

## Research Spotlight

Issue 1: April 2022

### Perinatal Palliative Care

Commentary by Alex Mancini-Smith, National Lead Nurse for Neonatal Palliative Care

Perinatal and neonatal palliative care are emerging specialties. In recent years there have been significant advancements in relevant studies, aimed at improving healthcare professionals' understanding in enhancing and maximising support and care for babies and their families. The last decade has seen unprecedented developments in antenatal care and diagnostic technologies, helping to identify unborn babies who have conditions which may shorten their lives or contribute to an uncertain future. As healthcare professionals we are placed in a unique position to support, gently guide and explore choices available in partnership with parents and the wider families, enhancing the care their babies and unborn babies receive.

Advance Care Planning is a term used frequently alongside antenatal care planning and birth plans, an approach which creates a space for families to share their wishes and hopes for their baby's care, an opportunity to be listened to and be heard (**Downie et al 2020**). This period of time provides space for discussion of what is most important for parents, their wishes, and choices available during pregnancy, the delivery, birth and the immediate period after birth. Where they want to be, and who they would like to be there with them, this planning must be made alongside consideration of the mother's own health and how that may impact where the birth and subsequent care may be delivered.

**Cortezzo et al (2020)** discuss the creation of a 'palliative care birth plan' enabling healthcare professionals to truly understand what is important for the parents, and how to support them to achieve this. Each palliative birth plan is unique and individualised for each family and will assist the healthcare team understand their goals of care for their baby and wider family, alongside wishes regarding the medical care for their baby. Parents tell us that they seek opportunities to observe family traditions, rituals, honour and celebrate their baby's life - all of which can be documented in a 'palliative care birth plan'.

In their descriptive study, **Cote-Arsenault et al (2021)** report that a perinatal palliative care coordinator is an essential role within a perinatal palliative care programme. This role contributes and enables the creation of a 'safe space' for the family, whilst supporting the interdisciplinary team to coordinate birth planning. Their unique contribution, knowledge and skills are not well reported, however, this study included interviews of 12 expert perinatal palliative care coordinators, identifying guiding principles including the importance of facilitating *perinatal parenting* and *treating the baby as a person*. Furthermore, the perinatal palliative care coordinators can 'create a safe space' for families to discuss their hopes, fears and realities for their baby's life, embracing the pillars of family integrated care.

Approaches to family centred care, promoting a mutually beneficial partnership between parents and healthcare professionals, can be further extended to the delivery room (**Clarke et al 2020**). Family Integrated Care, enabling and supporting parents to be their baby's primary caregiver, by ensuring the very first cuddle, direct physical contact and bonding opportunity can be achieved at the very beginning of life, is essential in nurturing and enhancing the family experience, particularly when their future is uncertain (**BAPM 2021**). With appropriate planning and safety measures in place, delivery room cuddles are possible and achievable for extremely preterm babies on the margins of viability, and with babies whose future is not known.

Perinatal and neonatal palliative care have gained momentum in offering plans of care focusing on enhancing the quality of life when a baby is critically unwell or has a life limiting condition with an uncertain future. However, training for healthcare professionals caring for these babies and their family has not maintained the same impetus or consistency. Ensuring and maintaining an equitable approach to high quality care for babies, their parents and the wider family continues to be a challenge for healthcare professionals. Our combined knowledge and learning from parents' experiences and consensus of opinion from colleagues can shape our practice, however as a perinatal and neonatal palliative care community, our workforce also requires appropriate opportunities and access to formalised training opportunities.

Various training programmes have been developed globally, one example is a 3 day intensive Perinatal/Neonatal Palliative Care training course created by an interdisciplinary team at Columbia University Irving Medical Center. This programme was evaluated to ascertain the efficacy of attending this course via self-reporting by the participants. The study design was cross-sectional, obtaining data from 88 healthcare professionals who participated in the training using a validated questionnaire, at the beginning and conclusion of the course. This included 32 items which queried their self-assessed competence and served as outcome variables, and further clustered into eight domains of palliative care, including structure and process; physical; psychological and psychiatric; social; religious and spiritual; cultural; care of the imminently dying; legal and ethical. The development of this evidence-based curriculum in Perinatal/Neonatal Palliative Care training course improved the self-reported competence of participants across disciplines and addressed a training need. The information gathered provides a framework for the development of perinatal/neonatal palliative care curriculum (**Hammond et al, 2020**).

There are many other examples of training programmes which have been developed and can be accessed in various ways, such as E-learning modules, virtual training and face to face in person programmes, and it is recognised that healthcare professionals need to be able to access training and education in a mode which is suitable for them at the time which suits them (**Nurse et al, 2020**). There is an urgent and immediate need for improved and increased development of perinatal/neonatal palliative care education at undergraduate and postgraduate levels. The authors suggest that innovative and multi modal approaches should be incorporated into the curricula, including opportunities for reflection and debriefing, enabling healthcare professionals to further develop their knowledge and skills.

It is evident that with the advancements and development of perinatal and neonatal palliative care teams and pathways, that we must ensure the workforce is appropriately skilled and have the confidence to provide equitable high-quality care.

- **British Association of Perinatal Medicine (BAPM) (2021)** Family Integrated Care: A Framework for Practice. Nov 2021
- **Clarke P, Allen E, Atuona S and Cawley P (2020)** Delivery room cuddles for extremely preterm babies and parents: concepts, practice, safety, parental feedback *Acta Paediatrica*. 2020;00:1-11
- **Cortezzo DE, Ellis K and Schlegel A (2020)** Perinatal Palliative Care Birth Planning as Advance Care Planning. *Frontiers in Pediatrics* 8:00556
- **Cote-Arsenault D, Denney-Koelsch E and Elliott G (2021)** 'Creating a safe space': how perinatal palliative care coordinators navigate care and support for families. *International Journal of Palliative Nursing* 2021, Vol 27, No 8

- **Downie J, Kerr-Elliott T and Craig F (2020) Advance Care Planning in Mancini A, Price J and Kerr-Elliott T (2020) Neonatal Palliative Care for Nurses (2020) Springer Nature**
- **Hammond J, Wool C and Parravicini E (2020) Assessment of Healthcare Professionals' Self-perceived Competence in Perinatal/Neonatal Palliative Care After a 3-Day Training Course *Frontiers in Pediatrics*.8:571335.**
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With thanks to Sue Langley, Library & Information Services Manager, EACH

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