

Fifteen minute consultation: Perinatal palliative care

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Abstract

Perinatal palliative medicine is an emerging subspecialty within paediatric palliative medicine, neonatal medicine, fetal medicine and obstetrics. It comprises patient-focused, non-judgemental shared decision-making and aims to provide holistic multi-disciplinary support for families. In this paper we define and describe one model for providing perinatal palliative care, drawing on the personal and professional experience of the authors.

Background – Walking along with us

Ana was pregnant with her second child, Nadia, when a growth scan at 37 weeks (performed because of poor growth in Ana's first child) identified unexplained dilated cardiomyopathy with hydrops. *“Then he sat with us, together with the first doctor, and they told us that we had to make a choice. We could get in an ambulance and go to Southampton, where I would have a caesarean, [Nadia would be put on life support, but would likely still die.] The alternative path would be to “put her to sleep” with a needle to the heart, after which her birth would be induced and it would all be over”^{1,2}.*

Introduction

Perinatal palliative care draws on the shared expertise of paediatric palliative care, neonatology, fetal medicine and obstetrics. Whilst there are established national frameworks and clinical pathways for palliative care after birth^{3, 4, 5} there is no unified pathway guiding care for women and families in Ana's situation, who have received

a diagnosis of confirmed or potential Life Limiting Conditions during pregnancy. *Confirmed* Life Limiting Conditions have a certain diagnosis and prognosis, including a very high chance of death in utero or in infancy despite medical treatment. *Potential* Life-Limiting Conditions include diagnoses where there is a significant chance of death in utero, in the newborn period, or in early infancy, and are often associated with substantial burden of treatment or illness in survivors. Prognosis may not always be clear at the time of diagnosis (Box 1)

Confirmed life-limiting conditions	Potential life-limiting conditions
Trisomy 13, 18	Severe multicystic dysplastic kidneys and oligohydramnios
Anencephaly	Severe hydrocephalus
Bilateral renal agenesis	Severe congenital cardiac conditions that may not be amenable to surgery, or only with severe morbidity
Severe skeletal dysplasia	Severe fetal cardiomyopathy
Severe osteogenesis imperfecta	Severe Hydrops fetalis
	Hydranencephaly
	Holoprosencephaly

Box 1 The range of conditions in which perinatal palliative medicine input may be appropriate

Establishing the diagnosis and prognosis

Referral to perinatal palliative care may occur at any point during pregnancy and perinatal palliative care input may be valuable at any point after diagnosis. Definitive diagnosis may follow early or mid-trimester ultrasound. Neonatal input may be necessary to ascertain prognosis, and paediatric surgeons, cardiologists, geneticists and neurologists may be consulted as necessary. Where diagnosis or prognosis is uncertain there may still be a role for perinatal palliative care input, however, definitive plans about post-natal care may need to be deferred until after birth. If there are differing opinions within this team then a formal multi-disciplinary team meeting or ethical review may be necessary.

Discussing Perinatal Palliative Care with families

“It was an appointment with a couple of palliative care paediatricians that changed everything. ‘What would you like to happen?’ I knew exactly what I would like: I would like her to survive until the day I went into labour. In the space of a couple of hours, they transformed what we were going through from something purely dreadful to something potentially meaningful. She could be a person, a person whom we might not have the chance to meet properly, but a someone nevertheless”.

Initial discussion about prognosis and options will usually be conducted by a fetal medicine consultant/obstetrician with fetal medicine training with input from a specialist midwife. It may be helpful to arrange a follow-up visit to meet neonatologists or the palliative care team. Women should be provided with value-neutral information about all options, including termination of pregnancy, continuation with palliative care, or (in some cases) continuation of pregnancy with an active post-natal care plan. It is particularly important to discuss openly parents’ priorities, hopes and fears, in order to facilitate shared decision-making that is respectful of parents’ values, and tailor support to their needs (Box 2)

SETTING UP the Interview	<i>Consider the location and ensure all appropriate participants are present and briefed beforehand.</i>
Assessing the Patient’s PERCEPTION	<i>“Tell me about your pregnancy. What have you been told?”</i>
Obtaining the Patient’s INVITATION	<i>“Would you like to talk about what might happen during labour and after your baby is born?”</i>
Giving KNOWLEDGE and Information to the Patient	<i>Break information into small chunks and focus on key messages. Occasionally check if the patient understands. “Is this clear so far?”</i>
Addressing EMOTIONS with empathic responses (these can be family or MDT emotions)	<i>“I wish that these results were different...” “I can’t imagine how difficult this news must have been to hear” “What is most important to you?” “What worries you the most?”</i>
Strategy and Summary	<i>“What would you like to ask?” Follow up with a letter</i>

Box 2 Helpful phrases drawing on the SPIKES framework⁶ to counsel parents

Pre-birth planning

This is a wide-ranging and highly personalised process to address both obstetric and neonatal concerns. Issues that may be covered include deciding the mode and timing of delivery, monitoring during labour, resuscitation after birth and symptom management. If time allows, complex issues such as organ or tissue donation can be explored. In the context of uncertain prognosis, parallel planning enables clinicians to compassionately explore with parents potential care in the event of death in-utero, palliative care after birth or potential on-going care (where longer survival is possible or where prognosis appears subsequently better than expected) and further tests after birth may be needed. A proportion of newborns in palliative care are later discharged home⁷ and families should be prepared for unexpected, unforeseen complications after birth that may call for difficult ethical decisions, even if the diagnosis appears certain. The establishment and maintenance of trust is crucial in this evolving relationship, and it is vital to communicate clearly with all parties about the certainties and, importantly, the uncertainties of each individual case.

Plans may evolve over several meetings held in a variety of locations and should, where possible, be formalised in a written palliative care and birth plan, to be shared with the fetal medicine and palliative care teams, referring centre labour ward and neonatal teams, community midwifery and general practice teams. Documentation and clarity of communication with all parties are key at this stage.

Location of care

Palliative care in this context is highly mobile, and might be delivered in the hospital of delivery, in a hospice or at home, or as a combination of all three, with the lead team varying according to the location with specialist support as needed being provided remotely by other teams. Wherever possible, delivery and care after birth should be planned to be as close as possible to the family's home and parents may find it helpful to visit the relevant neonatal unit or hospice prior to delivery. This flexible approach involve the community and secondary care teams in the referring centre, and successful delivery of such care depends on the establishment of close working relationships.

Resource implications

At present much of this work is undertaken from existing budgets but, as the demand on current services increases with improved antenatal diagnosis, greater public awareness and increasing birth rates, there is an urgent need for a nationally led specialist commissioning review to seek dedicated funding for this work. This need is acknowledged by NICE and formal guidance on this is due to be published in December 2016⁸.

“In the past, it was considered best to forget and move on when children were stillborn. How did people do it, how did they deal with their loss without all these anchoring points that I had been given?”

Summary

- Respect for the values and choices of parents is central to providing compassionate, tailored supportive care
- Parents who have chosen to continue their pregnancy following antenatal diagnosis of a life limiting condition should be offered multidisciplinary support from professionals with experience in providing perinatal palliative care.
- Personalised antenatal, birth and postnatal care plans should be drawn up in conjunction with parents, obstetric, paediatric and palliative care teams. These plans should be appropriately communicated to all centres likely to be involved in the family’s future care.

Footnote

Nadia died during her delivery. Ana and her family, including Nadia, spent a day in the hospital and four days at Helen House hospice in Oxford, as planned before her birth.

References

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