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
- 1 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 participated (21 children)

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<thead>
<tr>
<th></th>
<th>11 Non-bereaved</th>
<th>23 bereaved</th>
</tr>
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<tbody>
<tr>
<td>Age at time of follow-up/death</td>
<td>5.7 years (2-10)</td>
<td>17 months (0-116)</td>
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<tr>
<td>Type I</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>Type II</td>
<td>9</td>
<td>1</td>
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<tr>
<td>Type I or II</td>
<td>0</td>
<td>1</td>
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HEALTHCARE STAFF DID NOT TAKE ANY DECISIONS WITHOUT INFORMING PARENTS (%)
1/3 did not get information about what SMA entails (%)

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

- Yes
  - Non-bereaved: 64
  - Bereaved: 68

- No
  - Non-bereaved: 36
  - Bereaved: 32
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 (%)

- Yes, at home: 44%
- Yes, in a children's hospital: 26%
- Yes, in another place: 4%
- No: 26%
Yes, it was as I had wanted and planned for

Yes, it was as I had wanted, but different than what I had planned

No

Not applicable – I had no particular wishes

39

17

4

30
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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