

Paediatric palliative care in Canada: A national survey of paediatricians

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Michael, a 16-year-old adolescent, was diagnosed with acute lymphoblastic leukemia at 10 years of age. He experienced a relapse one year after completing his initial treatment and received a bone marrow transplant. He was well until he recently experienced a central nervous system relapse.

Michael resided with his parents and two brothers. His primary physician and nurse practitioner spoke with him and his parents regarding his physical status (relapse, no further curative treatment indicated), and he was referred to a small paediatric palliative care (PPC) team (nurses and physician). Michael continued to be followed by the PPC service for six months; their primary focus was to maximize his quality of life. He received home care visits by the nurse for pain management. He continued to receive chemotherapy and platelet transfusions for palliation. The staff nurses continued to provide emotional support to Michael, his parents and his brothers. With various therapies and pain management options, the team helped him to accomplish a few remaining wishes that he expressed during his care, such as visiting his friends at school and celebrating his birthday in less pain.

Michael's physical condition continued to deteriorate and he was hospitalized for pneumonia shortly after returning home. He experienced an increase in pain and bleeding. He was readmitted to the paediatric unit. Morphine was adjusted via patient-controlled analgesia and, later that evening, Michael's pain was significantly improved, although he still had a restless night. He died the following morning. Michael's brothers arrived shortly after he died and many other family members and friends followed. The family remained on the paediatric unit for most of the day receiving support from staff.

Several PPC team members attended Michael's funeral service and remained in contact with the family long after his death. The doctors and nurses who followed Michael's care believed that he could have benefited from other PPC services had they been available in the community.

LEARNING POINTS

- PPC focuses on achieving the best possible quality of life for children and their families with life-threatening conditions.
- Clinical PPC programs exist in the major Canadian geographical centres; however, published studies indicate that a small percentage (between 5% and 12%) of Canadian children who would benefit from these services actually receive them (1).
- PPC teams are multidisciplinary and comprise various specialties; however, because of limited resources or access, a team often consists of a physician and nurse as the core team (1).
- To gain a better understanding of their patients' needs and their own needs, a one-time survey (2) was sent to Canadian Paediatric Surveillance Program (CPSP) participants in September 2013. The majority of paediatricians (78%) defined palliative care as consistent of end-of-life care and more. Fewer (17%) defined it as end-of-life care only, and 5% did not include a definition.
- Although paediatricians cited the need for many types of palliative care services, only 35% had referred their patients to a palliative care team and 18% did not have access to such a team. Of a total of 416 respondents (17% response rate), 219 (53%) indicated having cared for a patient(s) with palliative care needs during the month before receiving the survey.
- More than one-half of respondents (58%) agreed that all four broad groups (commonly known as quadrants) of children would benefit from PPC:
 - 1) progressive conditions in which treatment is exclusively palliative after diagnosis (92%);
 - 2) conditions for which curative treatment is possible but may fail (82%);
 - 3) conditions involving severe, nonprogressive disability, causing extreme vulnerability to health complications (77%); and
 - 4) conditions requiring intensive long-term treatment aimed at maintaining quality of life (75%) (3).
- Most frequently identified palliative care needs were support for family members (94%), coordination of services in the community (88%), physical symptom management (84%), respite care (81%), support for the patient (80%) and care at the time of death (78%). Only 48% of respondents believed that their patients were receiving all services needed.
- Paediatricians cited their professional needs, such as more support to manage their palliative patients with multidisciplinary teams (19%), more education about palliative care (14%) and easier access to a palliative care team (13%).

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CONCLUSIONS

Canadian paediatricians care for a large number of children with varying palliative care needs. Enhanced exposure to palliative care during residency training and continuing education programs would be beneficial to ensure paediatricians are aware that palliative care is meant to offer the best possible quality of life for children with life-threatening conditions and their families, and is not limited to simply providing end-of-life care. Educational opportunities may include topics such as palliative medicine, grief and loss, decisions to forgo life-sustaining medical treatments, and spiritual dimensions of life and illness.

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The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Canadian Paediatric Society and the Public Health Agency of Canada, which undertakes the surveillance of rare diseases and conditions in children and youth. For more information, visit our website at www.cpsp.cps.ca.