Outcome measurement for children and young people

Letter to the Editor

Richard Harding  BSc, MSc, DipSW, PhD
Department of Palliative Care, Policy and Rehabilitation,
King’s College London,
Cicely Saunders Institute,
Bessemer Road,
London,
SE5 9PJ
richard.harding@kcl.ac.uk
0207 848 5518

Joanne Wolf MD, MPH
Dana-Farber Cancer Institute, Boston Children’s Hospital, Department of Psychosocial Oncology and Palliative Care,

Justin Baker MD
Quality of Life & Palliative Care, St. Jude Children’s Research Hospital
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.