

PedPalASCNET:

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Monthly Commentary

Dr Amanda Evans Paediatric Palliative Care Specialist CEO and Founder - *Rei Kōtuku Charitable Trust, Aotearoa, New Zealand* Amanda is a paediatric palliative care specialist based in Wellington, New Zealand. She founded Rei Kōtuku Charitable Paediatric Palliative Care Service in June 2023, being the second PPC specialist service in Aotearoa providing care to children in the lower North Island.

Feature Article

Grossoehme, D. H., Sellers, J., Accordino, S., Smith, S. M., Jenkins, R., Richner, G., Moore-Forbes, Y., & Friebert, S. (2023). ["It's a Different Conversation": Qualitative Analysis of Pediatric Home-based Hospice/Palliative Care Visits' Perceived Value.](#) *Pediatr Qual Saf*, 8(4), e663.

Commentary

This study centered on the perceived value of providing home-based hospice and/or palliative care (HBHPC) for caregivers responsible for children with palliative care needs. Carried out in the Midwest region of the United States, semi-structured interviews were conducted with 22 caregivers, including those who had experienced bereavement. The caregiver demographics consisted mainly of parents and grandparents, with a predominant representation of white individuals and women. The authors accounted for the lack of diversity due to geographic sampling.

In terms of methodology, the authors employed a grounded theory analytic framework with a triangulation approach to ensure the consistency of the analyzed interviews. Theme saturation was reached in the 18th out of the 22 interviews. The study's outcomes revealed six primary themes that ultimately contribute to enhanced family-centered and goal-concordant care.

The themes identified as benefits of HBHPC in this study are as follows:

- a) Improved communication and openness: Home environments encourage candid conversations, enabling discussions about sensitive subjects such as hospice care and child mortality.
- b) Fostering emotional and physical safety: Home settings cultivate emotional well-being and accommodate complex physical care, mitigating challenges and stressors associated with travel.
- c) Building and maintaining relationships: Home interactions establish a strong foundation for enduring relationships, providing families solace and even unexpected moments of entertainment and companionship.
- d) Empowering the family: Recognizing and respecting familial, cultural, and religious values is particularly crucial within home settings.
- e) Gaining broader insight: Understanding a child's life within their family context enhances clinicians' comprehension and fosters trust in the care provided.
- f) Sharing burdens: Acknowledging the time and effort required to transport a child for a brief medical appointment highlights the family's struggles and underscores the critical role of home care.

The authors concluded that HBHPC provides value to caregivers and aligns with most quality domains of palliative care.

When considering these themes I note the emphasis lies on relationships, communication, being within the family space, and the idea of integrating our care and compassion within THEIR world. Certainly, when reflecting on my practice and that of my team, the themes resonate with what I believe makes the biggest impact for families. Although I may have only seen a child and their family twice before they start deteriorating, many families remark the level of trust gained from those meetings taking place within their own homes, matching that of clinicians who may have known them for years.

Key to my practice is the focus on connection. The themes of Grosseohme et al (2023) study are absolutely rooted in the power of relationships. In Aotearoa New Zealand, we refer to this as 'whanaungatanga,' signifying authentic relationships, connections, or the bonds that unite us.

A local NZ study investigating ways to build relationships with adolescents is a good example of this. Hamley et al. (2022) identified three priorities: "Ko Wai au" (know me), "He Wā pai" (make space for me), and "He Kaupapa Pai" (engage me in activities I'm interested in). The authors devised a care model, Te Tapa Toru, to guide clinicians in establishing whanaungatanga with youth. My team integrate this

model when working with adolescents to strengthen connections. Te Tapa Toru was not a model designed solely for palliative care however it serves as a reminder of the significance of showing up, relating to youth on their terms, and doing so in an environment where they feel secure which the authors reveal... is their home.

Considering these studies together, despite a distance of 8,378.06 miles (13,483.18 km) and cultural disparities, the need for connection emerges as the universal language for child and family-centred care. HBHPC helps us to achieve this due to the disruption of power imbalance that is often found within the health care system. It is only with real open-hearted relationships that we understand children and families enough to reach goal-concordant care. Thus, I commend the authors of both these studies for reminding us of our purpose.

In conclusion, to paraphrase Maya Angelou, what remains in our memory is how people make us feel. As practitioners, we are reminded that genuine healing commences with fostering authentic connections. Grossoehme and Hamley's studies reinforce this notion, reaffirms motivation to continue HBHPC and speaks to the privilege of being invited into the home of these children and families because it really makes a difference.

References

- 1 Hamley, L., Le Grice, J., Greaves, L., Groot, S., Latimer C.L., Renfrew, L., Parkinson, H., Gillon, A. & Clark, T.C. (2022): [Te Tapatoru: a model of whanaungatanga to support rangatahi wellbeing](#). *Kōtuitui: New Zealand Journal of Social Sciences Online*

Citation List

This month's featured articles:

Bristowe, K., Braybrook, D., Scott, H. M., Coombes, L., Harardottir, D., Roach, A., Ellis-Smith, C., Fraser, L., Downing, J., Murtagh, F. E., & Harding, R. (2023). [“My Life Is a Mess but I Cope”: An Analysis of the Language Children with Life-limiting and Life Threatening Illnesses Use to Describe their Own Condition](#). *Palliative Medicine*, 37(1), 57.

Engel, M., Brouwer, M. A., Jansen, N., Leget, C., Teunissen, S. C. C. M., & 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*.

Walker, M., Nicolardi, D., Christopoulos, T., & Ross, T. (2023). [Hospital, hospice, or home: A scoping review of the importance of place in pediatric palliative care](#). *Palliat Support Care*, 1–10