

## Letter to the Editor

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# “Hospital, hospice, or home: A scoping review of the importance of place in pediatric palliative care”: A reflection from clinical practice

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Dear Editor-in-Chief,  
Dr. William Breitbart,

We were pleased to read the article “Hospital, hospice, or home: A scoping review of the importance of place in pediatric palliative care” by Walker et al. (2023), which presents essential conclusions concerning three contexts for professionals practicing pediatric palliative care (PPC).

The article focuses on how PPC is almost always associated with preferences on the place of death. Although this is a significant theme for children’s comfort, the authors of this letter believe that discussing the place in PPC deserves a more dedicated approach for promoting children’s quality of life at home and in the community.

Although palliative care is not equally accessible worldwide, its mission is to improve the quality of life, relieve suffering, and prevent complications for patients and families facing problems related to life-limiting conditions (World Health Organization 2002). In a pediatric setting, every child should benefit from individualized PPC beginning at diagnosis and in parallel with any curative approach (International Children’s Palliative Care Network 2008, 2009).

Children with complex chronic conditions and their families are frequent PPC users (Worldwide Hospice and Palliative Care Alliance 2020). These conditions are associated with a severe and incapacitating nature, but not all have an imminent life-threatening profile (Benini et al. 2022). These children live increasingly more, mainly depending on care provided by their caregivers. And is that the wrong path to go? Is palliative care only for the ones who are in a dying process?

Providing PPC allows children who will not get better from their condition to benefit from holistic and proactive care toward physical, psychosocial, and spiritual well-being (Bona 2006; Goldman et al. 2012). This mission can be pursued out of the hospital for many more reasons than dying. A child receiving PPC should not be defined by the disease and be able to go for a stroll, watch a movie, go to school, or do any activity appropriate to her development without forgetting the necessary healthcare interventions.

This perspective demands communities to be compassionate, supportive and involved with the life journey of people with palliative needs (Dumont et al. 2022). Awareness about symptom management, clear communication, and psychosocial support gather particular concerns in a pediatric context, as well as the demystification of PPC (Aoun et al. 2022; Chowdhury et al. 2023).

As end-of-life situations demand reflection on the place for caregiving, we believe that children with palliative needs deserve advanced planning while living in the community. Furthermore, community health teams are responsible for ensuring continuity of care, including managing health/disease needs and empowering communities to optimize their response to these children and their families, contributing to the normalization of chronic complex conditions (Charepe 2020; Jorge et al. 2016). Every place – hospital, hospice, home, and community – is needed to support PPC in a continuum that respects children’s rights, promoting a hopeful and joyful life.

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## References

- Aoun SM, Stegmann R, Deleuil R, et al.** (2022) “It is a whole different life from the life i used to live”: Assessing parents’ support needs in paediatric palliative care. *Children* **9**(3), 322. doi:10.3390/children9030322
- Benini F, Papadatou D, Bernadá M, et al.** (2022) International standards for pediatric palliative care: From IMPaCCT to GO-PPaCS. *Journal of Pain and Symptom Management* **63**(5), e529–e543. doi:10.1016/j.jpainsymman.2021.12.031
- Bona KO** (2006) Palliative care for infants, children, and adolescents. A practical handbook. *Journal of the American Academy of Child & Adolescent Psychiatry* **45**(3), 375–376. doi:10.1097/01.chi.0000196428.73094.24
- Charepe Z** (2020) A criança e o jovem com doença crónica ou incapacitante. In Ramos AL and Barbieri-Figueiredo MDC (eds), *Enfermagem Em Saúde da Criança E Do Jovem*, 1ª. Edição, Lisboa: Lidel, 231–237.
- Chowdhury MK, Bezzahou M, Khanom M, et al.** (2023) Developing community-based palliative care for children: A community case study from an urban informal settlement in Bangladesh. *Health Services Insights* **16**, 117863292311629. doi:10.1177/11786329231162996
- Dumont K, Marcoux I, Warren É, et al.** (2022) How compassionate communities are implemented and evaluated in practice: A scoping review. *BMC Palliative Care* **21**(1), 131. doi:10.1186/s12904-022-01021-3
- Goldman A, Hain R and Liben S** (2012) *Oxford Textbook of Palliative Care for Children*, 2nd edn. Oxford: Oxford University Press.
- International Children’s Palliative Care Network** (2008) The ICPCN Charter of Rights for life limited and life threatened children. <https://icpcn.org/resources/publications-resources/> (accessed 1 November 2023).
- International Children’s Palliative Care Network** (2009) Declaration of Cape Town. <https://icpcn.org/wp-content/uploads/2022/10/THE-ICPCN-DECLARATION-OF-CAPE-TOWN-2009.pdf> (accessed 1 November 2023).
- Jorge AM, Carrondo EM and Lopes FMT** (2016) Cuidados paliativos pediátricos domiciliários centrados na família: Contributos para uma Orientação Salutogénica. *Egitania Scientia* **1**(18), 75–87. doi:10.46691/es.v1i18.69
- Walker M, Nicolardi D, Christopoulos T, et al.** (2023) Hospital, hospice, or home: A scoping review of the importance of place in pediatric palliative care. *Palliative and Supportive Care* **21**(5), 925–934. doi:10.1017/S1478951523000664
- World Health Organization** (ed) (2002) *National Cancer Control Programmes: Policies and Managerial Guidelines*, 2nd edn. Geneva: World Health Organization.
- Worldwide Hospice and Palliative Care Alliance** (2020) *Global Atlas of Palliative Care*, 2nd edn. London: WHPCA.