

PARENTS' EXPERIENCES OF INFORMATION AND DECISION-MAKING IN THE CARE OF THEIR CHILD WITH SEVERE SPINAL MUSCULAR ATROPHY A POPULATION SURVEY

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ASSESSING EXPERIENCES AND WISHES OF INFORMATION AND DECISION-MAKING

- treatment options for children with SMA - increases
- the choices and decisions that need to be made by healthcare staff and parents caring for them increase as well
- difficult ethical decisions about the wellbeing or survival of the child
- rare disease

- Small samples, qualitative research
- I Swedish study

FULL POPULATION SURVEY IN PARENTS

Denmark

2015

Children with severe SMA

Born between 1 January 2003 and 31 December 2013

Study specific questionnaire

Items: experiences and wishes concerning the provision of information and decision making

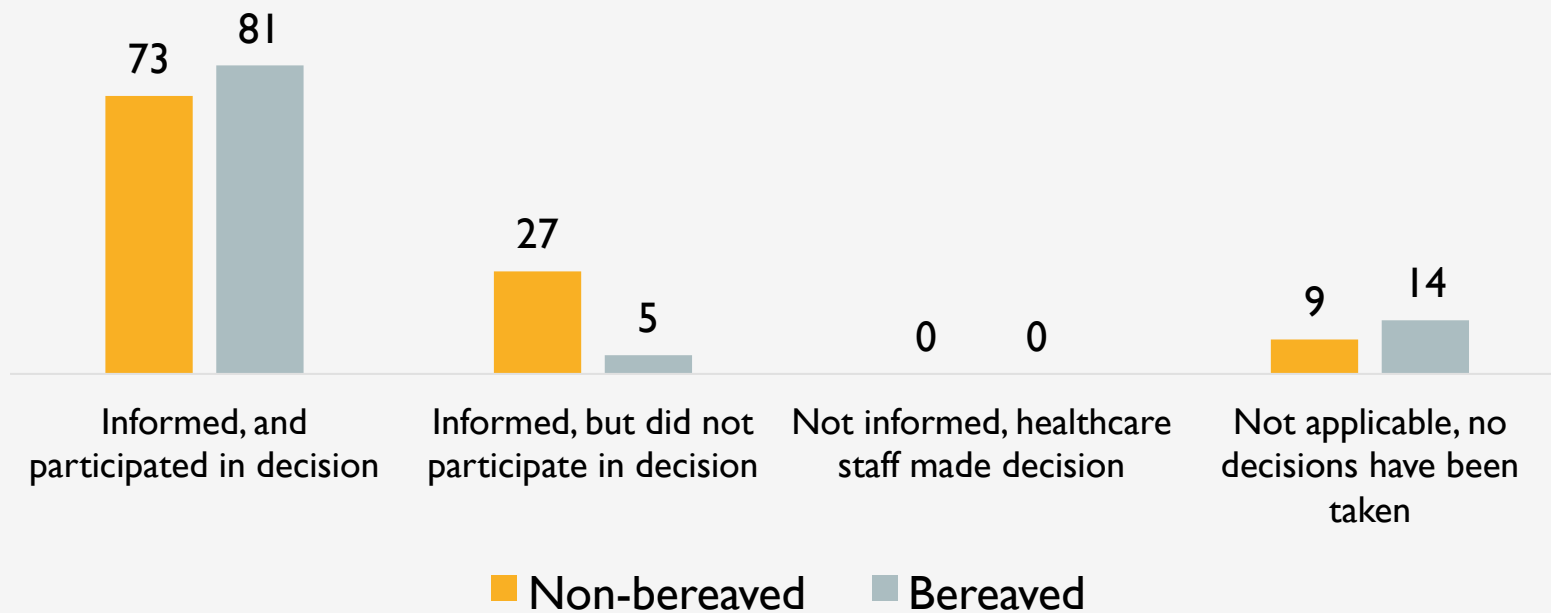
- Diagnosis
- Treatment
- End-of-life care

34 PARENTS

34/47 parents participated (21 children)

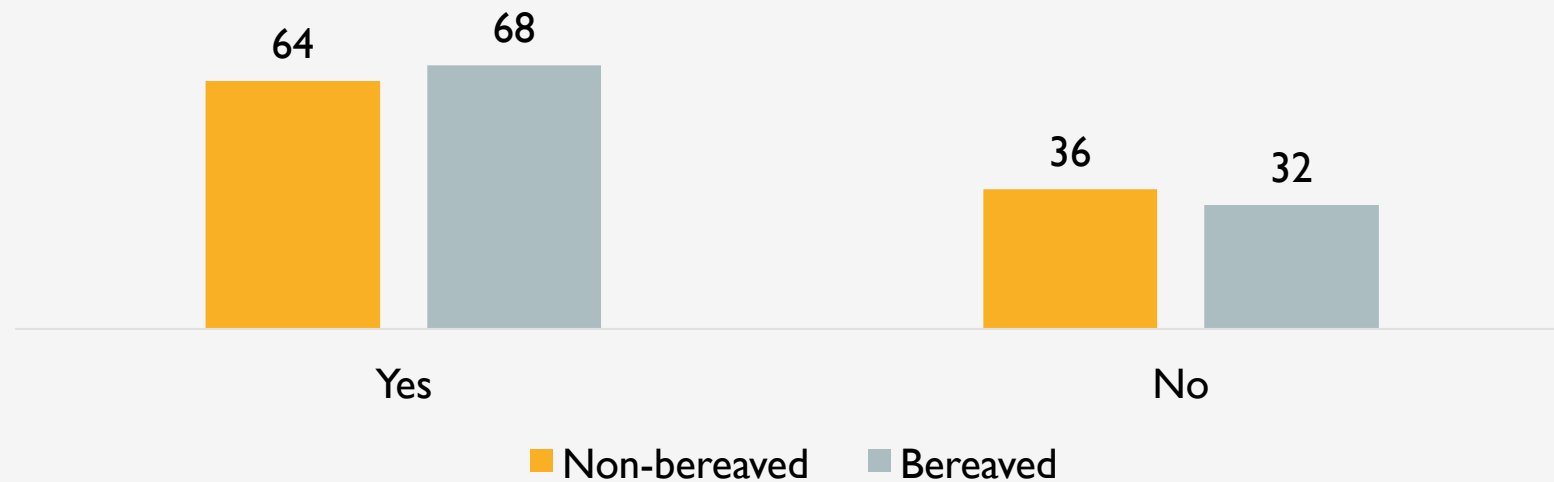
	11 Non-bereaved	23 bereaved
Age at time of follow-up/ death	5.7 years (2-10)	17 months (0-116)
Type I	2	19
Type II	9	1
Type I or II	0	1

HEALTHCARE STAFF DID NOT TAKE ANY DECISIONS WITHOUT INFORMING PARENTS (%)

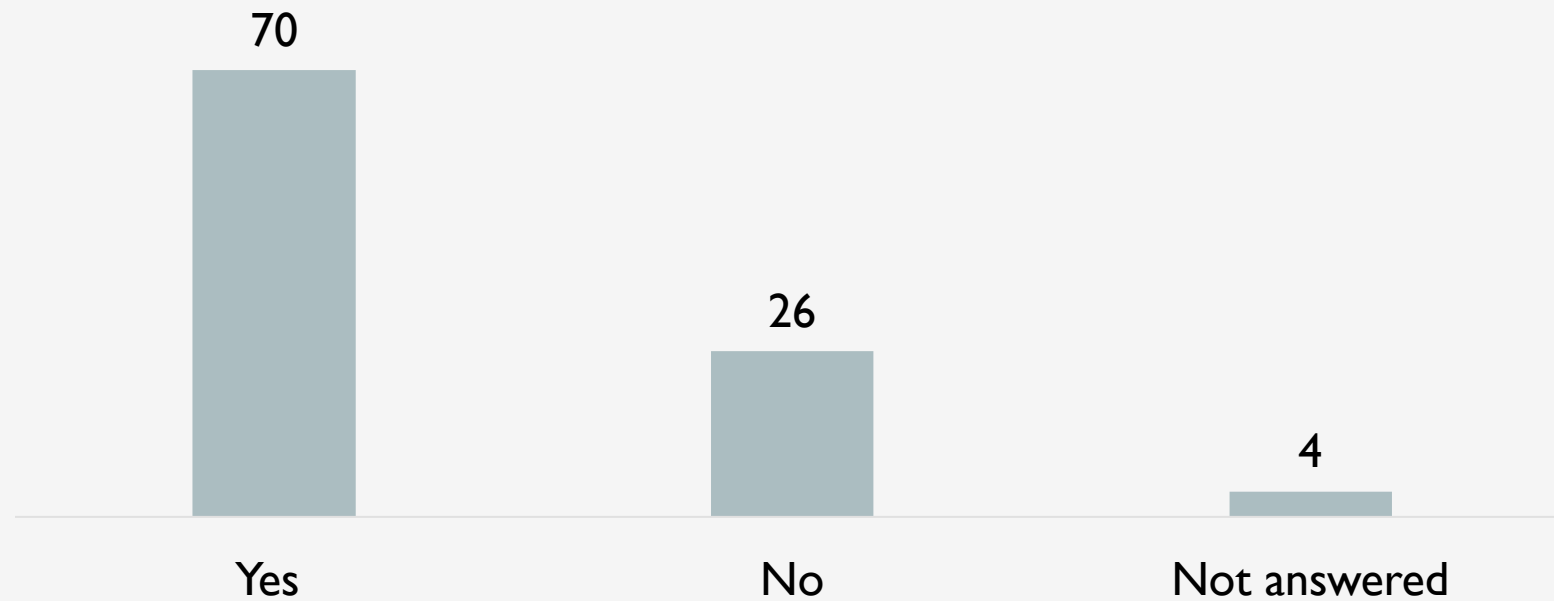


I/3 DID NOT GET INFORMATION ABOUT WHAT SMA ENTAILS (%)

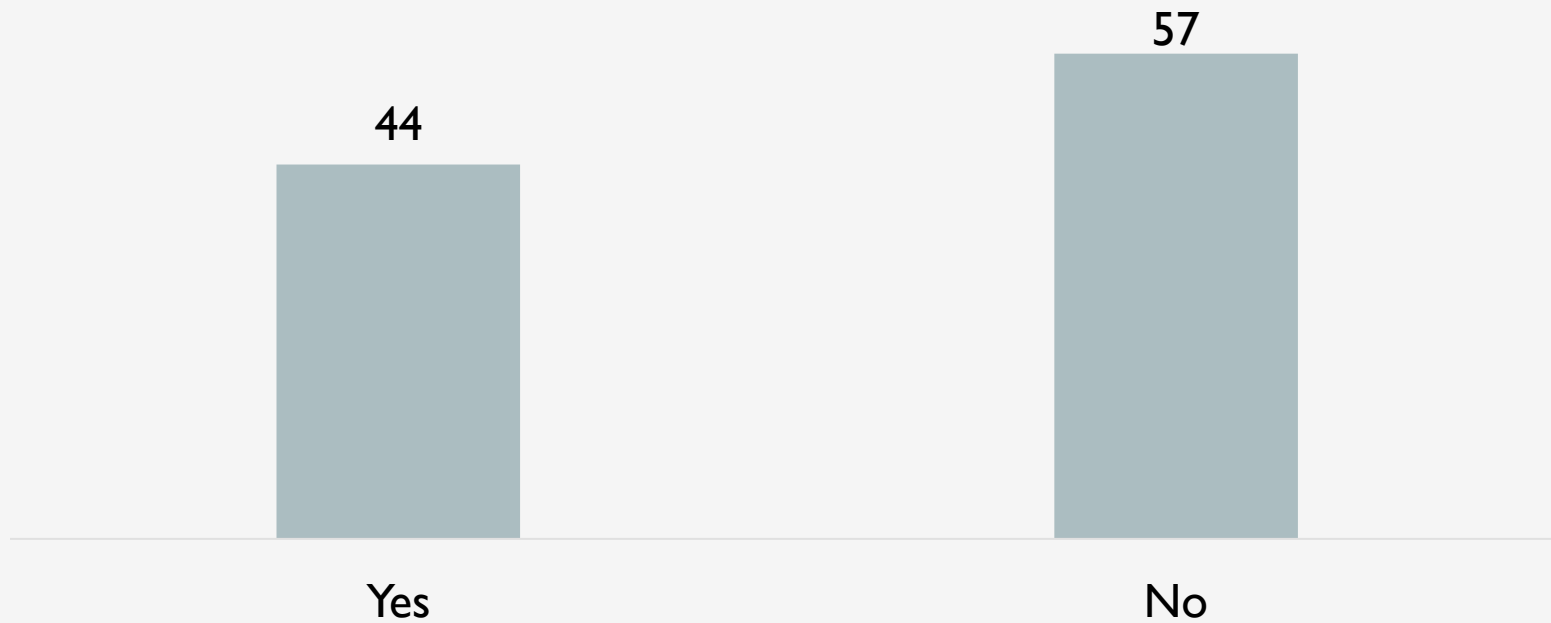
Were you given information that helped you understand what spinal muscular atrophy is?



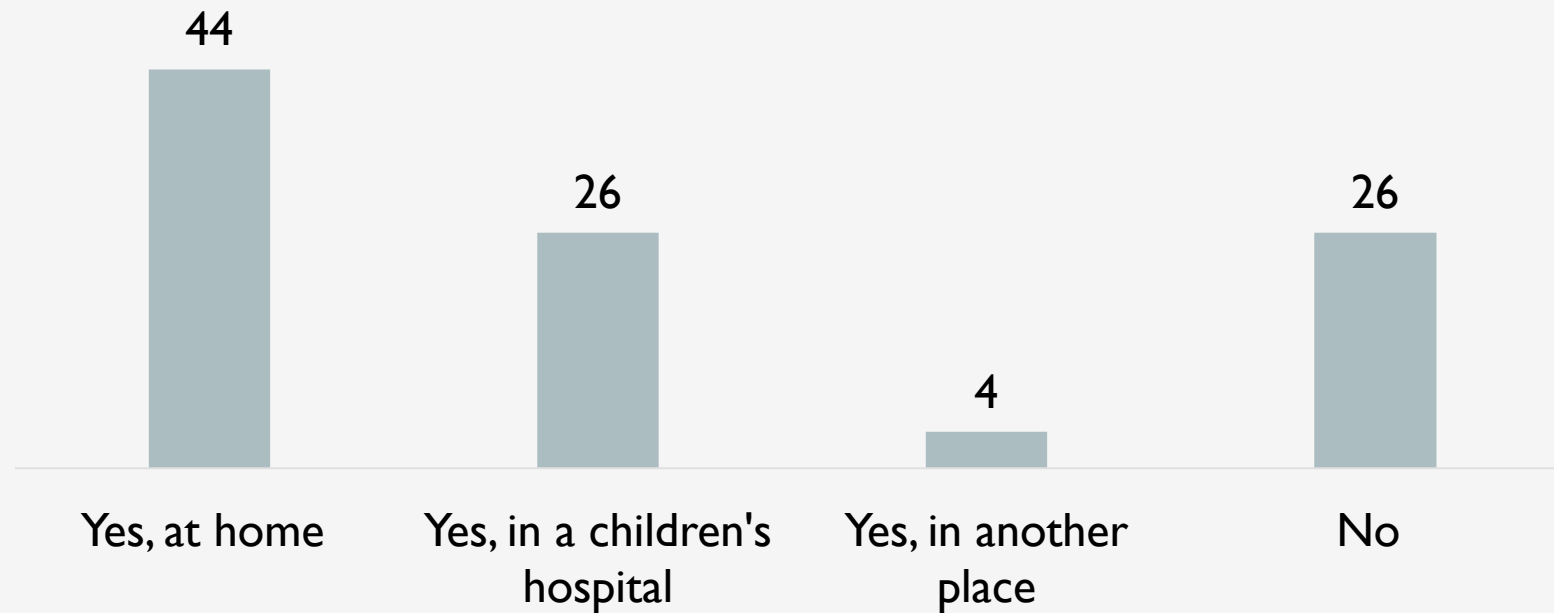
**¼ WAS NOT INFORMED THEIR CHILD
WOULD HAVE A SHORT LIFE (%)**



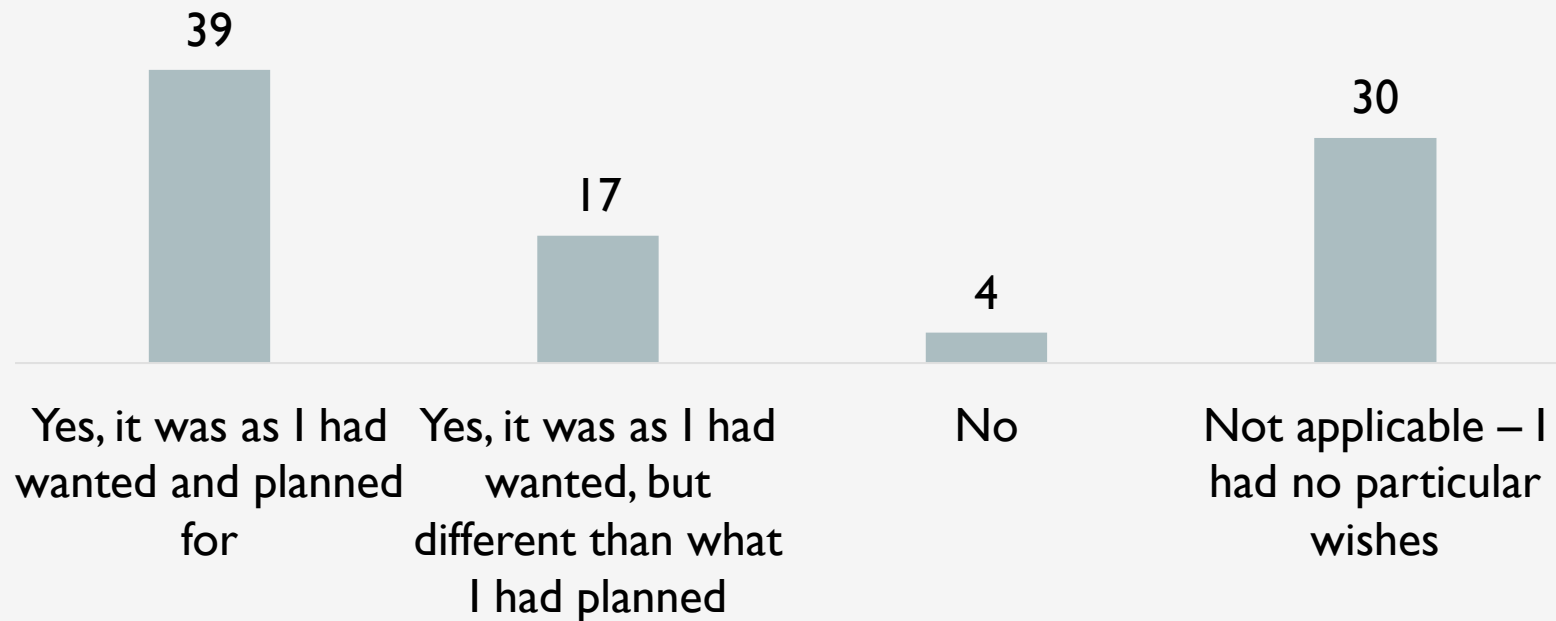
MORE THAN HALF OF THE PARENTS WERE NOT
TOLD THEIR CHILD WOULD PASS AWAY SHORTLY
(%)



WISHES CONCERNING *WHERE* THEIR CHILD WOULD PASS AWAY (%)



WISHES ABOUT *HOW* YOUR CHILD WOULD PASS AWAY (%)



TAKE HOME MESSAGES

- Health care staff did not take treatment decisions without parents being informed
- Room for improvement concerning information about what SMA entails, different treatment options and prognosis
- Possibilities of palliative care and advance care planning should be investigated for these parents, their child and health care staff

QUESTIONS

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