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Outcome measurement for children and young people

Letter to the Editor

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Dear Editors

We read with great interest the recent review of outcome measures in paediatric palliative care (1). This publication in Palliative Medicine is an essential step in advancing the science for this underserved and understudied population.

The lack of an appropriate tool is a fundamental challenge when attempting to evaluate the impact of care. The authors rightly highlight the importance of developing and validating a tool that is relevant to the diverse range of conditions and problems that are typically seen in palliative care services for children and young people.

To address the lack of a measure, we note a series of additional population-specific methodological challenges that must be considered. Firstly, a tool should not focus on end of life as increased survival has led to disease trajectories for children that are characterised by slow deterioration and high dependency and disability(2). In terms of children's ability to participate in Patient-centred outcome measures (PCOMs), we do not yet know the optimal length, format, or whether optional items are needed for sub-populations. These issues of acceptability form a key aspect of validity, and any tool must be appropriate to the child's developmental phase as opposed to chronological age, complexity of language and communication needs (3). Social and educational engagement problems are also potentially radically different from

those outcomes measures from adults, and include play needs and sibling support.

PCOMs have paid inadequate attention to children with serious illness and their parents (4). This may be a direct result of the complexity of the science and implementation, including challenging issues of consent and proxy validity between children and parents.

It is timely to develop research protocols that can address these challenges, using the highest scientific principles of tool validation, while ensuring attitudes to the use of a resulting PCOM is optimised by engaging professionals in the planning stage (5). Involvement of all key end users (children, families and providers) is essential to ensure that clinically useful PCOMs can become routinely used in paediatric palliative care (6) so that access, equity and quality of care are optimised(7). As the number of children needing palliative care increases, the need for a valid and useful tool is urgent. Advances in the development and validation of outcome measures for children and their families accessing palliative care have been made in sub-Saharan Africa (8). South-North partnerships should be established to share learning and inform tool validation in high-income countries. We recommend core times are proposed wherever possible to facilitate international collaboration and comparison of outcome data.

1. Coombes LH, Wiseman T, Lucas G, Sangha A, Murtagh FE. Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use. *Palliat Med*. 2016.
2. Watson M, Hoy, C.; Wells, A. Paediatric Palliative Care. *Handbook of Palliative Care*. 2nd ed: Oxford Univeristy Press; 2009.
3. Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for Practice. 2004.
4. Child and Parent reported outcome measures: a scoping report focusing on feasibility for routine use in the NHS. 2009.
5. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ quality & safety*. 2014;23(6):508-18.
6. Antunes B, Harding R, Higginson IJ, EUROIMPACT. Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliat Med*. 2014;28(2):158-75.
7. Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. *BMJ*. 2010;340:c186.
8. Downing J, Atieno M, Powell RA, Ali Z, Marston J, Meiring M, et al. Development of a palliative care outcome measure for children in sub-Saharan Africa: findings from early phase instrument development. *European Journal of Palliative Care*. 2012;19(6):4.