

Title

Paediatric palliative care in the NICU: a new era of integration

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Abstract

We are entering a new era of integration between neonatal medicine and paediatric palliative care, with increasing recognition that the role and skills of palliative care extend beyond care of only the terminally ill infant. This paper addresses the principles of paediatric palliative care and how they apply in the NICU, considers who provides palliative care in this setting and outlines the key components of care. We consider how the international standards of palliative care pertain to neonatal medicine and how a fully integrated approach to care may be realised across these two disciplines.

Palliative care is so much more than end-of-life care, offering a proactive and holistic approach which addresses the physical, emotional, spiritual and social needs of the infant and family. This is a truly interdisciplinary endeavour, relying on a harmonisation of the skills from both the neonatal and palliative care teams to deliver high-quality coordinated care.

Key words

Neonatal
Neonatal intensive care unit
Palliative care
Perinatal

1. Introduction

Paediatric Palliative Care (PPC) has developed into a distinct paediatric subspecialty since its origins in the 1980s and is now recognised as a structured multidimensional approach to the care of children and young people with life-limiting conditions ^{1,2}. The integration of a fully holistic and interdisciplinary model of palliative care into neonatal care has arguably been varied and slow to come to fruition. Only now are we beginning to witness a new era of integration between neonatal medicine and palliative care. This brings together highly experienced professionals from different disciplines, who independently possess some of the most nuanced skills in the management of society's most vulnerable patients. Indeed neonatal teams are well versed in the overall management of infants with life-limiting conditions and in applying highly technical solutions to the care of a complex patient population with comparatively high mortality rates ³. These skills are complemented by those of palliative care teams who bring expertise in complex symptom management, advance care planning, family support, and end of life and bereavement care.

As well as an appreciation that many infants on the Neonatal Intensive Care Unit (NICU) can benefit from a palliative care approach ⁴⁻⁶, there is now an increasing understanding that families value palliative care support even before an infant is born, when a life-limiting or potentially life-limiting condition is diagnosed during fetal life ⁷⁻⁹. The provision of palliative care throughout the perinatal period, commonly referred to as perinatal palliative care, allows for emotional, social, and functional support of pregnant persons and their families and provides a continuum of care from pregnancy through delivery and beyond. Perinatal palliative care support includes helping the parents and the medical teams to anticipate

possible outcomes, often in a context of uncertainty, in order to make decisions and plan for an infant's future care.

2. Principles of Paediatric Palliative Care

The World Health Organisation (WHO) defines palliative care for children as follows:

“the active total care of the child's body, mind and spirit and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.”¹⁰

This definition encapsulates two of the core principles of palliative care for children, the fact that is an active and total approach and the fact that it should begin early and irrespective of disease-directed treatment. We will consider how these two core principles apply to palliative medicine in the NICU.

2.1. An active and total approach to care

Whilst in the past, palliative care has frequently been equated with end-of-life care alone, we now appreciate its potential to benefit children and families at all stages of the illness trajectory. It involves actively anticipating and addressing potential symptoms and managing these with a combination of both pharmacological and non-pharmacological techniques. This aligns with recent advances in neonatal pain management, which have also taken an active and anticipatory approach, recognising that frequent objective assessment of pain on the NICU and proactive management of procedural pain should be a priority^{11,12}. Pain is,

however, only one aspect of symptom management and a total approach involves addressing all of the symptoms an infant may be experiencing.

PPC is total care and as such embraces physical, emotional, social, and spiritual elements, and focuses on enhancing quality-of-life for the child ¹³. This holistic conception of the child requires that care goes beyond medical interventions and symptom management and embraces the entire family (including siblings and grandparents).

The majority of deaths on neonatal units occur after a planned withdrawal of life-sustaining support ¹⁴. This provides an opportunity for planning and reflection with families, and a time to ensure that support and care is enhanced rather than 'withdrawn'. Families deserve to know that whether curative treatment is possible or not, there remains an overriding commitment to treatment and to caring for their infant ¹⁵: total care throughout the illness trajectory. The approach to care remains active at all times; whilst life-sustaining support may be withdrawn, care itself must never be.

2.2. Care that begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease

Many families with an infant in the NICU face the possibility of a prolonged admission with multiple procedures, accompanied by periods of apprehension and uncertainty. Introducing palliative care at the time of diagnosis or recognition of a potentially life-limiting condition allows for care to be delivered in tandem with therapies directed at curing or improving an infant's condition; if the infant's condition deteriorates it also allows parents time to feel

prepared for the circumstances around their child’s death. Importantly, evidence suggests that parents embrace this approach and do not conceptualise cure-directed care and symptom-directed care as mutually exclusive or alternative approaches ¹⁶.

PPC specialists work within a framework known as parallel planning – planning for life while also planning for potential deterioration or death ¹⁷ – which allows families to be prepared for the worst possible outcome but also simultaneously focused on plans for if their infant survives. An infant does not have to be facing certain death to benefit from a period of support from palliative care services and may later be discharged from their care if the infant’s condition stabilises or improves.

Broadly speaking there are four categories of paediatric conditions that may benefit from palliative care as illustrated in Table 1. All of these groups of conditions can be exemplified by patients routinely cared for in the NICU.

Table 1: Groups of conditions that may benefit from palliative care as defined by Together for Short Lives, a UK charity ¹⁸

<p>Group 1</p>	<p>Life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. There may be acute crises where palliative care input is required, but on reaching long-term remission or following a successful curative treatment, palliative care services are no longer needed.</p> <p><i>Examples may include: extreme prematurity, severe necrotising enterocolitis, congenital heart disease</i></p>
<p>Group 2</p>	<p>Conditions where premature death is inevitable. Includes conditions requiring long periods of intensive care aimed at prolonging life and allowing participation in normal childhood activities.</p>

	<i>Examples may include: chromosomal abnormality, bilateral multi-cystic dysplastic kidneys, bilateral renal agenesis</i>
Group 3	<p>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples may include: skeletal dysplasia, severe neuromuscular disorders</i></p>
Group 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p><i>Examples may include: severe hypoxic ischaemic encephalopathy</i></p>

Improvements in fetal imaging and prenatal diagnostics have led to a growing number of life-limiting conditions being diagnosed before birth, with families increasingly being referred for palliative care support antenatally. This allows an opportunity to make birth plans which honour the families' wishes and may include plans for mode of delivery, fetal monitoring and goals of care for the infant's management ^{19,20}. This type of care planning often involves preparing for a range of potential outcomes (if, for example, the infant's diagnosis requires postnatal confirmation or if the infant's condition at birth is difficult to predict) and requires close collaboration between obstetric, fetal medicine, neonatal and palliative care teams.

3. Who delivers palliative care?

Palliative care need not always be delivered by specialist teams; rather it provides a structured way of delivering appropriate clinical care in a more holistic and supportive way. Upholding the principles of palliative care is the responsibility of all healthcare professionals who care for children with life limiting or life-threatening conditions regardless of where they

are being cared for. Core palliative care skills exist in most neonatal and paediatric teams, in community paediatric and community nursing teams, in children's hospices and in general practice/family medicine. Specialist palliative care is usually provided by a multidisciplinary team of healthcare professionals with expertise in complex symptom management, advance care planning and bereavement support and will compliment, but not replace, the core skills delivered by other healthcare professionals.

Delivering good quality palliative care in the NICU is largely dependent on the skills and compassion of frontline neonatal staff. Good communication is at the core of providing high quality care to families and when done well it can help parents to feel more able to deal with difficult information ²¹. Families remember how health care professionals communicate with them and it is often the style of that communication (rather than the content itself), and the compassion that accompanies it, that can have a profound and lasting impact ²². For critically unwell neonates in the NICU, communication may involve having difficult conversations and making complex decisions about an infant's care. Neonatologists should approach decision-making in a way that engages parent participation and allows for exploration of parental values ²³. Even when death is inevitable it is possible to make choices about how death is managed that align with parental values.

A qualitative study which focused on the experiences of mothers whose infant had died as a newborn found that physical contact with their infant was of paramount importance, as was being treated as a parent and given the opportunity to fulfil their role as such ²⁴. Neonatal teams play a fundamental part in supporting and empowering parents to have an active role in providing care for their infant wherever possible, and in maximising opportunities for

contact both before and after the death of an infant. The same study highlighted the profoundly positive psychological impact for parents when they receive sensitive and responsive care and when they feel 'heard' by health care professionals ²⁴.

In an intensive care setting (either NICU or PICU) professionals are more likely to cite the fact that the patient's prognosis is uncertain as a reason not to refer to palliative care ²⁵ but this uncertainty should not preclude early referral. Specialist palliative care teams can complement the care provided by neonatal teams and provide additional expertise, support and access to services beyond the NICU. In all cases early referral to a specialist PPC team allows families to develop a relationship with the team, not based purely on planning for an inevitable death, and enables discussion regarding which components of palliative care are most suitable for a given patient at any one time. The extent to which specialist palliative care services are required may vary and fluctuate over time, and, as noted earlier, it is not unusual (or problematic) for a patient to be discharged from specialist palliative care if their input is no longer required.

Models of service delivery will vary widely but consultant-led PPC teams are typically found within tertiary hospitals or based within a children's hospice or a community team ²⁶. Specialist palliative care teams will usually be able to deliver care across settings and provide support in hospitals, in children's hospices, and at home.

4. Components of palliative care

- *Symptom Management*

Neonates with a life-limiting or life-threatening illness may experience a wide range of symptoms including pain, breathlessness, agitation, seizures, and feeding intolerance. Whilst neonatal teams will have expertise in managing all of these symptoms, palliative care teams may be able to advise on alternative and novel approaches to management, particularly when symptoms are refractory to standard treatment and when the goals of treatment may be shifting towards a focus on comfort and quality of life.

- *Advance care planning*

Paediatric advance care planning is a simple, structured way of facilitating decision-making and provides a framework for healthcare professionals, patients, and their families to document and reflect on discussions about what might happen in the future. Discussions may address preferred place of care and place of death, organ and tissue donation, management of life-threatening events (including plans for resuscitative efforts or life support) or specific wishes, for example around funeral arrangements or spiritual care at the time of birth and/or death²⁷. Importantly, having an Advance Care Plan in place can help to ensure that teams are mobilised to deliver care with an individually tailored approach.

Advance care planning is particularly useful for the increasing numbers of families who receive a diagnosis of a life-limiting fetal condition before birth but where there may still be significant prognostic uncertainty. Having pre-emptive discussions which take into account multiple possible scenarios after birth can ensure that the postnatal care delivered is both clinically and ethically sound and reflects a family's wishes for their infant's care. It may, for example, include making plans for disease-directed interventions alongside plans for symptom-directed care if, after birth, the former is deemed impossible.

- *Coordination of care*

One of the ambitions of PPC is to ensure that children receive palliative care, including end of life care, in the place that they, or their family, choose. In practice, however, neonates are far more likely to die in a hospital setting, with some series showing up to 97% of infants <28 days old dying in hospital ²⁸.

As palliative care teams out-reach across many settings, they can play a valuable role in discharge planning and on-going care-coordination and can often help facilitate transfer home, to a children's hospice or to another hospital closer to home. Whilst there can be practical reasons why a family's preferred place of care or place of death cannot be achieved, exploring the options available is important. Professional assumptions about what a family will want should not limit the choices available ²⁹.

- *Family support*

Holistic, family-centered care involves caring for the family as a whole, whilst honouring the needs of individual family members. While parents are often the main point of contact for an unwell infant in the NICU, understanding the needs of the extended family, including siblings and grandparents, is critical. Parents may require specific guidance and support to convey information about their infant's condition to family members.

All family members will benefit from access to emotional, spiritual, and practical support which may be provided both in the hospital setting and via community-based resources. Siblings and grandparents of infants admitted to the NICU will be emotionally impacted by

the infant's condition, as well as the effects of the parents' or caregivers' distress, and require targeted psychological support.

- *Bereavement support*

Staff who were involved in the care of an infant who has died can be a great source of support to bereaved parents. Both families and staff attest to the value of continuing relationships after an infant's death and of creating tangible keepsake memories when the infant is in NICU³⁰. Specialist psychology support including bereavement support is available within most specialist PPC services, for both professionals and families.

Parents may have specific wishes for family members to meet their infant either before or after death. Even where siblings of an infant on the NICU may have limited direct contact with their brother or sister during admission it can be helpful to involve them in memory-making and bereavement activities^{31,32}. Additional support may be available via professionals such as Family Support Workers or Child Life Specialists, and most children's hospices run programmes of activities for the siblings of children with life-limiting illnesses, and/or for bereaved siblings.

- *After death care*

An often under-recognised role of nurses in the NICU is the crucial part they play in the care of their patients after death. As well as the physical care of the body, neonatal nurses may be involved with the facilitation of memory-focused activities or 'legacy building' which can support families in their bereavement through the construction of social identities for both

infant and parent ³³. Where available, some families may also wish to explore the option of taking their infant home or to a hospice after death with the support of cooling facilities. Cooling facilities may include the use of 'cold bedrooms' as well as portable, electric-powered cooling blankets, mattresses and cots which act to cool the body, thus slowing its physical deterioration, and allowing an extended period (usually a few days) in which parents can freely spend time with their child ³⁴. This has been shown to offer comfort in both the early days of grieving and influence longer-term bereavement outcomes for families ³⁵.

5. International Standards

Globally 2.4 million children died in the first month of life in 2020 and newborn deaths accounted for nearly half (47%) of all child deaths under the age of 5 years ³⁶. Most neonatal deaths (75%) occur during the first week of life and are caused most frequently by preterm birth, childbirth-related complications (birth asphyxia or lack of breathing at birth), infections and birth defects ³⁶. Despite the majority of newborn deaths occurring in the developing world, children living in low to middle income countries are less likely to access palliative care ³⁷. In 2022 an international group of experts in PPC came together to define international standards in PPC whilst acknowledging the diversity of settings and resources that exist globally ³⁸. The standards emphasise that PPC should be provided in all settings where paediatric care is provided including obstetrics and neonatal care. Some of the fundamental points from the international standards, particularly those that pertain to perinatal care, are summarised in Table 2.

*Table 2: Fundamental points relevant to perinatal palliative care from the International Standards for PPC*³⁸

- PPC is a right for all children with a life-threatening or life-limiting illness and their families
- All children with a life-limiting, life-threatening or terminal disease are eligible for PPC
- PPC should improve Quality of Life and address the needs, choices and wishes of children and their families
- PPC should not be limited to end-of-life care but introduced at the time of the diagnosis of a life-limiting or life-threatening condition, or in some instances prior to diagnosis
- The level of care provided should be defined according to the specific needs of the child and family and may change over time
- There are distinct levels of palliative care (palliative approach by all healthcare providers, generalized PPC, specialized PPC), which should be offered by professionals with appropriate levels of training in PPC
- Perinatal Palliative Care (PnPC) should be considered in routine obstetrics and neonatal care
- Hospitals providing neonatal and maternal care need to develop PnPC pathways
- PnPC may be provided in the delivery room, post-partum ward, in the neonatal intensive care unit (NICU), at home, or wherever is thought to be most appropriate and provided this approach is consistent with family goals of care

These are aspirational aims, and rightly so, but the authors concede that a standardised approach to PPC will be difficult to achieve, not only where resources are limited (e.g., access to essential analgesic drugs is still limited in many countries³⁹) but also in high-income settings where considerable barriers still exist. A further challenge remains that although

appropriate guidelines in perinatal care have been developed in a number of locations across the world, their implementation can easily fail to be meaningful if not accompanied by appropriate professional training and education ⁴⁰.

6. An integrated and interdisciplinary approach

In this new era of perinatal and neonatal palliative care, further progress will rely on a truly interdisciplinary approach, drawing on expertise from a host of specialists working across the spectrum of maternal and child health and synthesising this expertise into a coherent whole. Whilst a multidisciplinary approach requires different specialists to collaborate whilst staying within their disciplinary boundaries, interdisciplinarity requires a harmonisation between disciplines to deliver coordinated care that is focused on a common goal ⁴¹.

There is increasing support for a mixed model of palliative care on neonatal intensive care units, where the neonatal team provides primary/core palliative care and the specialist paediatric palliative care teams are involved only in more complex or refractory situations ⁴². This approach will need to be predicated on early integration between services, however, to avoid a situation where palliative care teams are brought in late in the disease trajectory, only to manage end-of-life care. A shared model of education and training will enhance such an approach and requires that both medical and nursing training curricula prioritise palliative care and advanced communication skills training from an early career stage. Targeted palliative care educational programmes for neonatal units also have the potential to shift staff attitudes away from a focus on dying and end-of-life and towards integrating palliative care as part of a holistic treatment plan ⁴³.

NICU teams working in synergy with palliative care teams can significantly enhance the care of infants on the neonatal unit; one study found that infants of families that received palliative care consultations had shorter lengths of stay, fewer invasive procedures and more frequent referrals for supportive services compared with families that did not have palliative care consultations ⁴⁴. Palliative care can also improve experiences for staff. Those working in the NICU are vulnerable to moral distress and burnout related to end-of-life decisions, and evidence suggests that the psychological support currently offered to staff is insufficient ⁴⁵. The consistent and effective implementation of palliative care in the NICU, however, can act to improve staff outcomes ⁴⁶.

Specialist palliative care teams can play an important role in legitimising and role-modelling the palliative care approach within healthcare organisations, particularly in helping professionals navigate high levels of clinical uncertainty which are not always openly acknowledged ⁴⁷. As neonatal care becomes ever more complex, learning to sit alongside families in this space of uncertainty will become increasingly important and allows for open conversations about the possibility of death to start early where needed.

Ultimately the goal must be an integrated system of care throughout the entire hospital structure, informed by the principles of good palliative care and incorporating both bereavement support for parents and families and support to care providers themselves ⁴⁸. Successful development of palliative care in the NICU will need to prioritise not only education and training for staff, but also targeted psychological support and policies for routine debriefing both before and after an infant dies.

7. Research agenda

Whilst research in PPC has seen important advances in recent years there is a pressing need for further research in this area, particularly in the evolving subspecialties of perinatal and neonatal palliative care. Central to this is a recognition that the routine collection of high-quality standardised data is crucial to evaluate both the need for PPC services and the effectiveness of their delivery ⁴⁹. Integration of routine data collection regarding infants receiving palliative care into existing medical record systems on the NICU would be an important first step in research in this area. Areas which would particularly benefit from further research include:

- The safety and efficacy of medications for symptom management in the neonatal population
- The impact of receiving palliative care support in the antenatal period on the experience of families
- How best to train and support staff who are caring for infants with palliative care needs in the NICU
- Parental experiences and preferences surrounding after death care for their infant

8. Conclusions

A new era of integration of palliative care into neonatal medicine is upon us, offering promising advancements in the quality of the care provided to infants with life limiting conditions and to their families. Continued progress will rely on ongoing interdisciplinary collaboration centred on providing early and longitudinal care utilising a holistic approach.

The cornerstone of success will be the delivery of excellent palliative care by every team member, through ongoing staff training and education, research focused on the effectiveness of palliative care delivery, as well as robust psychological support for staff working with those infants who face an uncertain future.

Practice points

- PPC is an active and total approach to care and should begin early and irrespective of disease-directed treatment
- Palliative care in the NICU can be provided by frontline neonatal staff with support from specialist PPC teams
- The level of care provided should be defined according to the specific needs of the child and family and may change over time
- Where a life-limiting condition is diagnosed antenatally families will benefit from palliative care support before birth to help to plan their infant's care

Conflict of interest statement

The authors have no conflicts of interest.

Funding

This research was funded in whole, or in part, by the Wellcome Trust [224744/Z/21/Z]. The funders had no role in the preparation of this manuscript or the decision to submit for publication. For the purpose of open access, the author(s) has applied a Creative Commons Attribution (CC BY) license to any Author Accepted Manuscript version arising from this submission.

All research at Great Ormond Street Hospital NHS Foundation Trust is made possible by the NIHR Great Ormond Street Hospital Biomedical Research Centre.

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