

Paediatric palliative care: There is always more we can do

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A noticeable shift in both acuity and complexity has occurred in the care of ill children over the past decades. Children with conditions that previously required intensive care are now routinely cared for on the wards of our paediatric hospitals; those who once needed supervision in a tertiary care centre with each deterioration are now commonly admitted to community hospitals; and children whose health care needs at one time forced them to reside in group homes or institutions are now living at home with their families. Enhancements in our ability to address acute medical problems and advances in medical technology have resulted in a growing number of children who live with chronic complex conditions (1).

These children should rightly be viewed as part of the success of modern paediatric health care; however, to stop there is to tell only one part of the story. The number of technology-dependent medically fragile children account for a large and growing proportion of hospital admissions (2). They are living longer, but many still have conditions considered to be life-threatening, if not life-limiting, in nature. And unfortunately, our ability to improve the quality of life for many of these children, and their families, has not been as remarkable as our achievements in extending the duration of life.

While these changes were occurring in the field of paediatrics, palliative care emerged as a response to new, unmet needs. Born out of the modern hospice movement of the 1960s, care of the dying was the initial focus. Until that point, end-of-life care was primarily the responsibility of family members, often with the assistance of religious institutions (3). In the 1970s, Dr Balfour Mount, a Canadian urologist dismayed by the suffering experienced by terminally ill patients at Montreal's Royal Victoria hospital, helped to bring the hospice movement into the fold of the modern health care system (4). Mount called this discipline 'palliative care', from the latin word *palliare*, to cloak, partly in an effort to emphasize the goal of relieving pain and other forms of suffering, and partly to move away from the negative association with death that 'hospice' had acquired. More recently, the field of palliative care has evolved to include the goal of maximizing quality of life (5), which involves decreasing the 'bad stuff' (eg, alleviation of physical, emotional, psychological and spiritual suffering) and increasing the 'good stuff' (eg, providing necessary support, creating legacies). In so doing, the orientation of palliative care is now relevant not only to those who are dying, but to anyone living with a serious or chronic illness, regardless of prognosis.

Although paediatric mortality rates have decreased significantly over the past 60 years, the shift in palliative care toward maximizing quality of life has made it more relevant than ever to those working with infants, children and youth. Given the increasing numbers of children living with serious chronic complex conditions, the philosophy of palliative care is often appropriate from the time of initial diagnosis, and not necessarily by a paediatric palliative care subspecialist but, rather, by the clinician who knows the child best. Why should we wait until curative therapies have been exhausted to ensure that a child is comfortable? Why wait until issues become critical and panic sets in to initiate discussions about goals and limits of care (often by health care providers who barely know the child or family)?

Most of us worry about destroying hope, but all parents of children with life-threatening conditions worry about death. Most choose to focus on the good things and stay positive, but all have their moments of fear and doubt. Talking with children and/or parents about concerns and openly discussing challenges that may be ahead can be difficult, but such conversations may be desired and often bring relief (6). In reality, paediatricians engage in 'advanced care planning' everyday, we just typically prefer to call it 'anticipatory guidance'.

The current issue of *Paediatrics & Child Health* explores some of the significant questions that health care providers may have in addressing these issues.

For example, what happens when physicians and parents disagree on the use of potentially life-sustaining treatment? How do patients and families manage life-threatening illnesses, and how can clinicians help? Who should have access to paediatric palliative care, and what patients qualify for this type of support? Most importantly, what is the specific role of a health care provider in the delivery of palliative care for children, and when might physicians and patients both benefit from consultation with a paediatric palliative care team?

We realize and appreciate that the topic of life-threatening illness is complex, and includes differences of opinion on how to deliver the best care. As a most recent example, consider the Supreme Court of Canada decision on 'physician-assisted death'. While the decision opens the door for new legislation permitting physician-assisted death to consenting adults (children are not included at this time), debates on the subject both before and since the ruling have demonstrated strong feelings about end-of-life care in our society.

Despite the complexities that can surround discussions about approaches to life-threatening illness, there are basic premises that

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Canadians (who hold health care as a defining Canadian trait) do agree on. One is that Canadians need better access to palliative care. Moreover, we believe that all those who work with infants, children and youth with serious illness have a part to play in providing care that is best not relegated exclusively to paediatric palliative care specialists.

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We are deeply grateful to live and work in a country that places such a high value on health care, which is another way we express our ardor in placing our highest values on quality of life, even, and perhaps especially, for those whose lives may end early. May we all continue to strive to better serve those most vulnerable and in need.