

Trends in Pediatric Palliative Care Research (TPPCR) 2024; Issue #8: Commentary on *Brouwer et al.*

Helena Dunbar, PhD, MSc, PG Cert, BA (Hons), RGN/RSCN

Together for Short Lives, UK

Email: Helena.dunbar@togetherforshortlives.org.uk

Abstract:

This TPPCR commentary discusses the 2024 paper by Brouwer et al., “The spiritual dimension of parents’ experiences caring for a seriously ill child: An interview study.” published in the *Journal of Pain and Symptom Managements*.

This commentary is a part of the Trends in Pediatric Palliative Care Research commentary series. To

learn more or to sign up for our monthly newsletter visit: <https://pediatricpalliative.com/research-blog/>

In the collection of articles this month there are several which encapsulate the experiences, needs, challenges families face in their caring responsibilities of a child with a life-limiting condition. However, it was the article by Brouwer and colleagues “The spiritual dimension of parents’ experiences caring for a seriously ill child: An interview Study”¹ which caught my eye. Alongside physical, psychological and social needs, spiritual care is acknowledged as an essential component of palliative care.² Spirituality has predominantly been associated primarily with faith and religion but as the European Association of Palliative Care (EAPC) reference group definition describes, it is now much broader and “is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.”³ The idea that spirituality goes beyond religion, beliefs and the supernatural has been shown in previous work by Brouwer and colleagues⁴ but as one of the core domains of palliative care spiritual needs appear to be less understood. In the previous publication by this group, a mixed-methods systematic literature review found that parents’ needs for spiritual support were often not explicitly stated.

In this qualitative study a purposeful sample of bereaved and non-bereaved parents of children aged 0-21 years diagnosed with a life-threatening condition in the Netherlands, participated in in-depth interviews, via video-conferencing software or telephone. Of the 24 parents recruited, six were fathers. Interestingly 50% of the sample claimed to have either no religious beliefs or were none practicing. Thematic analysis of the data collected produced seven themes which described the experiences of parents regarding spirituality: 1) identity; 2) parenthood; 3) connectedness; 4) loss or adjustment of goals; 5) agency/control; 6) navigating beliefs and uncertainties; and 7)

decision-making. There was no way of identifying within the paper if there were any differences in views between those parents with a belief system compared to those who were not.

I was reminded that parents are connecting to who they are as a person, often when parents receive the life-threatening diagnosis for their child, they themselves are in a transitional period of their lives, developing as parents, partners, professionals and friends. Whilst we know from other literature that the role of parent is often subsumed by the role of becoming a carer, in this study parents struggled by the thought of not connecting with their child as parents, trying to create a sense of togetherness was very important to them. This sense of connection carried through in the theme related to social connectedness and the loneliness and isolation that parents' experiences.

This study highlights the various dimensions of spiritual care, reminding us all that a diagnosis of a life limiting condition for their child can have a profound effect on parents' identity, their experience of parenthood, their ability to cope with loss, their experiences, views and belief systems.

In addition to understanding the physical, psychological and social aspects of caring for a child with a life limiting condition it is vital that health care professionals understand how families conceptualise and express spiritual concerns. In this study giving parents the opportunity to explore their spiritual needs also revealed positives, such as, their ability to adapt and refocus, realising the value of the new 'normal' for their family and finding new meaning and purpose.

As demonstrated in this study and others⁵ the spiritual dimension is an important, although not always visible, aspect of how parents experience caring for a child with a life-threatening condition. For parents, spirituality relates both to everyday experiences as well as bigger issues

regarding life, their identity, their motivations and what is important to them. However, it is an area where health care professionals may need additional training 5 to help them understand that spiritual care is not just about belief systems but instead understand the various dimensions of this vital domain, equipping them to explore it more fully with parents and consequently offer support to parents of seriously ill children effectively.

References

1. Brouwer, M. A., Engel, M., Teunissen, P. D. S. C. C. M., Leget, P. D. C., & Kars, M. C. (2024). The spiritual dimension of parents' experiences caring for a seriously ill child: An interview study. *Journal of Pain and Symptom Management*.
<https://doi.org/10.1016/j.jpainsymman.2024.06.021>
2. World Health Organization. (n.d.) Palliative Care. Retrieved October 11, 2024, from <https://www.who.int/health-topics/palliative-care>
3. European Association for Palliative Care. (n.d.) Spiritual Care. Retrieved October 11, 2024, from <https://eapcnet.eu/eapc-groups/reference/spiritual-care/>
4. Engel, M., Brouwer, M.A., Jansen, N., Leget, C., Teunissen, S.C. and Kars, M.C., 2023. The spiritual dimension of parenting a child with a life-limiting or life-threatening condition: A mixed-methods systematic review. *Palliative Medicine*, 37(9), pp.1303-1325.
5. Scott, H.M., Coombes, L., Braybrook, D., Roach, A., Harðardóttir, D., Bristowe, K., Ellis-Smith, C., Downing, J., Murtagh, F.E., Farsides, B. and Fraser, L.K., 2023. Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliative Medicine*, 37(6), pp.856-865.

6. Best, M., Leget, C., Goodhead, A. and Paal, P., 2020. An EAPC white paper on multi-disciplinary education for spiritual care in palliative care. *BMC Palliative Care*, 19, pp.1-10.