

Bereaved parents' experiences and wishes at the end of life of their child with spinal muscular atrophy (SMA) type I-II: A 10-year Swedish follow-up

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Conclusion

Parents' communication with the physician about their wishes and concerns regarding their child's end-of-life care and preferred location of death contributed to their wishes being fulfilled. Arranging that a child with severe SMA can die at home if the parents so desire must be facilitated, and the psychological support to healthy siblings needs to be improved.



Introduction

SMA is a rare, autosomal recessive disorder characterized by slowly progressive muscle weakness. Without respiratory support most children die within the first two years of life. Despite this there is poor empirical data regarding how the care of children with severe SMA is perceived by the parents.

Purpose

To explore experiences and wishes of bereaved parents concerning end-of-life care for their child with severe SMA.

Material and Method

This 10-year Swedish follow-up survey was conducted in 2013 on parents of children born between 2000 and 2010 and later diagnosed with SMA type I or II (N=48, response rate: 86 %) and for whom respiratory support was discussed during the first year of life. Questions in this sub-study covered location of death, support from staff, and parents' wishes and concerns about their child's end-of-life care.

Results

	Parents, N=48 N (%)
Parents present at time of death	48 (100)
Parents who did say goodbye before death	44 (92)
Parents who spend as much time as they wanted with their child after death	43 (90)
Preferred location of death*	
• Home	16 (33)
• Hospital	15 (31)
• Hospice	1 (2)
• No preference	17 (35)
Fulfilled wishes about location of death if parents preferred:	
• Home	6/16 (38)
• Hospital	15/15 (100)
Parents who had wishes about <u>how</u> the child would pass away	31 (65)
Twenty-six out of those (N=31) talked to a physician about their wishes at end-of-life of their child	
• Parents who had their wishes fulfilled	24/26 (92)
Sibling support offered	4/22** (18)

*More than one response alternative could be chosen.

**26 parents reported that the child did not have siblings or that the siblings was too young.

This was **especially supportive** in connection to the child's death:

- When staff:
 - showed respect, empathy and did their utmost
 - were present in the moment
 - made it possible to say goodbye
 - gave information to the family
 - dressed the child after death, held him/her and made the room beautiful
 - collected mementos
 - gave the parents time with the dead child
 - showed feelings

This was **especially distressful** in connection to the child's death:

- When staff or the funeral agency treated the child and/or the parents insensitively
- Inadequate pain relief
- Incorrect or no information
- That there was a change in shift on the ward at the time of death
- That the staff were stressed
- When the staff did not listen to the parents about how to treat their child



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