

# The dying child: Room for improvement in end-of-life care

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Many pediatricians and pediatric subspecialists believe that their clinical care extends from treating ill children through end-of-life care. However, are pediatricians actually meeting the needs of families and their dying child? In a new study scheduled for publication in *The Journal of Pediatrics*, researchers surveyed bereaved parents and found that pediatric end-of-life care needs improvement.

Dr. Malin Lövgren and researchers from Ersta Sköndal University College and Karolinska Institute in Stockholm, Sweden, surveyed 48 parents of children who did not survive [spinal muscular atrophy](#) (SMA) type I or II. SMA is a rare disorder characterized by slowly progressing [muscle weakness](#); most children with the most severe forms, type I and II, die within the first two years of life without respiratory support. According to Dr. Lövgren, "This survey aimed to explore the experiences and wishes of bereaved parents concerning end-of-life care for their child." The survey covered the time from diagnosis to after death, and included questions about their experiences with [end-of-life care](#) and their perceived role in decision making.

Thirty-two parents expressed wishes regarding where they wanted their child to die, half of whom wanted their child to die at home instead of the hospital. All of those who wanted their child to die in the hospital had their wishes fulfilled, but only 62% of those who wanted their child to die at home got their wish. Siblings were rarely engaged in the process; only four of 24 siblings received professional psychological support after the death of a brother or sister. Although 83% of parents

reported that health care staff said or did something in connection with the death of the child that was remembered as being especially supportive or considerate, more than 25% reported that health care staff did or said something distressing at the end of life.

Although the results show that health care staff typically provide strong support for families, more work needs to be done. Siblings have long been overlooked, and their need for continued support should be addressed. "Health care staff have found meaning and satisfaction from their role in bereavement care, but they experience logistical barriers, lack of training, and lack of support," notes Dr. Lövgren. In general, everyday clinical practices may need to be altered or even radically changed to ensure that both families and health care staff receive the bereavement support they need.

**More information:** Malin Lövgren, et al., "Parents' experiences and wishes at end of life in children with spinal muscular atrophy type I-II," *The Journal of Pediatrics* (2016). [DOI: 10.1016/j.jpeds.2016.04.062](https://doi.org/10.1016/j.jpeds.2016.04.062)

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