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Commentary

B.P. Himelstein[a,b,*]

[a]Program Director, Palliative Care, Children's Hospital of Wisconsin, Milwaukee, WI, USA
[b]Associate Professor, Department of Pediatrics, Division of Hematology/Oncology, Medical College of Wisconsin,
9000 W. Wisconsin Avenue, PO Box 1997, MS#7792, Milwaukee, WI 53201, USA

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1. Introduction

Although there are many practical differences between the UK and US in terms of healthcare systems delivery and finance, Mss Beardsmore and Fitzmaurice have identified many universally applicable aspects of an agenda for change in paediatric palliative care. In this commentary, I will emphasise some of these aspects with regards to clinical practice, education and research.

2. Clinical practice

A contemporary view encourages the partnership of palliative and curative therapies for children with cancer. For contemporary palliative care to be successful, families need 24-h access not only to expert paediatric care, but also to expert palliative care, the availability of respite, and a care coordinator to shepherd the family and healthcare team through the complex task of providing effective palliative care for a life-threatened child. There are several available models of palliative care delivery, including the nursing-based model described by Beardsmore and Fitzmaurice. In the US, demonstration programmes are being developed with an overall aim of moving principles of palliative care practice 'upstream' in healthcare delivery, to deconstruct the artificial separation between curative and palliative care so that they can be provided together, and to improve 'care coordination' for patients, families and treatment teams. Examples include the 'Program for All-Inclusive Care for Children' sponsored by Children's Hospice International, with federal government funding, and the 'Pediatric Advanced Illness Care Coordination' programme under development by a team of paediatric oncologists (Drs Himelstein, Kane, Friebert and Hilden) in conjunction with Dan Tobin and the Life Institute.

There are, however, major barriers within each of these care models. In the US, for example, (i) home health regulations exclude hospice and home health nurses from sharing care, (ii) care coordination services are non-reimbursable and (iii) meaningful respite benefits, and facilities capable of providing respite services for life-threatened children with complex medical, emotional and spiritual needs, simply do not exist [1]. As an international community, we must advocate for the rights of families and children to such services.

3. Education

Quality educational materials in paediatric palliative care are becoming more widely available. For example, the Children's International Project on Palliative/Hospice Services (ChIPPS) is developing a curriculum for interdisciplinary staff in addition to their already-published 'Compendium of Pediatric Palliative Care' [2], and a new paediatric palliative care textbook is in preparation (Drs Brian Carter and Marcia Levetown, Editors). Unfortunately, the availability of materials does not guarantee practice change. For example, process data for the 'Education for Physicians on End-of-Life Care (EPEC)' curriculum, a 'train-the-trainer' approach to education created by the American Medical Association, suggests that it has not actually been successful in the creation of new palliative care educators [3].

Research in educational methodology is needed, and funding and infrastructure for specialist training in palliative care are essential. Not only do we need to understand how to disseminate knowledge, but we also need to understand how to shape personal and professional core beliefs and values about life and death, and

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[*] Tel.: +1-414-266-6360; fax: +1-414-266-1761.
E-mail address: bhimelstein@chw.org (B.P. Himelstein).

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to encourage organisational and political changes that will 'open the door' to the acceptance and use of palliative care principles and practice.

4. Research

The research agenda in paediatric palliative care is broad, but also is conceptually and practically challenging because of the demographics of death in childhood, perceived ethical and emotional barriers to involving life-threatened children and their families in research, and limited funding. Our agenda must include funding for national and international collaborative research efforts in paediatric palliative care, including support for exploratory trials in all realms of clinical practice, and for the development and testing of relevant and reliable outcome measures. Here are just a few questions one could raise:

- Does an 'upstream' transition to palliative care, or palliative care provided in concert with curative therapies, have any short-term and/or long-term benefit for children and families?
- What are the relevant outcome measures for multidisciplinary paediatric palliative care interventions? We do not yet know how to accurately assess quality of life at the end of life, parental coping or efficacy surrounding facing death, the 'quality' of parental and sibling bereavement, or cost-effectiveness of our care.
- Is honesty always the best policy in discussing terminal care with children? How do we know when, and if, children and families should be escorted away from 'mutual pretense?' [4].
- When are families 'ready' for palliative care, and how do we gauge readiness?
- What is required to predict duration of survival in children with cancer? The data of Wolfe and adult data from Christakis [5,6] suggest that even if we have accurate prognostic information, we may not share it with our patients.
- What is appropriate symptom management? The data of Wolfe and Collins suggest that children with cancer suffer from many symptoms, with pain being less common than others such as fatigue [7–9]. How do we treat fatigue? When is it appropriate to use local or general anaesthetic techniques for pain? What is the role of non-pharmacological, pain and symptom management such as acupuncture or massage? What is the impact of different symptom control algorithms, if used, on quality of life? Why are the most basic pain management algorithms such as the 'World Health Organization (WHO) Ladder' not followed [10]?
- What role does transfusion play in palliative care? The adult literature suggests that red cells in selected situations may improve quality of life [11–13]. Anecdotally, prophylactic platelet infusion may prevent bleeding for children who have bled previously, but how does it impact upon quality of life?
- What is the role of complementary and alternative medicine in paediatric palliative care? Published adult data suggest an astonishingly high prevalence of use, yet there is little rigorous data examining the potential for benefit or harm [14].

Attention to physical, emotional and spiritual comfort—the hallmarks of palliative care—should always be provided with phase I therapies for malignant disease, and in some instances phase II or even upfront therapies. Realistic and non-coercive information, such as a description of the overall reported objective response rate to phase I therapies (7.9%), is critical [15]. Some families may see participation in phase I trials as a chance for cure or a chance to help others; others may not see the value at all. The child's and family's perceptions, goals of care and informed choices must be respected.

5. Conclusions

As so eloquently outlined by Mss. Beardsmore and Fitzmaurice, and expanded in this commentary, the 'wish list' for paediatric palliative care is a long one. The American Academy of Pediatrics [16] , ChIPPS [17] and the National Cancer Policy Board [18] in the US alone have recently published comprehensive wish lists, and the Institute of Medicine will soon publish comprehensive recommendations for change in the practice of paediatric palliative care this summer. The next step—the step that will require an extraordinary feat of collaboration between the multiple stakeholders—will be to move beyond the 'what to do' phase in order to figure out the 'how to do it', in order to create the action plans that will bring these wishes to life for the benefit of our children and their families.

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