

## **The role of children's hospices in supporting the implementation of perinatal palliative care and advance care planning in the United Kingdom**

**Commentary on:** Shaw KL, Spry J, Cummins C, et al. Advance care planning in perinatal settings: national survey of implementation using Normalisation Process Theory. *Archives of Disease in Childhood - Fetal and Neonatal Edition* Published Online First: 14 September 2023. doi: 10.1136/archdischild-2023-325649

### **Implications for practice and research**

- Workforce priorities include supporting practitioners to improve competence in perinatal advance care planning (PnACP) and approaches to collaborative working.
- Future research should explore optimal models(s) of PnACP.

### **Context**

The need for the integration of palliative care into perinatal services is increasingly acknowledged across the United Kingdom (UK). This is due to the increased prevalence of babies with life-limiting conditions (LLCs), and advances in perinatal care, technologies and treatment options.

PnACP is widely recognised as central to the provision of perinatal palliative care (PPC), regarded as an essential element of care that babies and their families receive. PnACP offers opportunities for parents and professionals to share information and discuss current needs of their baby, and consider future priorities for care, over a series of discussions, including the management of deterioration and end of life care.

### **Methods**

A cross-sectional survey, using Normalisation Process Theory<sup>1</sup> was used to understand how PnACP was embedded in, and accepted as routine practice. All UK-based services represented in the PCC pathway<sup>2</sup> were eligible to participate in the study, comprising approximately 246 neonatal services. Invitations were shared via professional organisations and networks, and social media. SPSS was used to analyse quantitative data, using standard descriptive statistics. Directed qualitative content analysis was used to analyse qualitative data. PPI activities with mothers and hospice-based practitioners confirmed the relevance of the study.

### **Findings**

A total of 108 practitioners, from 90 organisations responded, representing approximately 45% of services which are part of the UK Neonatal Collaborative. Examples of good practice and effective PnACP resources were identified, although there was inconsistency in how these were applied. The quality and depth of information contained in plans varied significantly between organisations. Available pathways, frameworks and tools were not always embedded into practice; barriers preventing this included time-limited opportunities for discussion and decision-making, prognostic uncertainty, insufficient resources and service variation.

Stronger integration of PPC approaches into acute settings, as well as professional education to prepare practitioners to support families throughout their perinatal journey is needed. Enhanced interagency collaboration, staff education and the sharing of best practice, enabled through policy and practice development, would result in service improvement.

## Commentary

Parents who choose to continue with their pregnancy following the diagnosis of a LLC of their baby face an uncertain perinatal journey. PnACP is at the heart of PPC, however, despite national tools and guidance to support PnACP, variation in practice remains. Some families, depending on the services they use, may not be offered opportunities for advance care planning.

Shaw et al.<sup>3</sup> note that parents value clear and honest communication, which enables PnACP. Earlier recognition, and parental involvement in decision-making leads to improved symptom management and end of life care for babies, and better bereavement outcomes for parents and other family members. The importance of effective therapeutic relationships, characterised by communication, connection and trust was recognised in a recently published meta-ethnography<sup>4</sup>. Opportunities for parents to engage in decision-making and planning, enhances their experiences of parenthood. PnACP leads to parents feeling a sense of control, empowerment and validation of themselves and their baby at all stages of their perinatal journey.

Children's hospices play an important role in the provision of PPC<sup>3</sup>. Recently published works exploring the impact of children's hospices on PPC found this extended beyond the provision of care<sup>5 6</sup>. Children's hospices provide training to support the development of hospital-based colleagues in PnACP and around the value of family-centred, biopsychosocial and spiritual approaches to PPC. Interagency approaches to care, facilitated by appropriate care pathways result in care that is responsive and flexible to babies and parents at all stages of their perinatal journey.

## References

1. May C, Finch T. Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology* 2009;43(3):535-554.  
<https://doi.org/10.1177/0038038509103208>
2. Together for Short Lives. A perinatal pathway for babies with palliative care needs. 2017. Bristol, UK. <https://www.togetherforshortlives.org.uk/app/uploads/2018/01/ProRes-Perinatal-Pathway-for-Babies-With-Palliative-Care-Needs.pdf> (last accessed 26 November 2023)
3. Shaw KL, Spry J, Cummins C, et al. Advance care planning in perinatal settings: national survey of implementation using Normalisation Process Theory. *Archives of Disease in Childhood - Fetal and Neonatal Edition* 2023;0(0);.  
<https://doi.org/10.1136/archdischild-2023-325649>
4. Tatterton MJ, Fisher MJ. 'You have a little human being kicking inside you and an unbearable pain of knowing there will be a void at the end': A meta-ethnography exploring the experience of parents whose baby is diagnosed antenatally with a life limiting or life-threatening condition. *Palliative Medicine* 2023;37(9):1289-1302.  
<https://www.doi.org/10.1177/02692163231172244>
5. Tatterton MJ, Fisher MJ, Storton H, et al. The role of children's hospices in perinatal palliative care and advance care planning: The results of a national British survey. *Journal of Nursing Scholarship* 2023;55(4)864-873  
<https://doi.org/10.1111/jnu.12866>

6. Tatterton MJ, Fisher MJ, Storton H, et al. "Holding Families in Uncertainty": A Framework Analysis of the Role and Impact of Children's Hospices in the Provision of Perinatal Palliative Care. *Illness, Crisis & Loss* 2023;0(0):1-20.  
<https://doi.org/10.1177/10541373231202473>

**Commentator details**

**Name:** Dr Michael J Tatterton

**Affiliation:** clinical associate professor of children and young people's nursing, University of Bradford, UK and Clinical Director, Bluebell Wood Children's Hospice, Sheffield, UK.

**Correspondence address:** Faculty of Health Studies, University of Bradford, Richmond Road, Bradford BD7 1DP

**Email:** [m.tatterton@bradford.ac.uk](mailto:m.tatterton@bradford.ac.uk)

**Twitter:** @MJTatterton

**Competing interests**

Michael is an editor of Evidence-Based Nursing.