Bereaved parents are more satisfied with care than non-bereaved parents - a survey study of parents to children with severe Spinal muscular atrophy (SMA)

Elin Hjorth, RN, PhD student
Ulrika Kreicbergs, RN, Professor
Thomas Sejersen, MD, Professor
Malin Lövgren, RN, Associate Professor

Jørgen Jeppesen, Journalist, PhD
Ulla Werlauff, PT, PhD
Jes Rahbek, MD, PhD
About SMA

- A rare neuromuscular disease
- Progressive muscle weakness
- SMA type 1, 2, 3
- Vital functions such as breathing and eating are affected
- No cure
Aims

To explore Swedish and Danish parents’ perceptions concerning:

1) whether the professional caregivers has taken every opportunity to help the child to feel as good as possible

2) parents’ satisfaction with the various locations of care

3) coordination of care between settings
Nationwide surveys in Sweden and Denmark

• Bereaved and non-bereaved parents of children with severe SMA in Sweden (N=61) and Denmark (N=34)
• Response-rate: 84 %
• Study specific questionnaires
• Descriptive statistics/content analysis
Characteristics

• 71 parents had lost their child and 24 had not
• 50 mothers, 45 fathers

• Deceased children - mean age at time of death: 1 year
• Living children - mean age at time of data collection: 7 years
If professional caregivers had done everything for the child

- 2/3 reported that the staff had taken every opportunity to help the child feel as good as possible

- Difference between bereaved and non-bereaved parents ($p<0.001$)
  - 81% of bereaved parents satisfied
  - 29% of non-bereaved parents satisfied
Free hand comments from parents (n=52):

- Disagreement regarding care
  
  *They didn’t agree to do what we wished*

- Proactive parental involvement
  
  *We have taken initiatives for all actions in contact with the care. They do as we say*

- Satisfaction with care

- Unequal care
  
  *I wish everyone had the same rights, regardless of where you live*

  *They are good at supporting and listening*
Satisfaction with various locations of care
• 1/3 reported coordination between care settings as poor

• Bereaved parents more satisfied with coordination than non-bereaved
Free hand comments from parents (n=41)

- Communication between settings
- Lack of knowledge and understanding about SMA
- Poor continuity of care
- Proactive parental involvement
- Geographic distances between settings

When we were moved from hospital to respiratory center, the center wasn’t updated on his condition.

It seemed as there was a lot of uncertainty about which hospital would handle our follow-up.

We had to be proactive to have a doctor to follow up his respiratory condition.
Bereaved parents were more satisfied with care than non-bereaved parents

- Importance of inter-professional communication and knowledge exchange
- Dialogue with family
Thank you for your attention!