Canadian paediatic palliative care: Challenges and promises

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I am a community paediatrician who practices far from a children's hospital. I have the honour and the challenge of caring for many infants, children and adolescents with conditions that put them at an increased risk for dying before they reach adulthood – children with profound cerebral palsy, difficult cystic fibrosis, severe congenital and genetic problems, complex cancers and several forms of rare degenerative neuromuscular and metabolic diseases. Each year, several of my patients receive end-of-life care, either at home or in our local hospital.

I am always grateful for the services of subspecialty colleagues (which, in my case, includes a paediatric palliative care specialist) who are available by phone, e-mail and teleconferencing from the IWK Health Center in Halifax, a 5 h drive away. I am also lucky to have a dedicated nursing colleague from our local adult palliative care service, who has a special interest in paediatrics.

We have a duty as physicians, working with allied professionals on established local and regional palliative care teams, to help our patients and families with difficult decisions, symptom management (physical and psychological), advanced directives, respite care, financial support and enquiring about parental, marital or sibling distress.

Often, parents will initially balk at the thought of inviting palliative team members to become involved, especially early on. Palliative care is often equated with terminal care: "Is the end so near?" "Are you giving up? Aren't there other aggressive or alternative interventions we should try?" "My aunt read something on Google." "Isn't palliative care for adults with cancer who have just a few days left to live?".

To help address this public discomfort with the term 'palliative care team', and get their foot in the door early, some centres, such as The Hospital for Sick Children (Toronto, Ontario), have changed their name to the 'Paediatric Advanced Care Team'. Whether more education or a name change is needed is up for debate. But to be clear, palliative care is so much more than just end-of-life care. It is about focused, organized efforts to maximize the quality of life for these children and their families, regardless of whether they have weeks or years to live.

There are many challenges. Prognostication is always difficult. So is tailoring developmentally appropriate conversations with our young patients. What should I have said to one of my eight-year-old patients dying of cancer who told me, "I want to grow up to be a fireman. I'm only eight. I'm too young to die"? Other challenges include understanding a young adolescent's role in decision making and working with parents who are estranged. End-of-life care calls for a special skill set for symptom management.

Being there for families during bereavement is also important, both for our families and ourselves. As I write this, I realize I need to devote more attention to my bereaved families, and maybe also to my own self-care. It is almost unworldly to transition from a rich and intense therapeutic relationship with a dying child and their family, whom you may have cared for for years, and then one day having it all disappear. This is where local and regional team partnerships can help.

Canada does not have enough paediatric palliative care physicians to serve all of the children and families in need, train paediatric residents and perform the necessary research to advance safe, good-quality care. The few specialists we do have are located in most, but not all, of our children's hospitals. This may mean that not every resident gets the opportunity to rotate on a palliative care service. Given the increasing number of children surviving with complex chronic illnesses, the demand on paediatric palliative care services to address quality of life issues will surely grow as well. It will be important for our academic leaders to address this gap as we move toward competency-based training programs. Some of our larger paediatric training programs should consider offering fellowship programs.

It will also be important for community paediatricians and family physicians to step up and address care gaps with a deliberate and professional approach. We need to be part of strong regional teams, and also build our local teams. We should embrace and participate in programs such as Education in Palliative and End of life Care (EPEC) Pediatrics Canada, which, starting this past year, will train regional instructors to deliver prepared curricula to frontline paediatric teams across the country. Refer to the extended abstract by Dr Kimberley Widger on page 157 of the current issue of the *Journal* for more information on this program.

The Royal College of Physicians and Surgeons of Canada, to its credit, has decided there will be a subspeciality certification in paediatric palliative care in the near future. They may wish to refocus the scattered paediatric palliative care objectives into a dedicated section, as does the College of Family Physicians. This may underscore the importance of this skill set to both trainees and educators.

The Canadian Paediatric Society is to be applauded for publishing this special theme issue on paediatric palliative care, and for offering frequent educational sessions at its annual meetings. The next step may be to consider creating a Section for Paediatric Palliative Care, in conjunction with the established Canadian Network for Palliative Care for Children.

Finally, as a young medical student, I remember hearing Dr Balfour Mount, a surgical oncologist from Montreal (Quebec) and the 'father' of palliative care in Canada, quote 19th century physician Edward Trudeau: "We cure occasionally, relieve often and we comfort always". Let us "comfort always" our young patients and their families with compassion and deep skill, supported by local and regional teams, and academic mentors who will both educate us, and discover and share the best evidence for safe, quality palliative care.

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