Anxieties of Junior Neonatal Nurses in providing end-of-life care in the NNU: a qualitative study

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Over 95,000 babies in the UK are admitted to neonatal units each year (Bliss, 2016).

In 2015 there were >4,400 extended perinatal deaths in the UK (MBBRACE-UK, 2015).

Neonatal Palliative Care has received increased recognition and undergone a number of key developments over recent years.

The complexities inherent in neonatal palliative care have made the headlines internationally over the last months.
End of life care for infants, children and young people with life-limiting conditions: planning and management

NICE guideline
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Practical guidance for the management of palliative care on neonatal units

1st Edition
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A Mancini, S Uthaya, C Beardsley, D Wood and N Moori

After Trump vows to help desperately sick boy, the Pope's hospital says: Let us take care of him

WORLD REACHES OUT TO CHARLIE
Is the NNU suitable for end-of-life care?

- Noisy, busy environment
- Is there flexibility in care provision and family involvement?
- Large staff numbers- continuity of carer?
- Neonatal nurses’ experience in e-o-l care?
- Collaboration with other disciplines?
Current literature reinforces that caring for dying babies is very stressful for neonatal nurses.

Much of the literature around neonatal palliative care focused on decision-making, ethical issues and parental involvement.

Evidence regarding professionals’ experiences suggests lack of confidence in caring for infants at the end of life (De Lisle-Porter, 2009; Parker et al, 2013).
Aim of the study

- Few studies explored the actual anxieties of nursing staff and their education needs.

- In order to redress such gaps in knowledge, this study explores the anxieties of junior neonatal nurses in providing e-o-l care and addresses their educational and professional needs.

- The ultimate aim to improve e-o-l care for the babies and families.
Methods

- Qualitative methodology was used.
- Ethical approval was granted.
- Focus groups (n=2), adopting the nominal group technique (NGT), were adopted to collect data from a purposive sample from a class of 17 neonatal nursing students.
- 12 students with less than 3 years experience within the specialism participated (from 7 Neonatal Units).
- Each focus group consisted of 6 participants with 2 facilitators.
Nominal Group Technique was used to collect data

Questions used in Focus Groups

- **Question 1**: Consider the challenges regarding your practice in relation to e-o-l care in the NNU?

- **Question 2**: In light of the challenges, consider opportunities for future development of this aspect of care?
Findings: Challenges in caring for dying infants

- A total of 13 challenges were identified, encompassing environmental, personal and professional issues.

Three main themes emerged:

1. **Lack of experience**: identifying when the baby gets worse and knowing what to do.

2. **Lack of competence**: being able to show empathy and involve the family appropriately including making memories.

3. **Lack of knowledge**: scared of not providing the right kind of comfort measures for the dying baby – needing guidance from senior nurses.
1. Lack of experience

- Inexperienced in identifying when an infant’s condition worsened - impacted on confidence.

- Palpable anxiety about caring for a dying infant and their family, but most nurses appeared willing to take on the challenge with suitable support and guidance.
Quotes from participants

“We don’t get the opportunities to care for dying babies- senior nurses always get to do it in our unit.”

“Parents pick up on our lack of experience and may want someone more senior to take over baby’s care.”

“I’m afraid of seeming disconnected from the parents – not acting appropriately or saying the wrong thing at the wrong time.”
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.
2. Lack of competence

- Lack of competence highlighted anxieties around:

  - their ability or lack of ability as they perceived it, to show empathy in a way that did not overstep professional boundaries
  - being unable to involve families in an appropriate and meaningful way in care
  - facilitating memory making for the future
“I would want to balance ‘being there’ with not giving enough support.”

“I’m not sure I would know how to involve parents in making memories of their baby.”
Discussion

- Competence included
  - meeting the babies’ physical needs
  - sensitive and complex communication with parents.

- Some junior nurses feared doing or saying the wrong thing or becoming upset in front of parents.

- A fear of being unable to assist parents in making memories and therefore impacting negatively on the grieving process later on.

- Junior nurses feared that only with experience and the associated essential support would they develop the necessary competence to ensure best care.
3. Lack of knowledge

- Anxiety caused for the nurses by what they perceived as their own lack of knowledge regarding care.

- Support included guidance from more senior staff or a care pathway that would give them triggers to follow.

- Such guidance was seen as a potent means of decreasing their anxiety and increasing confidence.
“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 scared of missing any details in the documentation.”
A very real fear was that they did not have the required knowledge to deliver e-o-l care, causing worry and anxiety.

The lack of knowledge included aspects such as:

- Pain and symptom management for the baby
- Knowledge regarding signs of deterioration
- Documentation
- After death care.
Future developments for care

Collectively, 9 initiatives for future development were identified across the focus groups.

Whilst each identified strategy was viewed as holding merit, the top 3 ranked strategies were highlighted as:

1. Multiple opportunities for training and education, both externally and in-house.
2. Improved 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.
3. Feedback from previously bereaved parents would be important in shaping future care.
Other suggestions:

- External courses on end-of-life care and bereavement follow up
- Information packs for junior staff offering a point of reference when required.

- Debriefing was another support strategy that was identified as an important issue for junior nurses:
  - to learn in terms of confidence and knowledge building.
  - enabling nurses with less experience to express their emotions.
  - to learn ways of managing emotional reactions.
The way forward?

- The discussion and the strategies suggested, 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’.

- ‘Appropriate support’ and ‘appropriate education and training’ were viewed by the junior nurses as crucial mechanisms to assist in buffering the ‘pressure’ they experienced.
“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.”
This theme arose from a collection of suggested support strategies proposed.

These strategies were varied enabling them to develop much needed competence, knowledge and experience in a supportive environment.
“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.”
Appropriate education

- Education and training was viewed as crucial, whether it be in-house or from external sources.

- Research suggests that current education provision to neonatal nurses does not meet their distinctive needs and suggests more focused educational input (Peng et al, 2013).

- More education around alternatives to dying in the NNU such as Children’s Hospice.
Conclusions

- Collective findings indicate many challenges caring for babies at the e-o-l and their families leading to intense fear and anxiety.

- 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’.

- Fear of caring for a dying baby can cause much work related stress and associated health problems.
Recommendations (from the nurses)

- The voice of parents should be central to all teaching.
- Specialist training/education and support
- Nurse managers should ensure ‘buddying’ is considered in workforce planning and that attention is given to the skills mix - particularly when a baby is nearing the end of life.
- Greater collaboration between education and service to develop curricula that integrates education into everyday practice.
- Availing of expertise from sources such as Children's Hospice
This study:

- Enabled the often unheard voice of junior members of the nursing staff in the NNU to be heard.

- As well as gathering valuable data, 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.
Further research

Ongoing education and support (across professions)

More Collaborative working (options for families)
The Neonatal students in the School of Nursing & Midwifery, QUB: September 2015 cohort who gave of their time to participate in this study.

Dr. Kevin Hugill (MSC supervisor) University of Central Lancashire
Discussion – your thoughts?
References


