British Association of
Perinatal Medicine

Recognising Uncertainty: An integrated framework for palliative care in perinatal medicine

A BAPM Framework for Practice

July 2024

Developed in
Partnership with

Association for Paediatric Palliative Medicine

Bliss for babies born premature or sick

Child Bereavement UK REBUILDING LIVES TOGETHER

together for short lives

Sands Saving babies' lives. Supporting bereaved families.

NEONATAL NURSES ASSOCIATION

Neonatal Palliative Care

Introduction

Most newborn babies cared for by perinatal teams survive. Advances in fetal and neonatal care mean that mortality rates in neonatal intensive care units (NICU) have decreased over the past two decades in high income countries like the UK(1,2).

However, the prevalence of children with life-limiting or life-threatening conditions has risen over recent years, with the largest increase seen in infants under the age of 1 year(3). New forms of diagnostic testing (such as genome sequencing and advanced imaging technologies before or after birth) are identifying a growing cohort of fetuses and babies with potentially life-limiting illness(4). Furthermore, success in acute stabilisation of critically ill newborns born extremely prematurely(4) or with major congenital malformations can be followed by a long period when outcome is uncertain. Some such babies will die after a long period of intensive care whilst others will live with medical complexity and additional care needs linked to the underlying disease and its treatments. Owing to these factors, the number of babies who are now eligible for palliative care is increasing. It has been estimated that at least 2500 babies each year in England and Wales cared for in NICUs would benefit from palliative care(5).

Perinatal teams have for some time recognised and embraced the importance of palliative care for newborn infants with terminal illness(6). Children's palliative care is life-long supportive care. It is all-encompassing, wide-ranging care, provided to children and their families in the knowledge that strong, consistent relationships are key to providing the best care(7). Traditionally, however, uncertainty about whether the baby will or could survive has been a barrier to considering a palliative approach to care(8). Professionals and families sometimes worry that they would be 'giving up hope' by agreeing to (or even discussing) a palliative care plan. But waiting until there is certainty about outcome can mean that some of the significant potential benefits of palliative care are lost. It can impede planning, it can compromise the care of those babies who do end up dying in infancy or early childhood, and it can result in families feeling unprepared for the loss of their child.

It is this central challenge for perinatal care that we focus on in this framework.

To inform the scope of this framework, in collaboration with Together for Short Lives we undertook a survey of perinatal healthcare professionals. Our findings from 152 doctors, nurses, midwives, allied healthcare professionals, clinical support workers, and service managers highlighted the need for information on identifying babies with palliative care needs, decision-making practices, how and when to involve and refer to paediatric palliative care teams and how and when to use parallel and advance care plans. The framework also applies key learnings from direct feedback from families and from recent research studies involving both families and healthcare professionals. Evidence shows that health care inequalities, including socioeconomic and racial disparities, have recognised consequences on maternal and perinatal mortality(9–11), further emphasising the need to ensure equitable access to palliative care services(12).

The Framework for Practice has been developed by consensus as a joint initiative by BAPM and APPM, taking into account the input of a large working group, and follows wide consultation. BAPM is grateful for input from parent representative organisations including Bliss, SANDS, Child Bereavement UK and Together for Short Lives.

The central message of this framework is that palliative care is not just for those babies who are dying or will certainly die early in life. Where there is uncertainty about survival or diagnosis and

TREAT: Symptom management

Babies with a life-limiting or potentially life-limiting illness may experience a wide range of symptoms including pain, breathlessness, agitation, seizures, and feed intolerance. Neonatal teams have expertise in managing these symptoms but should consider involving specialist palliative care teams for babies with complex or refractory symptoms(40–43). In some cases (particularly if a baby is being discharged home) it will be helpful to develop and document a symptom management plan with specific guidance on pharmacological and non-pharmacological approaches to managing symptoms. These plans should be developed with the support of a neonatal or paediatric palliative care pharmacist.

LOSS: Grief and bereavement care

All families of babies with palliative care needs will experience loss. Even if the baby recovers, parents potentially experience loss of a normal pregnancy or birth experience, anticipatory loss (at the possibility or expectation that their baby may die), and trauma relating to experiences during birth or in NICU(44).

After the death of a baby, parents and the extended family will require bereavement support(45). Ongoing contact with the staff who cared for their child can be a great source of support to families(46). Specialist psychology support may be accessed via maternal mental health services, neonatal units, specialist paediatric palliative care teams and/or children's hospices(47).

Care of the baby after death is an important element of bereavement care and parents may wish to participate in the physical care of their baby's body after death as well as memory-making activities. Some families may also wish to explore the option of taking their baby home or to a hospice after death with the support of cooling facilities(48). Consideration should be given to providing lactation care, drawing on the support of the local infant feeding team. This includes option of milk donation as well as anticipatory guidance around lactation suppression, for all mothers facing the possibility of a stillbirth or neonatal death(49,50).

Although neonatal organ donation is currently rare, in babies where there may be potential for neonatal tissue and/or organ donation this should trigger early discussion with the local Specialist Nurses in Organ Donation(51).

It is important to give families an opportunity to feed into the institutional, regional and national processes for review after a baby dies such as the Child Death Review Meeting and the Perinatal Mortality Review Tool. Even in cases when a baby doesn't die, but has experienced palliative care needs, collecting feedback from families is essential to service improvement.

In situations where a family experience the loss of a twin, triplet or higher order multiple, there may be the additional complexity of needing to care and support surviving siblings. Please see Appendix D for information resources on supporting bereavement from a multiple birth perspective.

Families who go on to have a subsequent pregnancy should be offered tailored care and support which takes their previous loss into account (see Appendix D for information on the Care of Next Infant scheme and The Rainbow Clinic).