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Published in:
Acta Paediatrica

DOI:
[10.1111/apa.15032](https://doi.org/10.1111/apa.15032)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2020

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):
Verhagen, E. (2020). Addressing fragmentation in paediatric palliative care. *Acta Paediatrica*, 109(3), 620.
<https://doi.org/10.1111/apa.15032>

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Addressing fragmentation in paediatric palliative care

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Paediatric palliative care (PPC) is an emerging specialty that aims at improving the quality of life for patients and their families. The main goals of PPC are to evaluate and minimise suffering in all domains (physical, psychosocial and spiritual), promote shared decision-making and coordinate care. PPC is complex, and fundamentally different from adult palliative care in that it involves rare conditions, high-tech care, children in diverse developmental stages and complex proxy decision-making. One of the challenges of PPC today is to make sure patients receive continuity of care through the different stages of illness.

With the aim of improving continuity of PPC in their own institution, Côté et al¹ invited professionals caring for children with medical complexity requiring palliative care for focus group interviews. The interviews sought to explore the professionals' experiences and beliefs in acute teams (Emergency Department and Intensive Care Unit) and in long-term care teams (Complex Care Service and Palliative Care). The result of this qualitative study offers a nice institutional portrait of PPC practice and its difficulties. Although all teams have excellent understanding of the theoretical mission of PPC, professionals expressed different group values, relationships with families, daily practices and roles in palliative care. This complicates discussions about goals of care, results in negative assessments of the care delivered by other services and challenges the quality of care. The suggested ways to improve interprofessional collaboration and address the care dissatisfaction include professionals' (a) transparency about a child's potential profit from a palliative approach to allow early engagement of services, (b) curiosity in others' perspective, (c) reflection on their own role to facilitate PPC by others and to remain informed about family preferences and (d) compassion as a part of team interactions to enhance trust.

The reason why I like this study and why I think the paper is noteworthy is twofold. First, the study is another example of the feasibility and potential usefulness of simple, institutional analysis of problematic practice and conflicts to improve bedside care.² The problem of fragmented palliative care is multifactorial and complex, and implementation of evidence-based interventions to defragment

often takes years.³ In contrast, the approach by Côté et al could be copied and started tomorrow.

Second, the differences in perspectives and expectations between acute and long-term care services reflect the broader discussion about division of roles in palliative care. The rapid development of the paediatric palliative care specialty, from mainly end-of-life care to a treatment starting after the diagnosis, created an extra layer of care on top of already complex care for children with complex conditions. This contributes to the risk of fragmentation. Knowing that there are not enough PPC specialists to take on all palliative care tasks, we should maybe aim at a model that strictly distinguishes basic skills, that all paediatricians should have, from specialist palliative skills to manage complex and difficult cases.⁴ This model should be taught to students, residents and paediatricians. Education as a starting point to align expectations and maybe change perspectives and cultures. An optimistic view!

CONFLICT OF INTEREST

The author has no conflicts of interest to declare.

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