

Some parents weigh 'hastening death' for children in extreme pain with terminal cancer

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A survey of parents who had a child die of cancer found that one in eight considered hastening their child's death, a deliberation influenced by the amount of pain the child experienced during the last month of life, report Dana-Farber Cancer Institute researchers in the March issue of *Archives of Pediatrics & Adolescent Medicine*.

The study, the first to explore this sensitive area, suggests that many parents worry that their children will suffer from uncontrollable pain, and that some parents might consider that an early death would be preferable. The researchers say the findings underscore the importance of managing patients' pain, and of communicating with parents about the tools available for easing progressive pain.

"The problem is that conversations about these family worries may not always happen," said senior author Joanne Wolfe, MD, MPH, Division Chief of Pediatric Palliative Care at Dana-Farber and Director of Palliative Care at Children's Hospital Boston. "Parents may not have the opportunity to express these feelings and considerations, and as clinicians, we may not be adequately enabling sufficient opportunity for them to talk about their concerns."

Wolfe, along with first author Veronica Dussel, MD, MPH, a Dana-Farber research fellow, undertook the research to gain an understanding of why some parents would consider a measure as extreme as intentionally ending a child's life.

The researchers interviewed 141 parents of children who had died of cancer and were treated at Dana-Farber, Children's Hospital, or Children's Hospitals and Clinics of St. Paul and Minneapolis, Minn.

The scientists queried parents about their behaviors and feelings leading up to their child's death and at the time the survey was conducted, which was a year or more after the death. The parents were also presented with hypothetical vignettes involving a terminally ill child with uncontrolled excruciating pain or who was in an irreversible coma.

One in eight (13 percent) of parents had considered asking caregivers about the possibility of ending their child's life, though only 9 percent reported having such a discussion. Five parents, or 4 percent, had requested that their child's death be hastened, and 3 parents said it had been carried out, using morphine. Wolfe commented, however, that "this may not reflect what actually happened, because morphine is used in increasing doses to manage worsening pain without the intent or the effect of ending life."

In response to the hypothetical vignettes, 50 percent of parents said they endorsed hastening death in situations of uncontrollable pain or if the child was in an irreversible coma. Parents were 40 percent more likely to approve hastening death for a child experiencing extreme pain than for a terminally ill child in a coma.

Wolfe said it is important to keep the findings in perspective. Only five parents reported having talked about hastening their child's death, and 19 said they considered it. Wolfe said it is her experience that parents are comforted by having conversations about pain management and that most are reassured by knowing what will be done to ease their child's suffering.

"We've come a long way, because we have a good palliative and

supportive care program for children with cancer," said Wolfe, who is also an assistant professor of pediatrics at Harvard Medical School.

But she acknowledged, "I can never promise that their child will be pain free. We still have quite a way to go in figuring out the best way to ease suffering at the end of life." The gap exists in part, Wolfe said, because this area is not one given high priority for research funding agencies.

More information: Archives: <http://www.archpediatrics.com>
Palliative care: <http://www.childrenshospice.org>

Provided by Dana-Farber Cancer Institute

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