, such education was particularly around Trust policies and procedures relating to e-o-l care. Viewed as equally crucial was that a concerted effort was required to improve support of junior nurses in gaining experience where they could further learn and develop their existing knowledge skills in a very practical way. 'Buddying' a senior member of staff was seen as an opportunity, negating the possibility that if one day one of the senior staff who usually cared for dying babies was not present, one of them would be required to step in. Given the intense anxiety about lack of knowledge and experience it is not surprising that the use of a pathway or checklist was suggested as a potential solution offering staff a much needed sense of security. The 3rd ranked strategy was related to getting feedback from parents and was explored further in the ensuing

discussions. It was felt that taking on board the experience of previously bereaved parents would be important in shaping future care; in essence an evidence- based approach in which the views and experiences of service users was central. Such views might be as participants suggested come from research studies, parent groups, audits or letters from parents. Other suggestions included external courses on e-o-l care and bereavement follow up, parental options such as children's hospice, and information packs for junior staff, again similar to the pathway idea offering a point of reference when required. Debriefing was another support strategy that was identified as an important way for junior nurses to learn in terms of confidence and knowledge building, but also in addition enabling nurses with less experience to express their emotions and learn ways of managing emotional reactions

Table 5: Combined group responses – the way ahead

Comments	Number of stars awarded	Ranking
Use of Neonatal Palliative Care pathways /checklist	10	2nd
Educating staff about other options for place of death ie. Children's Hospice	4	=6th
More courses study days on management of EOL care (external)	3	7th
Trust In-house training sessions with senior staff including Informal teaching about managing emotional needs	15	= 1st
Courses on communication and bereavement support/follow up	4	=6th
Debriefing after the event with senior staff	6	5th
Information pack for junior staff – symptoms, care, supporting parents.	7	4th

A mentor/ buddying system to guide junior staff through the process.	15	= 1st
Being more aware of parental feedback	8	3rd

Therefore the discussion, the strategies suggested and ranked, gave rise to 2 interrelated themes which clearly housed all the strategies and offered solutions to enable junior nurses to decrease 'the pressure of getting it right' through an increase of knowledge, experience and competence. 'Appropriate support' and 'appropriate education and training' were viewed by the junior nurses as crucial mechanisms to assist in buffering the 'pressure' they experienced (see table 6).

Table 6: Theme exploration

Theme	Explanation	Evidence from Quotes
'Appropriate support'	The theme arose from a collection of suggested support strategies proposed. These strategies were varied enabled them to develop as they saw it much needed competence, knowledge and experience in a supportive environment.	"*It would be good to have the chance to talk through the experiences with senior nurses- to find out what we did well and what we did that wasn't so good so that we might learn from this.*"
'Appropriate education and training'	This theme rose from a collection of strategies which centred round the specific areas pertaining to EOL care where learning and training was viewed as crucial.	"*More teaching around symptoms and observations – knowing what to look for and how to respond.*" " *..... more feedback from parents after they leave the neonatal unit – it would be good to learn from what they have to say.*" "*We need more study days and more in-house training on an ongoing basis.*"

Strengths and Limitations of study

The study has generated valuable findings, adding to the limited research base and is in line with identified priorities for further research in the field of neonatal and children's palliative care (ACT, 2009). Having gathered valuable data from junior nurses, the relevance has been upheld given that some of the issues raised by the study participants have been mentioned in previous studies (Kain, 2006; Kain, 2013; Zang and Lane, 2013). Organisations who champion parental issues such as Tinylife and Bliss might welcome this data for producing literature for both families and staff in neonatal and children's hospitals.

Use of the NGT as a data collection tool presented both strengths and weaknesses to the study. Whilst data was collected and reviewed in only one session and gave every participant equal opportunity to express their views and opinions, it also had the potential to skew some of the findings, particularly during the discussion phase of the focus groups after the initial statements had been recorded.

The study took place in Northern Ireland and although the participants were representative of all of the neonatal units in this region, it is recognised that the views of the nurses and indeed the practices in this region may not be representative of other regions within the UK or internationally. The sample size was small given that only one cohort of students was involved signifying a limitation given the overall number of neonatal nurses in this region and throughout the UK; however, the sample did represent nurses from all neonatal units in this region, both small and tertiary.

Discussion and conclusion

Collective findings from junior nurses indicate that whilst there are many challenges caring for babies at the e-o-l and their families leading to intense fear and anxiety, they are willing to undertake such care if they have suitable support and education. The awareness of nurses even when junior, that the day a baby dies has a lasting impact on parents' bereavement and grief reactions, exacerbates the anxiety these nurses experience in the attempt to 'get it right'. It is clear from this study that the fear of caring for a dying baby can cause much work related stress and associated health problems.

Junior nurses who took part in this study made clear in the second part of the focus group their recommendations for the way ahead in terms of diminishing their existing fears and challenges (previous section and table 5 & 6). Moreover, they were cognisant of the fact that this aspect of care will always bring with it a degree of stress regardless of experience gained. Central to their recommendations was the key role of specialist training/education and support something that the current study highlights is often missing for junior nurses, as they felt such strategies would appear to buffer the pressure. These findings corroborate existing work which suggests that current education provision to neonatal nurses does not meet their distinctive needs and indicate that the main areas requiring more focused educational input (Peng et al, 2013). This is particularly worrying given that educated and knowledgeable neonatal nurses and quality e-o-l care have been highlighted as being inextricably linked to quality care (Moon Fai and Gordon Arthur, 2009). Thus clear implications for practice and education emanating from this study exist.

Whilst it may be seen that senior nurses are protecting their junior colleagues from the cold face of caring for a dying baby and their family, another interesting finding from this study would suggest that they in fact are doing a disservice to less experienced nurses whose fear would seem to heighten the longer they are 'shielded' from this particular group of babies. Nurse mangers of NNUs should therefore ensure 'buddying' is in- built in workforce planning and that attention is made to the skill mix particularly when a baby is nearing the end of life.

Whilst education/training was raised as a requirement both from internal and external sources, such a recommendation would endorse the stance of Mancini et al (2013) who suggest the relative merit of greater collaboration between education and service to develop curricula that enables the integration of education into everyday practice. A further recommendation based on the experiences of the junior nurses in this study is that evidence based *e-o-l education should be initiated within both undergraduate and continuing nursing and midwifery programmes in a clear and explicit way (Zhang and Lane, 2013), ensuring that the voice of parents is central to such teaching.*

This study explored the perceptions of junior neonatal nurses around the perceived strengths and weaknesses of their practice, specifically around providing e-o-l care to babies and their families. As well as gathering valuable data, the study went further to explore the participants' learning needs; in looking for a way forward, this study highlighted the current gaps in education and training provision and how these might be addressed in the future.

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