



“So good; so late”: the strange love-hate relationship with paediatric palliative care

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There is little to fault paediatric palliative care (PPC). It has grown from strength to strength since early development in the nineteen seventies, following behind the adult hospice movements sweeping across different parts of the world (1). Yet, access to PPC remains patchy everywhere and many times late (2). Beyond structural limitations like policy, resource and training, barriers to early integration of PPC to benefit from evidenced-proven outcomes persist, interestingly, within internal stakeholders. In this issue of the journal, Saad and colleagues reviewed extant literature to report cognitive and psychological factors that perpetuate this anomaly (3). Depending on whether the reader is already a convert, findings will uncover or deepen individual appreciation of entrenched ignorance and misconceptions among professionals, beneficiaries, and wider community. Altogether, insights gleaned here are anticipated to support PPC advocates in envisioning targeted solutions—to deliver quality and timely palliative care in seriously ill children and their families.

Given its evolution along similar paths set by hospice and palliative care in the adult setting, PPC not surprisingly continues to be conflated with end-of-life care. This is particularly problematic when supporting children with life shortening illness for several reasons. With heterogeneity in medical conditions that are predominantly non-oncological and concomitant pervasive uncertainty in disease trajectories

or prognoses among children who may benefit from PPC support, help risks being offered late (4). This ultimately thwarts achievement of meaningful impact by providers, and failure in minimising preventable suffering among stricken families. Authors posit ‘lack of knowledge or awareness’ and ‘negative attitudes or beliefs’ as key factors underpinning barriers to early integration of PPC. These were explored in their narrative review from three vantage points—the perspective of healthcare professionals, parents, and communities.

Among healthcare professionals, it seems head knowledge does not necessarily translate naturally to right attitudes and best practice in the care of seriously ill children. Not uncommonly, until a child is deemed to be in the dying phase, early referral for palliative care support rarely happens. Empirical studies located in the review indicate this is prevalent across settings, regardless of stage of PPC development or extent of service provision locally. Considerations of triggers for attitude change and need for hands-on practice have already shaped current training initiatives in PPC (5) but still have room to expand within medical education at different levels, in the process of planning curricula and lesson delivery. The aspiration eventually is to align the head with the heart and hand. Formal support to professional staff by PPC specialists and routine interactions on the ward with the PPC team are

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examples proffered by the literature, where experiential opportunities for enduring practice change may reside.

Contrary to what clinicians believe, it appears from emerging evidence that parents may not be as averse to early integration of palliative care as perceived. This is an important point. Anecdotally, clinicians have often flagged concerns like parents' unreadiness for change in goals of care and possible feelings of abandonment whenever any referral to palliative care is raised. While acknowledging inherent tensions within these 'serious' conversations, the review paper cites Walter *et al.*'s work on "re-goaling" when engaging parents, and offers clinicians various strategies to optimise compassionate family-centred care (6). Examples listed include: providing prognostic certainty wherever possible, bringing awareness to the child's suffering, helping to establish new attainable hopes, equipping parents with skills to cope with negative emotions, and seeking congruence with personal "good parent" beliefs.

Lastly, it is fascinating that community perspectives on palliative care are sought in this review. In light of rising interest in the public health approach to palliative care and enactment of compassionate cities internationally, albeit mostly within adult palliative care, understanding the way our society sees PPC is now most relevant (7). Besides, experienced PPC practitioners, particularly social workers within the interdisciplinary team, have found Bronfenbrenner's Ecological Systems framework very useful in case work (8). The person-in-environment model that his theory encapsulates mandates evaluation of increasingly larger 'systems' (micro, meso, and macro) that the patient and family unit is situated within. 'Communities' in this instance refer to for example friends, school, or church at the meso level; likewise, the healthcare system or funding support that envelope all other systems at the macro level. Care and support at the micro level is contingent and influenced by forces and resources embedded at different levels or systems. Community perspectives on palliative care mentioned in the paper are hence pertinent in this context. Similar to the paradox within the professional group, just having "heard of" palliative care does not automatically change long-held perceptions (accurate or otherwise). "Accurate knowledge" is remarked as key. What this means is not elaborated by authors in the paper; however, higher education levels, prior experience with palliative care or knowing someone who had received care were found to be associated with more favourable knowledge, attitudes, and beliefs in palliative care.

Before summarising to conclude, a brief comment will

be made about the article's review methodology. The authors have adopted the Knowledge, Attitude and Belief (KAB) conceptual model to interrogate the literature and present their findings. While it is logical or intuitive to assume that enhancing knowledge (the accurate version!) with the view to shift attitudes or beliefs would lead to behaviour change (to embrace PPC!), evidence for the KAB triad remains weak (9). That said, factors that strengthen the attitude-behaviour relationship have been reported. Relevant ones that somewhat mirror examples highlighted in this review include personal factors like few competing motives, and high intellect or social abilities; situational factors like presence of a significant individual who supports the attitude or behaviour, and high expectations for the consequences of an act.

Where PPC is rendered, in the aftermath of a child's death, feedback from related stakeholders has always been good and occasionally even exceptional. Very frequently however, on looking back during bereavement, parents often wondered how it might be like if their sick child and the family had received support earlier in the course of disease. Similar experiences were shared with me during professional exchanges with colleagues at international meetings. The problem continues to plague practice every day, everywhere. These observations are now substantiated and mitigation measures have been suggested. A many-hands approach is needed from all stakeholders involved, to fulfil the promise that palliative care for seriously ill children is indeed a human right and help is always available, at the right time, in the desired place. Let us not disappoint our children and families anymore.

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aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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References

1. Sisk BA, Feudtner C, Bluebond-Langner M, et al. Response to Suffering of the Seriously Ill Child: A History of Palliative Care for Children. *Pediatrics* 2020;145:e20191741.
2. Knaul F, Radbruch L, Connor S, et al. How many adults and children are in need of palliative care worldwide. London: Worldwide Hospice Palliative Care Alliance (WHPCA) and the World Health Organization (WHO), 2020.
3. Saad R, Abu-Saad Huijer H, Nouredine S, et al. Pediatric palliative care through the eyes of healthcare professionals, parents and communities: a narrative review. *Ann Palliat Med* 2022;11:3292-314.
4. Benini F, Papadatou D, Bernad  M, et al. International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. *J Pain Symptom Manage* 2022;63:e529-43.
5. Friedrichsdorf SJ, Remke S, Hauser J, et al. Development of a Pediatric Palliative Care Curriculum and Dissemination Model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics. *J Pain Symptom Manage* 2019;58:707-720.e3.
6. Walter JK, Hill DL, DiDomenico C, et al. A conceptual model of barriers and facilitators to primary clinical teams requesting pediatric palliative care consultation based upon a narrative review. *BMC Palliat Care* 2019;18:116.
7. Kellehear A. Compassionate cities: global significance and meaning for palliative care. *Prog Palliat Care* 2020;28:115-9.
8. Bronfenbrenner U. *Ecological systems theory*. Jessica Kingsley Publishers; 1992.
9. Iverson DC. Reassessment of the knowledge/attitude/behavior triad. *Health Educ* 1977;8:31-4.

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