

High symptom burden in children with cancer and high parental satisfaction: why the disconnect?

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Pediatric palliative care (PC) has emerged over the past two decades as an approach aiming to ease suffering for children and their families coping with life-threatening illness, and has become increasingly integrated, concurrently, with disease-directed care. There is also recognition of the need for improved PC services in low- and middle-income countries. While most innovations occurring in PC are taking place in industrialized countries, over 90% of global child cancer deaths occur in low- and middle-income countries (1). Barriers to care include delayed diagnosis, limited access to therapies, insufficient and undertrained personnel and lack of infrastructure (2). Where services do exist, financial barriers may remain a significant concern (3). Especially frustrating is that access to even relatively inexpensive and easy to use treatments, such as morphine, remains inadequate due to both concrete and conceptual barriers (2,3).

A critical element to improving PC services in any country is the execution of careful, systematic studies both to provide evidence of need as well as to document areas of improvement and growth. In one of the first such assessments for low- and middle-income countries, Saad *et al.* examined the perspective of bereaved parents on the end-of-life experience for children with cancer in Lebanon (4). This study suggested that despite high satisfaction with the healthcare team, most children experienced significant symptom distress at end of life. Huijjer *et al.*, in a study published in the current issue of *Annals of Palliative Medicine* from the same center in Lebanon, attempt to advance previous findings by eliminating recall bias through a survey of parents of children currently receiving treatment for cancer (5).

Perhaps unsurprisingly, this study confirms previous findings, suggesting that despite high parental satisfaction, and despite the presence of a palliative care service at the institution, symptom management for children receiving cancer treatment remains a significant problem (6-10). The prevalence of significant symptoms was similar to that previously described (mean 7.42, SD 4.05), with irritability, nervousness, fatigue, and decreased appetite being most common. The notable emphasis on psychological and emotional symptoms may in part be due to the finding that nausea, vomiting, and pain were more likely to be addressed by the healthcare teams, though with treatment success of only 66.7-73.7%.

It is striking that the two major findings, high parental satisfaction and high symptom burden, would seem to be mutually exclusive. High parent satisfaction despite significant symptom prevalence might, as pointed out by the authors, be in part due to the quality of the medical center itself, ease of accessibility, and close monitoring. However, the finding of a relatively high PedsQLTM total cancer score (72.75, SD 15.47) despite reported symptom burden suggests that a major reason for parental satisfaction may simply be low expectations. Sadly, this finding is consistent with multiple studies across cultures and geographic locations; parents seem prepared to accept significant symptom burden on the part of their children simply because they do not think they should expect anything better (10).

The finding that the most prevalent symptoms, and the symptoms most troubling to parents, are psychological and emotional disturbances, should also act as a call for renewed efforts to address these concerns. Healthcare teams may focus on symptoms such as pain and nausea because

they are more easily elicited and clinicians may feel more qualified addressing them. However, psychological and emotional disturbances as reported here remain a major problem, and their prevalence increases in proportion to the length of time children are being treated, with parents of those treated for over nine months reporting significantly increased psychological, cognitive, and communication issues.

This finding highlights a perfect opportunity for an interdisciplinary PC team intervention. Palliative care, as has often been noted, is not simply about dying but rather about how to achieve the highest quality of living while facing potentially life-threatening illness. Palliative care teams have an opportunity to emphasize this by educating colleagues in other specialties, for example pediatric oncology, to improve their management of symptoms, including those less visible such as emotional and communication issues. Palliative care teams of course may also play an active role as consultants, integrating with the primary team and taking a leading role in managing symptoms. One limitation of the current study by Huijjer *et al.* is that it does not include a detailed description of the palliative care team at their institution; one wonders how and at what point the team is consulted for any given patient, as well as what sort of training the palliative care practitioners have received. It is difficult to know, therefore, whether earlier intervention by a palliative care team may have led to different results, as suggested by published data supporting greater success with earlier integration of palliative care (11,12). In addition, while the establishment of PC teams in low- and middle-income countries is to be applauded, the establishment of standards and guidelines for education and practice would also likely improve outcomes.

In brief, Huijjer *et al.* have contributed further valuable evidence of the need for improved palliative care for children with cancer. This type of study serves as a model for centers around the world seeking to improve the lives of children and families facing life-threatening illness. Their assessment provides an important foundation from which to grow, so that, ultimately, high parental satisfaction with care will be aligned with easing of suffering in children with cancer.

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