

Paediatric palliative care

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C Cyr

Paediatric palliative care focuses on achieving the best possible quality of life for children with life-threatening conditions and their families. To achieve this goal, paediatricians have to identify the needs of children with life-threatening conditions and provide care that responds adequately to suffering. This survey investigated how paediatricians define paediatric palliative care and their perception of the needs of children with life-limiting diseases.

A one-time survey was sent to 2485 Canadian paediatricians and subspecialists. Of a total of 416 respondents (17% response rate), 219 (53%) cared for a patient with palliative care needs during the month before receiving the survey. Most paediatricians (78%) defined palliative care as end-of-life care and more, 17% defined it as end of life only, and 5% did not include a definition. A majority (58%) agreed with the four broad groups of children who would benefit from paediatric palliative care (progressive conditions in which treatment is exclusively palliative after diagnosis, conditions for which curative treatment is possible but may fail, conditions requiring intensive long-term treatment aimed at maintaining quality of life, and conditions involving severe, non-progressive disability, causing extreme vulnerability to health complications).

Of a total of 1127 cases with palliative care needs, paediatricians cared directly for 861 cases (76%) without referral to a palliative care team. 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% felt that their patients were receiving all the services needed. Paediatricians cited the need for many types of palliative care services, such as more support to manage their palliative patients with multidisciplinary teams (19%), more education about palliative care (14%) and easier access to palliative expertise or a palliative care team (13%). Overall, only 35% had referred their patients to a palliative care team and 18% did not have access to a multidisciplinary team.

Canadian paediatricians care for a large number of children with palliative care needs. Despite recommendations to refer children to palliative care early in the course of illness, many paediatricians define palliative care as similar to hospice care. This survey suggests that Canadian paediatricians need to become familiar and comfortable with the provision of palliative care to children. Enhanced exposure to palliative care during residency training and continuing education programs would be beneficial and could include topics such as palliative medicine, grief and loss, managing prognostic uncertainty, decisions to forgo life-sustaining medical treatment, and spiritual dimensions of life and illness.

Principal investigator

Claude Cyr, MD, Centre hospitalier universitaire de Sherbrooke, Site Fleurimont, Sherbrooke QC J1H 5N4; tel.: 819-346-1110, ext. 74634; fax: 819-564-5398; Claude.Cyr@USherbrooke.ca