Trends in Pediatric Palliative Care Research (TPPCR) 2021; Issue #1: Commentary on *Taylor et al.*

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Abstract:

This TPPCR commentary discusses the 2020 paper by Taylor et al., “Consulting with young people: Informing guidelines for children’s palliative care.” published in Archives of Disease in Childhood.

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This paper is noteworthy first for its contribution in deepening our understanding of what youth with life-limiting or life-threatening conditions value in palliative care, and, what is missing in the literature. The authors utilized a qualitative (focus group or interview) approach to consult with 14 of these youth with a view to inform the development of policy and clinical guidelines. The premise explicitly takes account of the fact that while parents are often asked to represent these concerns, youth themselves are relatively voiceless, especially around policy and guidelines considerations. The desire for recognition of their individuality, quality of care rather than location of care, emotional well-being, and living as young persons emerged as the central themes. In paediatric palliative care we are always concerned about the patient but we are also concerned (rightly) with families. This research suggests that our ‘tilt’ may need re-orienting to the youth who deserve to be at the centre of our care, cognizant that the priorities of these youth can differ from parents and other involved adults (read: providers). Indeed medical experts and parents were seen as important sources of information to these youth but so were others (youth) who had lived their experience. Especially striking is the finding of unmet psychological needs with perceived barriers to access.

Secondly, and easily as important, is that this research places these youth at the centre of policy and clinical practice development in the larger sphere. To date, much research has focused on the views, experiences and solutions posited by healthcare providers and to a lesser extent, parents and other family members. Such work is certainly essential: in particular, impacts and needs relative to parents, siblings and extended family including grandparents acknowledges the continuing impact and consequent health needs of these persons. Healthcare providers can offer specialist knowledge as professionals as well as the accumulated experience of having work with many youth and families. Yet this study brings the voices of youth living with life limiting and life-threatening conditions to the fore. Attention to voice, whose story is heard, and whose is relegated to the margins are increasingly recognized as essential considerations in ethical analyses and direction for positive change. The conclusion that the priorities of these youth differ from those of their parents and their health providers is critical even while they value input from these

adults. At first glance, this may be difficult, especially for parents to appreciate. That said, I would expect the overwhelming majority of parents truly wish to know and support the needs and aspirations of their children during their shortened lives. This is a reminder for all of us concerned about these youth: this is their story. So what ought we to do with these observations?

First, of course is to re-double our efforts in attending to the voices of the youth we serve. We can make explicit our commitment to recognizing that their stories and their needs are best understood and communicated by them wherever possible. Secondly, in the development and application of policies and clinical practices we can acknowledge that there are limits to certainty around content as the priorities of health providers and parents do not always map effectively to the needs and aspirations of youth. In this context, it is key to recognize the importance of process, i.e. listening and attention, as youth themselves are diverse individuals. This diversity may arise in many ways and a clear appreciation may require the application of intersectional lenses if we are to understand the youth we encounter. These multiple (intersectional) viewpoints and experiences might include considerations such as gender, ability, ethnicity, indigeneity, community of origin, sexual orientation and so forth. Thus there is really no algorithm to inform the change that is needed in our practice, but rather explicit and habitual commitment to attending to the voices of youth. Taylor et al have demonstrated through this work there is much to be done in our clinical, research and policy efforts to recognize youth with life limiting conditions as the central figures in their own stories.

References

1. Taylor, J., Murphy, S., Chambers, L., & Aldridge, J. (2020). Consulting with young people: Informing guidelines for children's palliative care. *Archives of Disease in Childhood*. <http://dx.doi.org/10.1136/archdischild-2020-320353>.