

Caregiving demands in parental care for children with SMA

A qualitative study into the parents' experiences

M. van Kruijsbergen¹, M.C. Kars², M.J. Fischer¹, M. Verhoef^{1,3}, M. Ketelaar¹, W.L. van der Pol^{1,4}, C.D. Schröder⁵

¹Center of Excellence for Rehabilitation Medicine, UMC Utrecht Brain Center, University Medical Center Utrecht, and De Hoogstraat Rehabilitation, Utrecht, The Netherlands. ²Center of Expertise Palliative Care, Julius Center for Health Sciences and Primary Care, UMC Utrecht Brain Center Utrecht, Utrecht University, Utrecht, The Netherlands. ³Department of Rehabilitation, Physical Therapy & Sports, UMC Utrecht Brain Center, University Medical Center Utrecht, Utrecht, The Netherlands. ⁴Department of Neurology, UMC Utrecht Brain Center, University Medical Center Utrecht, Utrecht, The Netherlands. ⁵Ecare4you, Amerstroom, The Netherlands.

Background

Spinal Muscular Atrophy (SMA)

- A progressive neuromuscular disease
- Gradually leading to muscle weakness
- Causing difficulties in walking, sitting, swallowing and breathing.

When parenting a child with SMA, parents are confronted with increasing caregiving demands, which are perceived as a high burden.

AIM

To understand the caregiving demands parents experience when having a child with SMA

Method: qualitative study

- Data collection: 15 semi-structured interviews
- Participants: 22 parents (of 18 children with SMA)
- Data analysis: inductive thematic analysis

Table 1. Characteristics of parents and their child

Parents (N=22)		Children with SMA (N=18)	
Age	(26y - 52y) 36.2y	Age	(8w - 8y) 3.2y
Gender		SMA	Type 1 9
Female	(68,2%) 15		Type 2 6
Male	(31,8%) 7	Deceased	Type 3 3
			5
		Siblings	16

RESULTS

Caregiving demands

1. Management of the disease

Parents try to manage the disease by controlling the symptoms, organising optimal care or treatment and making medical decisions.

2. Create a life as comfortable or normal as possible

Parents try to create a life as comfortable or normal as possible by providing mental support to the child in coping with SMA, encouraging the independence of the child, and raising their child.

3. Family balance

Parents try to create a family balance by maintaining all family relationships, creating unity within the family, finding balance between work and care, and thinking of questions about expanding their family.



Feelings

Fear and insecurity

"What worries me the most is that I might lose him... that always worries me. It doesn't matter how many years will pass, that feeling is there."

Loss of control

"It was so scary because we don't have any control. We just heard that our baby was going to die, so we lost all control."

Guilt

"It is our fault, because we are the genetic carriers. That let us down and made us feel so guilty."

Loss of the dreamed life

"Our dream was to go on a backpack trip with our children. That is not possible now..."

CONCLUSIONS

- Parents report that their primary focus is on the fulfilment of many caregiving demands, mainly to manage the disease.
- Parents are confronted and struggle with several feelings, which sometimes interfere with their caregiving tasks.
- Parents report limited support from healthcare in dealing with their feelings and thoughts about their child and caregiving.

Clinical messages

- A shift to a more proactive approach to prevent psychosocial problems will improve care for parents and their children.
- Monitoring caregiving burden and need for psychosocial support, will...
 - ... provide healthcare professionals the possibility to discuss issues and to start proactive psychosocial support when needed.
 - ... acknowledge parents in their feelings and needs and support them by inviting them to discuss these important issues.