

## Commentary on children's palliative care

Julia Downing<sup>1</sup>, Joan Marston<sup>2</sup>

<sup>1</sup>International Children's Palliative Care Network and Makerere University, Kampala, Uganda and PO Box 7072, Kampala, Uganda; <sup>2</sup>International Children's Palliative Care Network and Beacon Centre Coordinator, Cluster Box 3050, Asagay, 3610, South Africa

*Corresponding to:* Prof Julia Downing. International Children's Palliative Care Network and Makerere University, Kampala, Uganda and PO Box 7072, Kampala, Uganda. Email: julia.downing792@btinternet.com.



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The provision of palliative care for children has long been seen as a global concern (1) and the International Children's Palliative Care Network (ICPCN) believes that the total need of life-threatened or life-limited children should be met to encompass physical, emotional, spiritual and developmental aspects of care (2) and that they deserve a high standard of total care, wherever they live in the world. Palliative care services need to be reflective of the diagnoses and number of children requiring palliative care, along with the needs of the children and their families.

This paper (3) highlights the needs of children with cancer in Lebanon from the perspective of their parents. The study was conducted at the only referral centre in the country that specialises in children's palliative care (CPC), thus demonstrating the emerging and developing CPC service provision within the country. In a systematic review of paediatric palliative care provision around the world, Lebanon, was identified as one of 18.8% of countries where capacity building activity has been identified. Activities include attendance at, or organization of, key conferences; personnel undertaking external training; lobbying; and an incipient service development (4).

Themes, pertinent, to ongoing debate in international CPC can be identified in the paper, such as the need for CPC; measuring outcomes in CPC; assessing quality of life, the prevalence and management of different symptoms; understanding the parent's perspectives; and the importance of research from different countries and settings.

There is much discussion on the need for palliative care for children, both internationally and in the local setting. It is hard to ascertain accurate figures on the number of children worldwide that would benefit from palliative care, with estimations varying as much as between 7 and

20 million. Quantification of the need is complicated by factors such as uncertainty of population numbers; unpredictability of disease trajectories; access to preventative and curative services and, which children need palliative care. Indeed, gaining accurate statistics even for specific groups of children, such as those with cancer, is problematic. The International Incidence of Childhood Cancer group (<http://iicc.iarc.fr>), is currently undertaking data collection and analysis in order to provide an up to date account of childhood cancers throughout the world. Previous publications by the IARC in the 1980's (5) and 1990's (6) showed marked variations in cancer incidence in children in different parts of the world, with the world age-standardised incidence rates being in the range of 70-160 cases per million children (7).

Until recently, few studies had attempted to describe the experience of symptoms in children with cancer, often due to the lack of validated symptom assessment scales in this population. Whilst various symptom assessment scales, such as the Edmonton Symptom Assessment Scale (ESAS), Memorial Symptom Assessment Scale (MSAS) and the Palliative care Outcome Scale Symptom List (POS-S) exist as validated tools in adults, it is only recently that work has been done on evaluating the reliability and validity of such tools in children e.g., the MSAS (8,9). Indeed much attention is now being paid to the use of outcome measures within palliative care (10) and which are most appropriate (11). Work is also ongoing with regards to a more holistic outcome measurement for CPC, particularly within Africa where the APCA African C-POS is under development (12). Such is the importance of the use of Patient Reported Outcome Scales that the European Association of Palliative

Care has a task force currently working on a White Paper on the use of outcome measures in palliative care.

Understanding the experience of children through their parents, has engendered much debate. The use of proxy-measures for understanding a patient's experience is not new, particularly at the end of life and clinicians often ask the opinions of family members or informal caregivers to promote optimal care decisions [e.g., Lobchuk *et al.* (13)]. A report to the Department of Health in the United Kingdom in 2009 addressed the feasibility of developing child and parent-reported outcome measures alongside other quality service indicators for routine use in service delivery. The report suggested this was feasible along as the following issues were taken into account: the purpose of measurement needs to be clearly defined; that chronological age is not a hard and fast criterion for self-report due to variability in development; a generic child and family reported outcome measure should be selected; informed consent from both the child and their legal guardian is required prior to use; Children's own self-reports should be gathered whenever possible, parents reports can be taken but should be aggregated with self reports; there needs to be a well developed instrument for assessment of family centred services (14). Thus, in order to understand the full experience of children it is important to gather data from a variety of sources, including both the child and their parents/caregivers, thus providing a richer, and more true to form picture of the child's experiences. Within Huijjer *et al.*'s study (3) the children were old enough to respond, albeit at different levels of understanding, and an evaluation of their responses in relation to their parents responses would have been interesting and illuminating. Attempts have been made to adapt measures for use with family caregivers as well as the patient/child such as the MSAS and the Peds QL 3.0 Cancer module (parents version) as used in this study. The APCA African C-POS also has questions for the parents/caregiver as well as the child. The impact of illness on a child and their family is great and measures need to be able to capture this in order to develop interventions to reduce the impact of the disease.

An important recommendation from this study is that CPC professionals need to treat not only physical but also psychological symptoms in order to alleviate unnecessary symptoms. Whilst symptoms such as pain and nausea rated highly in terms of the most burdensome symptoms, others such as feeling sad, irritability and issues around body image also rated highly and whilst psychological factors were seen as burdensome, interventions were more focused on the

physical symptoms rather than on psychological support. As the child lives longer with cancer, these psychological symptoms became more significant, thus there needs to be an emphasis on the management of such symptoms, supporting both the children and their families through the illness. The WHO public health strategy for palliative care (15) includes education as a foundation measure for the provision of palliative care. It is important that education is provided not just in terms of physical symptoms, but also for the more complex psychological, spiritual and existential issues, which are not so easy to manage, and need sensitivity, empathy and time. Education programmes must not only develop skills and knowledge but also change attitudes (16) and most importantly, practice. They need to be based on recognised CPC competency frameworks and standards to ensure that psychosocial and spiritual issues are covered as thoroughly as physical symptoms. In a recent White Paper on education the EAPC identify meeting patient's psychological needs along with responding to the needs of families as two of the ten core competencies within palliative care (17) and it is essential that health professionals are trained in CPC according to the needs of the child and their families.

The need to develop an evidence base for palliative care has been identified globally (18), and is particularly important in the field of CPC, for example, in a review of CPC in sub-Saharan Africa, only five peer-reviewed papers were identified (19). The appointment of the first Chair in Paediatric Palliative Care for Children and Young People in the UK in 2010, highlighted the need for the ongoing development of the evidence base for CPC. Alongside this, funding through the Department of Health in the UK enabled the implementation of a variety of research projects, many of which are still ongoing (<http://www.30millionstars.org.uk>). Within CPC there is a critical need for evidence, resources, guidelines on best practice and opportunities for collaboration (20) and research needs to be multi-professional, focused on the needs of the child, from a local, national and international perspective. The ICPCN is committed to developing the evidence base for CPC and has undertaken a Delphi study to identify global research priorities.

As CPC continues to develop around the world, it is essential that research from different services and countries is published so that we learn from each other, and adapt our services as appropriate. Studies, such as this one from Lebanon, are important in increasing that evidence base, and in understanding CPC provision in different settings.

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