© 2020 SNL All rights reserved

Supporting doctors to deliver paediatric palliative care on neonatal units: the development of a curriculum

Newly qualified neonatologists are required to confidently deliver excellence in communication, decision making and end of life care for neonates with palliative care needs. This study assesses perceived confidence of neonatal subspecialty trainees in delivering palliative care and reports the development of a regionally applicable curriculum to structure training, governance and palliative care team integration into neonatal units across Wales. This study is the first to generate a palliative care curriculum based on learning needs analysis specifically for neonatologists.

Timothy Warlow [1,2]
MBChB, BMedSc
Senior Registrar in Paediatric Palliative Medicine
twarlow@doctors.org.uk

Rebekka Jones [3]
Dr.med.univ (Austria)
Consultant in Neonatal Medicine

Jo Griffiths [1,4]
MBChB, DipPallMed(Paeds)
Consultant in Paediatric Palliative Medicine and Community Child Health

[1]All Wales Managed Clinical Network
[2]Ty Hafan Children's Hospice, Sully, Wales
[3]Neonatal Intensive Care Unit, University Hospital of Wales, Cardiff
[4]Swansea Bay University Health Board, Wales

Keywords

neonatology; palliative care; hospice; curriculum; competency-based education

Key points

Warlow T., Jones R., Griffiths J. Supporting doctors to deliver paediatric palliative care on neonatal units: the development of a curriculum. *Infant* 2020; 16(4): 142-45.

1. There is a need for formal training in palliative care for neonatal professionals.
2. Confidence in neonatal palliative care competency domains was assessed by electronic survey of neonatal subspecialty trainees.
3. The resulting data were used to develop the All Wales Neonatal Palliative Care Curriculum.

Deaths in the neonatal period account for 40% of all child deaths under 16 years of age.[1] The need for early recognition of infants with palliative care needs, excellence in communication and decision making, and quality end of life provision on neonatal units is now recognised in national standards for neonatal care.[2,3] Despite this, senior neonatal trainees feel unprepared for the challenges of decision making and caring for the dying child and their family.[4] Neonatal and paediatric palliative care (PPC) networks in Wales are experiencing a period of rapid integration. This mirrors similar situations across the world as the specialty expands and neonatal teams care for increasingly complex infants. An educational curriculum can provide structure on which to base key knowledge and experience, benchmark competence and foster greater service integration to drive up the quality of care for infants with palliative care needs.[5] Previous learning needs analyses of multi-professional neonatal staff have identified that communication skills and managing practicalities such as post mortem and organ donation are key areas for learning development.[4,5] This is the first study to focus on trainees undertaking a dedicated career course in neonatal medicine.

Aims

1. To assess perceived confidence of neonatal specialty trainees in delivering

- Understanding which neonates might benefit from paediatric palliative care
- Introducing palliative care to families of neonates for whom the prognosis is uncertain
- Leading conversations regarding withdrawing and withholding life sustaining treatment
- Referral to palliative care services for end of life care on neonatal units
- Ethical decision making
- Legal framework around decision making and death and dying
- Managing pain and other symptoms
- Organisation of transfer for end of life care to home or hospice
- Conducting compassionate extubation
- Death certification
- Discussing organ donation
- Discussing post mortem and consent
- Referral to coroner
- Understanding the scope of local community palliative care services, eg hospice, community nursing support
- Supporting staff after the death of a neonate

FIGURE 1 Key competency domains for neonatal palliative care.

Area of competence	Not confident at all (%)	Some understanding but would require support (%)	Relatively confident (%)	Confident under most circumstances (%)	Very confident (%)	Weighted mean average
Leading conversations regarding withdrawing and withholding life-sustaining treatment	7.6	43.4	28.3	18.9	1.9	2.54
Introducing palliative care to families of neonates for whom their prognosis is uncertain	5.7	47.2	28.3	17	1.9	2.62
Referral to palliative care services for end of life care on NICU	5.7	37.7	35.9	18.9	1.9	2.74
Understanding which neonates might benefit from paediatric palliative care	0	24.5	39.6	35.9	0	3.11
Ethical decision making	3.8	50.9	35.9	9.4	0	2.51
Legal framework around decision making and death and dying	7.6	49.1	28.3	15.1	0	2.51
Managing pain and other symptoms	3.8	39.6	39.6	17	0	2.7
Organisation of transfer for end of life care to home or hospice	18.8	37.7	34	7.6	1.9	2.36
Conducting compassionate extubation	9.6	30.8	21.2	30.8	7.7	2.95
Death certification	7.6	30.2	28.3	30.2	3.8	2.92
Discussing organ donation	26.4	47.2	17	7.6	1.9	2.11
Discussing post mortem and consent	16.9	30.2	32.1	20.8	0	2.57
Referral to coroner	5.7	39.6	28.3	26.4	0	2.75
Supporting staff after the death of a neonate	7.6	45.3	20.8	26.4	0	2.66
Understanding the scope of local community palliative care services, eg hospice, community nursing support	9.4	26.4	28.3	32.1	3.8	2.94

TABLE 1 Perceived confidence in key domains of neonatal palliative care among neonatal subspecialty trainees in the UK.

paediatric palliative care on neonatal units.

2. To develop a neonatal palliative care curriculum to structure learning and governance projects and strengthen integration between neonatal and paediatric palliative care specialties.

Methods

Competency domains for newly qualified neonatologists relating to neonatal palliative care were generated by the study team from review of existing training curricula and published multi-professional learning needs analyses of neonatal staff. Items were agreed by the study team including a PPC consultant and registrar, and a neonatologist, in broader consultation with a team of experienced paediatric palliative care specialist nurses. These competencies were used to develop a learning needs analysis questionnaire sent electronically to all neonatal subspecialty trainees in the UK in April 2019, (approximately 120), with two reminders sent in May and June 2019. Perceived confidence in each competency domain was rated 1-5 on Likert scales. A comprehensive list of curriculum items was developed from the survey results and agreed by both the All Wales Paediatric Palliative Care Team and the Welsh Neonatal Network to act as a structure for ongoing education, integration and governance initiatives. This study was discussed with the Cardiff and Vale Research Ethics Committee who decided that, as this project was part of a quality improvement initiative within neonatal care, no formal ethical approval was required.

Results

The current Association for Paediatric Palliative Medicine (APPM) level two curriculum identifies key skills, knowledge and attitudes required of a training paediatrician in general paediatrics, much of which is transferrable to neonatologists.[6] There is limited mention of palliative care competencies in the current national neonatal curriculum in the UK.[7,8] The study team generated the following key competency domains for trainee neonatologists, which remain consistent with both PPC and neonatal training curricula (**FIGURE 1**).

We received 53 survey responses from a total of approximately 120 neonatal trainees across the UK. Perceived confidence in the key competency domains is demonstrated in **TABLE 1**.

On average, trainees self-reported some understanding of all the competency domains but would require additional support to provide good care. Confidence increased with seniority. There was a broad spectrum of confidence across most domains. Broad PPC concepts perceived as well understood included appreciation

of the scope of PPC services and ability to identify neonates who might benefit from PPC support. This is perhaps a reflection of the recent development of national guidance for end of life care in children and results from a 2018 national audit of bereavement care provision by the charity Bliss. There is also rapid expansion of paediatric palliative care services in the UK, with improving integration into many of the regional training programmes for paediatric trainees.[3]

Less than 8% of trainees were 'very confident' in any of the domains, and for seven of the 15 domains, no trainees were very confident. Trainees were least confident in ethical and legal issues, and leading conversations about withdrawing and withholding life-sustaining treatment. This corroborates similar studies of multi-professional neonatal staff. These are very complex areas and typically taught in abstract terms that are difficult for trainees to conceptualise.[9,10] Low confidence was reported for specific discussions around organ donation, post mortem examination and organising transfer for end of life care at home or hospice. This emphasises the importance of training in communication skills to ensure optimal delivery of these discussions, as well as ensuring locally applicable information is available to trainees with regards to organ donation, post mortem procedure, and community palliative care and hospice provision. These results highlight the need for adaptation of education interventions to reflect the current level of integration of PPC on neonatal units, as well as local and national PPC provision, which varies widely between regions even within the UK.

APPENDIX 1 shows the curriculum generated from the competency domains and learning needs analysis. Extensive discussions within PPC and neonatal teams led to additional items relating to referral for psychosocial support for families and the need to consider antenatal cases. These were incorporated into the final curriculum selection.

Discussion

Trainee neonatologists report wide variation in confidence when managing palliative care in their patient population. Key areas of low confidence include developing a practical approach to more complex discussions with families around ethical and legal issues, as well as managing practicalities at the end of life in the context of local palliative care and community provision. There is currently limited comprehensive guidance for trainees in neonatology on expected competencies relating to neonatal palliative care. The importance of adapting competencies to local need, current palliative care team integration and local palliative care services including hospice provision is emphasised in this study. The resulting joint curriculum provides a locally agreed and applicable framework for directing further service integration and education between regional neonatal units and regional PPC teams. In Wales, we have developed joint guidance for transfer of neonates to hospice care for extubation and are developing national training days to address learning needs identified in this study.

This study provides valuable insight into training needs of future neonatologists in identifying the key areas to target for training and service development. This simple questionnaire design and collaborative working between teams represents an easily replicated process for other teams wishing to improve confidence of their neonatologists in providing palliative care. Limitations include a small sample size and the risk of responder bias with those particularly interested in the area more likely to respond to questionnaire requests. The addition of focus groups or interviews to explore the complex barriers and facilitators to newly qualified neonatal consultants providing palliative care would provide a rich data source and be a valuable next step in optimising training in this area.

Conclusions

The key points arising from this study are summarised in **FIGURE 2**.

- There is increasing recognition of the need for formal training in palliative care for neonatal professionals
- Only 8% of neonatal trainees were 'very confident' in any of the 15 neonatal palliative care competency domains
- Trainees are confident in identifying neonates who might benefit from palliative care support and understanding the scope of that support
- Training should focus on managing ethical and legal issues relating to the end of life, leading discussions on withdrawal of life sustaining treatment, organ donation and post mortem examination
- Curricula such as the one presented in this article should be adapted to take into account existing palliative and neonatal services in the community as well as the current state of integration of palliative care and neonatal teams and networks
- Generation of a regionally applicable joint curriculum may facilitate closer collaboration of neonatal teams and paediatric palliative care teams, providing a structure for education and governance interventions

FIGURE 2 The key points from this study.

Acknowledgements and funding

The authors would like to thank the team of paediatric palliative care specialist nurses in the All Wales Paediatric Palliative Care Team and from Ty Hafan Children's hospice, for their discussion and feedback in the development of the final curriculum items.

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. **Office for National Statistics.** Child and infant mortality in England and Wales [cited 2019 May 18]. Online at: www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2016
2. **Together for Short Lives.** A perinatal pathway for babies with palliative care needs. 2017 online at: www.togetherforshortlives.org.uk
3. **National Institute for Health and Care Excellence.** End of life care for infants, children and young people with life-limiting conditions: planning and management. Online at: www.nice.org.uk/guidance/ng61
4. **Gallagher K, Cass H, Black R, Norridge M.** A training needs analysis of neonatal and paediatric health-care staff in a tertiary children's hospital. Int J Palliat Nurs 2012;18:197-201.
5. **Harris LL, Placencia FX, Arnold JL, et al.** A structured end-of-life curriculum for neonatal-perinatal postdoctoral fellows. Am J Hosp Palliat Med 2015;32:253-61.
6. **Association for Paediatric Palliative Medicine, Paediatric Palliative Medicine College Specialty Advisory Committee.** Curriculum in paediatric palliative medicine. 2015.

7. **Royal College of Paediatrics and Child Health.** Neonatal medicine syllabus. Level 3 paediatric sub-specialty syllabus. 2018.
8. **Royal College of Paediatrics and Child Health.** Neonatal medicine - aligned framework for neonatal training - amended 2015. 2015.
9. **Larcher V, Craig F, Bhogal K, et al.** Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. Arch Dis Child 2015;100(Suppl2):s1-23.
10. **Bluebond-Langner M, Hargrave D, Henderson EM, Langner R.** I have to live with the decisions I make: laying a foundation for decision making for children with life-limiting conditions and life-threatening illnesses. Arch Dis Child 2017;102:468-71.

End of life care:

- Recognise signs of deterioration towards the end of life.
- Assess and manage pain in infants with life limiting conditions recognising the need to address the physical, psychosocial and spiritual aspects of any pain experienced.
- Confidently use validated neonatal pain measurement scales, understanding their limitations.
- Manage the following symptoms at the end of life: pain, dyspnoea, seizures, vomiting, cerebral irritation, anxiety/distress.
- Understand the benefits and limitations of subcutaneous, transdermal, rectal, transmucosal and intranasal routes of administration of medications at the end of life.
- Initiate, titrate, maintain and review opioid therapy in infants of various gestations who are opioid naive and already on opioids. Be aware of side effects.
- Be able to calculate opioid conversions by different routes.
- Understand the importance of using adjuvant medications for pain alongside analgesics.
- Be able to use the Association of Paediatric Palliative Medicine Formulary in prescribing medications for end of life care.
- Manage symptoms associated with palliative care emergencies: airway obstruction, rapid escalation of pain, catastrophic haemorrhage, status epilepticus.
- Be able to organise hospice or home transfer for end of life.
- Conduct compassionate extubation/removal of non-invasive ventilation, taking into account hydration, nutrition, symptoms and plans in case of ongoing survival.
- Understand the issues relating to care of the body after death.
- Complete death verification, certification and notification processes, understanding the role of the child death review and child death overview panel.

Communication:

- Be able to confidently introduce and discuss palliative care prognosis with families (breaking bad news).
- Conduct antenatal counselling for parents regarding high risk pregnancies and palliative care for possible lethal/severe foetal anomalies.
- Discuss withdrawing/withholding life sustaining treatment including do not resuscitate decisions.
- Understand the needs of siblings of a dying infant including talking to them about an infant's prognosis.
- Understand how siblings of various ages understand death and express grief.
- Counsel bereaved families.
- Understand the physical, psychosocial and spiritual dimensions of grief.
- Describe strategies for supporting staff through challenging cases, being aware of staff support services available.
- Conduct debriefs with staff following deaths on NICU.

Advanced care planning:

- Recognise physical, psychosocial, spiritual, cultural and practical issues for infants with life limiting conditions.
- Create parallel plans where prognostic uncertainty exists.
- Create end of life plans with families including place of death, wishes before, at time of and after death.
- Be familiar with documentation for advanced care planning and have used the All Wales Paediatric Advanced Care Plan with families.
- Discuss organ donation with families and be aware of local processes for involving organ donation teams.
- Be able to consent and explain the benefits and process of post mortem examination to families. Be aware of local processes for referring to the coroner's office.
- Be able to explore spiritual/existential issues such as grief, anger and sadness with families.
- Be able to explore psychosocial issues with families and identify available support (both informal and formal service provision). Be able to refer to appropriate specialists when required.
- Understanding the issues of last rites and particular funeral practices of common religions, eg Christianity, Judaism, Islam, Hinduism, Sikhism, Buddhism.

Decision making:

- Participate in MDT discussions facilitating ethical decision making with professionals and families.
- Be aware of ethical principles relating to palliative care from utilitarianism, deontology, and virtue ethics.
- Understand the concept of 'best interest decision making', demonstrating the ability to apply Beauchamp and Childress Four Principals approach to ethically challenging clinical cases.
- Understand UK law and guidance relating to withholding and withdrawing life sustaining treatment, hydration and nutrition.
- Be able to explain the issues surrounding the benefits and burdens of artificial nutrition and hydration at the end of life.
- Understand legal and ethical issues around euthanasia and infanticide.
- Describe strategies for conflict resolution between medical team and family including mediation, the role of ethics committees and seeking legal advice.
- Describe strategies for addressing moral distress within the team (disagreements, tensions, distress around direction of care and best interest decisions).

Other:

- Understand which infants may benefit from palliative care support, including antenatal referrals.
- Understand the distinction between palliative and end-of-life care.
- Be familiar with Royal College of Paediatrics and Child Health and Together for Short Lives guidance on the management of infants with palliative care needs.
- Be aware of community palliative care services available to patients and family.
- Understand the role of the Paediatric Palliative Care (PPC) Team and hospice team in caring for infants with life limiting conditions.
- Be aware of different models of PPC service and integration between neonatal units and community neonatal and paediatric teams.
- Demonstrate insight into personal impact of working with families of infants with palliative care needs, being able to explore own coping mechanisms and recognise signs of fatigue/burnout.

APPENDIX 1 The final All Wales Neonatal Palliative Care Curriculum.