

RESEARCH ARTICLE

‘This battle, between your gut feeling and your mind. Try to find the right balance’: Parental experiences of children with spinal muscular atrophy during COVID-19 pandemic

Irene L. B. Oude Lansink^{1,2} | P. C. Carolien van Stam³ | Eline C. W. M. Schafrat⁴ |
Manouk Mocking⁴ | S. Dido Prins⁵ | Anita Beelen² | Inge Cuppen⁶ |
W. Ludo van der Pol⁶ | Jan Willem Gorter^{1,2,7} | Marjolijn Ketelaar²

¹Department of Rehabilitation, Physical Therapy Science & Sports, University Medical Center Utrecht, Wilhelmina Children's Hospital, Utrecht, The Netherlands

²Center of Excellence for Rehabilitation Medicine, UMC Utrecht Brain Center, University Medical Center Utrecht, and De Hoogstraat Rehabilitation, Utrecht, The Netherlands

³Eleos Mental Health Care Institution, Amersfoort, The Netherlands

⁴Department of Pediatric Psychology and Social Work, University Medical Center Utrecht, Wilhelmina Children's Hospital, Utrecht, The Netherlands

⁵Department of Psychiatry, Tergooi Hospital, Hilversum, The Netherlands

⁶Department of Neurology and Neurosurgery, UMC Utrecht Brain Center, University Medical Center Utrecht, Utrecht University, Utrecht, The Netherlands

⁷CanChild, Department of Pediatrics, McMaster university, Hamilton, Ontario, Canada

Correspondence

Irene L. B. Oude Lansink, Department of Rehabilitation, Physical Therapy Science & Sports, University Medical Center Utrecht, Wilhelmina Children's Hospital, Utrecht, The Netherlands.

Email: i.l.b.oudelansink@umcutrecht.nl

Abstract

Aims: Parents of children with spinal muscular atrophy (SMA) often struggle with the all-consuming nature of the demands of caring for a child with substantial physical needs. Our aim was to explore experiences, challenges and needs of parents of a child with SMA in a COVID-19 pandemic situation.

Method: Nineteen parents of 21 children (15 months to 13 years of age) with SMA types 1–3 participated in semi-structured interviews in June to July 2020. The interviews were analysed using inductive thematic analysis.

Results: Parents mentioned the protection of the health and well-being of the child as the central perspective and driving force during the COVID-19 pandemic. Three subthemes were identified: (1) responsibility, (2) balancing vulnerability and resilience and (3) (in)security.

Some parents focused on the positive aspects during the lockdown, such as continuation of nusinersen treatment and family life. Some parents described helpful and positive cognitions to cope with the situation. In general, parents described a need for information with regard to COVID-19 and their child with SMA and a need for discussing their dilemmas and insecurities with a healthcare professional.

Interpretation: Parents put the health and well-being of their children first during the pandemic. From this study, we learned that parents of children with SMA need information and value direct contact with a healthcare professional to share their dilemmas and insecurities. The dialogue can help to empower parents in the conflicts and decisions they have to make during a pandemic.

KEYWORDS

COVID-19 pandemic, decision making, family, parenting, spinal muscular atrophy, well-being

1 | INTRODUCTION

Hereditary proximal spinal muscular atrophy (SMA) is a severe neuromuscular disease that causes progressive muscle weakness and impairment. Due to the weakness, children are in need of supportive (para)medical care, and there is a high caregiving demand from the parents. Recently, three genetic therapies have been introduced (i.e. nusinersen, risdiplam and onasemnogene abeparvovec) that improve motor function in a substantial percentage of patients.

Before the introduction of genetic therapies, parents already struggled with the all-consuming demands of caring for a child with substantial physical needs and the ways in which this affects the emotional and social lives of the entire family (Chan et al., 2020; Halanski et al., 2014; Higgs et al., 2016; Qian et al., 2015; Rempel et al., 2004). A qualitative study of parents' experiences of taking care of their children with SMA in the context of new treatments (van Kruijsbergen et al., 2021) showed that autonomy and a feeling of being in control are important factors for parents to be able to carry out their task of caregiver, especially when they are confronted with additional factors.

On 27 February 2020, the first case of COVID-19 was confirmed in the Netherlands (RIVM, n.d.). The COVID-19 pandemic resulted in a general 'lockdown' in the Netherlands in the spring and summer of 2020 with movement restrictions and social distancing of people other than your own household members. These restrictions especially affected patients with a chronic disease and their family members (Arim et al., 2020). People had to work from home and school and day care centres were closed. Regular outpatient hospital visits were postponed, but urgent and necessary care was continued if possible.

In the beginning of the COVID-19 pandemic, nothing was clear about the transmissibility of COVID-19 and the risk for children with neuromuscular diseases. SMA is characterized by respiratory muscle weakness and increased vulnerability to viral infections (Wijngaarde et al., 2020). From the start of the COVID-19 pandemic, parents with a child with SMA were confronted with new levels of challenges and uncertainty, including whether intrathecal nusinersen treatment could be continued, extra demands in caregiving, increasing stress and need for additional decision making about going to school and therapies.

Parents had to make many difficult decisions, often lacking sufficient and specific information (Arim et al., 2020; Cacioppo et al., 2020). Since the outbreak of the COVID-19 pandemic, several articles have been published about the difficulties parents of children with chronic disabilities experienced due to the COVID-19 pandemic (Arim et al., 2020; Cacioppo et al., 2020; Darlington et al., 2021; Dhiman et al., 2020; Disabled Children's Partnership, 2020; EACD COVID-19 Surveys Initial Report, 2020; Grumi et al., 2020; Majnemer et al., 2020). Families with children with disabilities or chronic diseases experienced difficulties due to social distancing, reduction in services (like rehabilitation), and the mental load (anxiety and depression) in combination with the lack of help/support and other restrictions to prevent the spreading of the virus.

All of the above-mentioned studies were online surveys (Arim et al., 2020; Cacioppo et al., 2020; Darlington et al., 2021; Dhiman et al., 2020; Disabled Children's Partnership, 2020; EACD COVID-19

Key messages

- Protecting the health and well-being of the child with SMA is the central perspective and driving force mentioned by parents, during the COVID-19 pandemic.
- During the COVID-19 pandemic, parents focused on keeping balance between the risk of getting affected by COVID-19 and the mental and physical well-being of their child with SMA, siblings and family.
- Parents appreciate information and conversation with healthcare professionals to reflect on the insecurities/decision-making process of parents.

Surveys Initial Report, 2020; Grumi et al., 2020), providing quantitative data. Only in one study (Darlington et al., 2021) added open text box questions qualitative data, providing some insight in the experiences of parents of children with cancer, in relation to the virus, lockdown and isolation in children with cancer. The results globally demonstrated views and experiences of this population, and the authors emphasize the importance of future studies in order to understand the ongoing experiences of families. In general, we feel it is important to get insight into the perspectives and experiences of parents, including the reasoning behind the choices parents made. The aim of this study was to explore experiences, challenges and needs of parents of a child with SMA in a COVID-19 pandemic situation.

2 | METHOD

We conducted an exploratory qualitative interview study with parents of children with SMA. This study is reported in accordance with the guidelines of the Standards for Reporting Qualitative Research (SRQR) checklist (O'Brien et al., 2014).

2.1 | Participants

We invited parents of a child with SMA Types 1, 2 and 3, aged <16 years to participate in this study. Treatment of SMA with genetic therapies in the Netherlands is centralized in the UMC Utrecht (UMCU). Not being able to communicate in Dutch or English was reason for exclusion from the study.

We recruited parents through an invitation in the widely read newsletter of the SMA Center at the UMCU that is being sent to all families of children with SMA. Parents of children with SMA Type 1 who were in regular contact with the social worker of our team were reminded of the invitation at the end of the conversation. Parents who were willing to participate received an information letter. Two weeks after this first announcement, all parents of children with SMA Type 1, 2 or 3, <16 years who had not responded to the invitation also received an information letter.

Parents were contacted to schedule the interview after their consent. We ensured anonymity of participants by changing names in the transcripts before the start of the coding process. We assigned a research number to all participants and the key to the corresponding personal data could only be accessed by researchers planning and conducting the interviews (ES, MM) and by the study coordinator (CvS).

The Medical Ethics Committee of the University Medical Center exempted this study from Medical Research Involving Human Subjects Act (17-904); all participants gave informed consent.

2.2 | Data collection

We collected data by means of semi-structured interviews using a topic list with relevant issues of the COVID-19 pandemic, including the impact of the COVID-19 pandemic on well-being of the family, resilience and expectations parents have from the hospital and clinicians (see topic list in Appendix A). The content of the topic list was based on expert clinician input and parent's questions and input in the first months of the pandemic. Two trained psychological assistants (ES, MM) performed these semi-structured interviews via telephone calls between June 3 and July 30, 2020. In this time frame in the Netherlands, we faced the original COVID strain. The interviews were audio-recorded and transcribed verbatim.

2.3 | Data analysis

We collected and analysed data simultaneously in an iterative process. A thematic analysis was conducted as described by Braun and Clarke (2019).

First, researchers (ES, DP, MM, CvS and MK) prepared and familiarized themselves with the data by listening to interviews and reading transcripts. Notes of the initial ideas were collected and discussed within the research team. Second, two transcripts were open-coded by two authors (ES and DP) independently. They compared and discussed findings and codes until they reached consensus. Next, four researchers (CS, ES, MM and DP) coded six interviews in different pairs and through discussions in regular team meetings constructed a preliminary code tree. ES coded the remaining transcripts.

Based on the list of codes, four authors (ES, CvS, DP, MM) discussed potential themes and interrelated elements, led by MK. We discussed and formed (sub)themes, checked if the themes worked in relation to the coded extracts (Level 1) and the entire data set (Level 2) and generated a thematic 'map' of the analysis. ES refined each theme in consultation with CvS, DP, MM, IOL, and MK. The proposed definitions of the themes were checked by ES with the original transcripts and codes. Finally, three authors (ES, IOL, MK) worked out the overall story line. The preliminary results were discussed with the entire team. QRS NVivo 12 software was used to support data analysis.

3 | RESULTS

3.1 | Participants

We sent the invitation for participation to 120 families. Parents from 24 families gave permission to be contacted (20%), with a withdrawal of five parents after initial permission. We included parents of 19 families with 21 children with SMA (Table 1). After 16 interviews, we approached code saturation, and after three additional interviews, we confirmed code saturation. Duration of the interviews varied from 40 to 90 min, with an average of 55 min. In two interviews, both parents were present. We interviewed 16 mothers without the father present and one father without the mother. Parents' and children's characteristics are summarized in Table 1.

Qualitative analysis of the interviews showed that the essence of the experiences of the respondents fell under four main themes, with one overarching theme and three subthemes. Protecting the health and well-being of the child was found as the central perspective and driving force mentioned by parents, with three subthemes (1) responsibility, (2) balancing vulnerability and resilience and (3) (in)security.

These (sub)themes cannot be interpreted separately, as they are intertwined (Figure 1). The overarching feelings regarding the health and well-being of their child affect parents' considerations regarding

TABLE 1 Characteristics of parents participating in the interview ($n = 19$)

Gender of the parent	
Mother	16
Father	1
Couples	2
SMA type	
SMA Type 1	6
SMA Type 2	10
SMA Type 3	5
Age child (years)	
Min-max	1–13
Median	7
Interquartile range (IQR)	5
Sex child	
Male	10
Female	11
Siblings	
Yes	12
No	7
Families with two children with SMA	2
Treatment for SMA	
None	1
Nusinersen (Spinraza [®])	17
Risdiplam	3

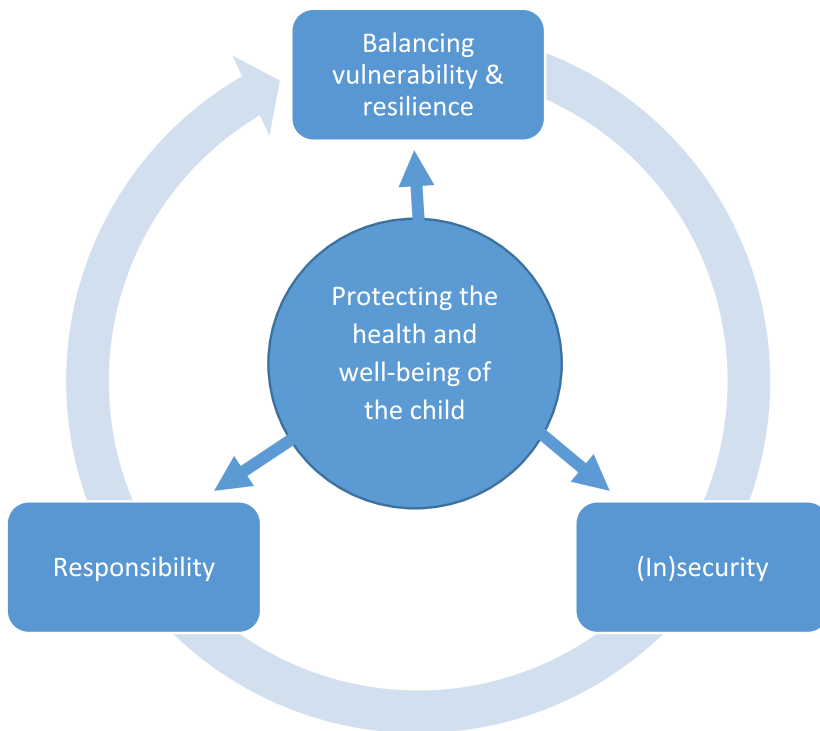


FIGURE 1 Overarching theme and three subthemes

responsibility, (in)security and the balance of vulnerability and resilience, which in turn in the interviews often were interrelated.

3.2 | Protecting the health and well-being of the child

This battle, between your gut feeling and your mind.
Try to find the right balance.

This quote summarizes the predominant feeling of parents with a child with SMA during the COVID-19 pandemic. The priority of all participating parents was to protect the health and well-being of their child. In an attempt to prevent any family member getting infected with the virus, there was no other choice than to withdraw from public life during the lockdown at the peak of the pandemic for most of the families.

I was so worried, that I decided that nobody could enter or leave the house, no caregivers. Our bubble reduces my worries.

We completely isolated ourselves, at least the first eight weeks ... we did not do anything, no therapy, no caregivers at our place, nothing: just the five of us.

Parents experienced various difficulties in decision making after some of the restrictions in the Netherlands were lifted (because of reduction of COVID-19 infections in the country).

... you have many things to consider, you have to overthink a lot and make a lot of decisions ...

Parents struggled with the necessity to keep their children inside in order to reduce the risk of a COVID-19 infection. For some children, it was difficult not to have social contacts, and parents described the struggle of their children because they missed their family members, caregivers, school and friends.

Yesterday, she went back to school again for the first time, which she found amazing. She had missed her friends at school a lot, she is really keen on social contacts, wants to play with other kids and is really nice to other children. Yes ... she missed that a lot.

Parents struggled how to make the best decision for the well-being of their child, balancing between the risk of an infection and the social-emotional well-being of their child by letting them go to school and play with friends.

My daughter also sees other children going outside. There was the limitation of COVID-19 restrictions, with children below 12 years old going outside. I felt like having two choices. I could anxiously keep my child home, to protect her from the risk of getting infected ... thereby creating a child that is sad, miserable and grumpy. Or I could choose to increase the risk of getting infected, but I see my child being happy, participating in society and enjoying her life.

3.2.1 | Responsibility

Yes, yes, we will manage to find the discipline to deal with the situation, because it is for the best of your child. We will do anything for our child.

Parents felt great responsibility to protect the health and well-being of their child with SMA. Most parents wanted to continue intrathecal treatment with nusinersen for their child to ensure continued effectiveness. Most parents considered treatment for SMA more important than doing everything to prevent infection with COVID-19. Sometimes, parents described the feeling that they did not even think about having a choice; delaying treatment was not an option. Also, some parents said they were lucky to have had an appointment for nusinersen injection prior to the lockdown, so there was no need to visit the hospital again soon.

... well you want your child to get the nusinersen treatment and therefore you need to go to the hospital, that's how it is.

Almost all supportive treatments, such as physical therapy, hydrotherapy and occupational therapy, were cancelled because of the lockdown. Parents were afraid that not having therapy for a long time would negatively affect their child's well-being and felt responsible to take over these therapies as much as they could, mostly using video consultation with a therapist. Sometimes parents allowed therapists to come over, but with restrictions and personal protective equipment. Staying at home was still favoured in comparison to going to a physical therapist or rehabilitation centre. When therapies restarted in the Netherlands (due to limiting of COVID-19 restrictions), parents often decided to slowly resume therapies, sometimes starting in their home environment. Parents felt a challenging balance in taking responsibility to make the right decision for their child with SMA: Physical therapy is medically necessary but with additional risk of getting infected with the COVID-19 virus.

So in this case the mind beats the gut feeling, because it is important to take care of the child's teeth and eyes, so the doctors' appointments had to continue.

... we really tried to keep our child active and putting him in the stander every day.

We did go to really important appointments, because there are also different welfare interests than the prevention of a COVID-19 infection.

Also, some parents described their child with SMA being more sad than usual because they missed their peers. Parents felt responsible for the mental well-being of the child with SMA and the (mental) well-being of their siblings.

I want for her to be able to participate in society, despite the fact that we from our point of view are afraid that she will be infected.

Parents and siblings also missed their social contacts. Parents expressed the dilemma to balance between the best practice for their child and relaxing/social time for themselves or siblings.

3.2.2 | Balancing vulnerability and resilience

At the start of the pandemic, parents felt anxious and vulnerable due to the increasing number of infections while information on risks for children were lagging behind. For example, in the first weeks of the lockdown, parents reported to be more scared, compared with the time of interview a few months after the start of the pandemic. Parents expressed that their anxiety decreased when it became known that children were less susceptible to (severe disease caused by) the virus and did not play an important role in virus spreading. This influenced their decision making.

Parents expressed having a hard time, but quickly followed with statements of always being capable of coping with the situation. One parent, for example, mentioned that she was glad her husband had to work from home and that she would not have known how to deal with everything if he would be working at the office. Another parent said: 'the restrictions were tough and if I wasn't able to go out for a walk to have some time for myself, I would not have been able to deal with the situation'.

Coping strategies for parents that stood out were (1) to compare with others: 'fortunately, we only have one child with SMA' or 'we are lucky, because our child is not in need of a lot of medical care in comparison to my sisters' child'; (2) to adapt to the situation: 'from the day our child was born we constantly need to adapt to new situations, now again we need to adapt to the COVID-19 situation, but we are used to adapting now'; (3) focusing on the positive aspects: 'it is a very challenging time, but thankfully we have a garden'.

Finally, one parent stated: 'a lot of people felt it was intense to stay at home and that it was difficult to cope with restrictions, but that's what we have to deal with all the time'.

Sometimes it helped parents to set their own hesitations aside in favour of their child. However, other parents still expressed their fear of infection as being extremely high at the time of the interview, thus maintaining their previously instated restrictions. Although parents felt vulnerable, with sometimes feelings of anxiety and depression, parents also showed resilience.

... well, I have experienced it as pretty tough, you know why? I have a very high workload and was also taking care of the children, combined with all the homeschooling and having to make telephone calls for work. Well, I managed, but every now and then it was tough and I wasn't happy at all. Absolutely not

It was tough and really heavy. Because next to taking over the therapy, I also had to home school my child and taking over all the caring. My day literally only consisted of three things: taking care, home-schooling and taking over therapy.

Your mood goes in all directions, from very confident and calm to just overtired and hysterical and then back again.

Parents felt there was less time for themselves to relax and go out with friends and siblings were missing their friends. They described that being a two-parent family, taking time for themselves, the thought that giving up was no option and a positive mindset had helped. Despite of these supporting factors, parents often experienced insecurities.

You know, we are not going to give up. We are fighters and we go for it. We have to deal with it, do what we have to do without realizing how hard it is.

3.2.3 | (In)security

The interviews showed that some situations created a feeling of insecurity in parents while other situations did not.

You have to make a lot more decisions, you have to think about a lot of things and make new choices, like could my child be in contact with other children?

Exactly, people ask whether she is going to school again or when we want her to go back to school. I do not know!

Almost all parents experienced a lack of information. During the COVID-19 pandemic, the frequency of the contacts between all parents and healthcare professionals was decreased. And when they did speak to each other, the health care professional often did not have the answers parents were yearning for. Many parents were disappointed with the scarcity and ambiguity of information they received. Parents often did not feel sufficiently in control to be able to fulfil the caregiving demands. Many parents described a feeling of insecurity to go to the hospital for an appointment. Sometimes this feeling disappeared after the hospital visit. One parent described to have been reassured after the hospital visit.

That first fear of going to the hospital. Is it safe to go to the hospital, do professionals maintain the 1.5 meter social distance, is everyone protected? But everyone was really relaxed in the hospital, after seeing that, I was more relaxed myself.

Parents felt more secure when it seemed that children were not severely affected, that children with neuromuscular disorders did not seem to have a higher infection rate nor being severely affected and that general infection rates decreased. Several parents decided to wait a couple of weeks (or during the summer holiday) and finally they felt safe to let their child go back to school.

... when it was clearly stated in the news that COVID-19 is not really dangerous for children, I became less anxious

We looked at the infection numbers, and technically it was going better. You should take the step, because you cannot keep them at home until December.

Going to school was a physical risk, but parents were tired from all weeks at home, working, teaching and caring for their children. Children were yearning to go back to school and see their friends. For most parents, these feelings supported the decision to overcome the insecurity of letting them go to school.

But I dared it anyway, although I still have doubts because I still find it scary, but yes I did it. It is important for her well-being and her 'mood', so to speak. Because sitting at home is quite difficult for them too.

One parent explained the difficulty to overcome the feeling of insecurity and letting their child go back to school again. This parent replaced the feeling of insecurity by creating a little security to go to school himself to help their child with going to the restroom, thereby reducing the risk of a COVID-19 transmission through an attendant helping their child. This in fact is also again an example of the parents balancing between vulnerability and resilience.

4 | DISCUSSION

This qualitative study highlights the main focus of parents in the COVID-19 pandemic situation: protecting the health and well-being of their child with SMA. Parents experienced a constant challenge to balance between the well-being of their child and the risk of introducing COVID-19 in their home, with three important themes underlying this central theme: responsibility, balancing vulnerability and resilience and (in)security. These three themes, underlying the central theme, are interrelated (Figure 1). With the physical and mental well-being of their child as central in their perspectives, the responsibility parents feel, in combination with (in)securities in situations that are constantly changing, they balance vulnerability and resilience. Because the themes are interrelated, they cannot be separated from each other. From the interviews, it became clear the COVID-19 pandemic in the early stages, when we performed the interviews, increased insecurity, and with the responsibility parents feel for the health and well-being of their child, affected the constant attempts of parents to balance

resilience and vulnerability. During the COVID-19 pandemic, parents experienced new and additional challenges to balance the physical health of their child and the social-emotional well-being of the family.

While protecting the health and well-being of their child with SMA was a general theme of this study, we also found variation between individual experiences. This variation, between parents and within parents over time, was most clear in the subthemes: balancing between vulnerability and resilience, balancing between feelings of security and insecurity and the feeling of being responsible for your child while risking to sacrifice their own needs.

For some parents, it was a tough time, and for others, it felt like they finally found some time to slow down, normalize and experience some relaxation. During the analysis, the research group identified self-sacrifice to be an important theme. However, this was not mentioned by the parents themselves, nor did they reflect on their experiences in this way. This is an interesting interpretation of the research group, which underscribes the importance of listening to parents to understand their individual perspectives and needs and preventing assumptions from a professional's perspective.

The needs of a parent can change over time, but typically are observed and compared between periods before and after a major change. The rapidly evolving pandemic forced parents to adjust to new information almost every day. As different parents have different needs at different times, it is important for healthcare professionals to tune in on parents' specific questions and (information) needs and to understand why they are important to them at that time. Obviously, parents described a need for information in regard to COVID-19 and their child with SMA. Clinicians can do well by having individual conversations with parents to reflect on their insecurities and challenges. Even if no clear answers could be given, parents often felt supported when they had the opportunity to discuss their uncertainties with a healthcare professional. It may be helpful for parents to know that they are not the only ones who are struggling and to normalize the challenges they face and the impact on their lives.

This study obviously has limitations. We cannot exclude selection bias, because parents experiencing huge challenges and stress may have declined participation in this study.

Although we found three fathers willing to participate (of which two couples were included), most of the participants were mothers. It may well be that the lived experiences of mothers differs from those of the fathers.

Nonetheless, the results of this study underscribe the importance of autonomy and feelings of control when taking care of a child with SMA. Our study also shows the important role that clinicians have to empower parents of children with special (care) needs especially when they are confronted with additional challenges, such as the COVID-19 pandemic. Even though the current study specifically focused on families of children with SMA, and did not examine other populations of children, it is likely that some of the themes identified could be comparable in children without disabilities and their families (e.g. Cusinato et al., 2020). Moreover, the themes identified have also been found in subgroups of children with other special (care) needs (e.g. Cadwgan et al., 2021).

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTIONS

Van Stam, Schafrat and Ketelaar conceptualized, designed and conducted the study. Van Stam, Schafrat, Mocking and Prins were involved in the data collection. Schafrat, van Stam, Mocking, Prins, Oude Lansink and Ketelaar were involved in the data analysis. Oude Lansink has lead the writing process and has written the first draft of the manuscript. Van Stam, Schafrat, Mocking, Prins, Beelen, Cuppen, van der Pol, Gorter and Ketelaar have contributed by critically reviewing and editing the manuscript. All authors have approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions. The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The Medical Ethics Committee of the University Medical Center classified this study as exempt from Medical Research Involving Human Subjects Act (17-904). All participants gave informed consent. Materials were not reproduce from other sources.

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APPENDIX I: TOPIC LIST

General questions

- How many children do you have?
- If several children, how many of your children are diagnosed with SMA and what type?
- How old are your children?
- How old is your child with SMA?
- What type of property do you live in?

Fear of COVID-19 infection

- Are you worried about a COVID-19 infection in your child with SMA?
- On a scale of 0–10, how much are you worried about a COVID-19 infection for your child?
- Which COVID-19 restrictions do you use?
- For your child with SMA? (completely at home/still outdoors for ...)
- For yourself? (completely at home/still outdoors for ...)
- For the other children in the family (completely at home/still outdoors for ...)
- Who do you allow to come to your place?
- Is your child with SMA going back to school?
- Are the other children in your family going back to school?

Impact of the COVID-19 restrictions on the care of the child with

The questions I am going to ask you are always first about what it was like BEFORE the COVID-19 pandemic and then about how that has changed since the pandemic.

Medical care:

- What treatment does your child receive for SMA?
- How often did you normally come to the hospital?
- How is that now? If different: why is that? Own decision or from others?
- What do you think about that?

Education:

- What type of education does your child admit or what kind of day care does your child attend?
- How many days a week?
- Is it changed during the pandemic, how is it now? If different: why is that?
- How do you feel about the current situation?

Care at home (paramedical, care etc.):

- What types of therapy and/or care does your child receive? (physical therapy, occupational therapy, speech therapy, home care, etc., and where?)
- Is it changed during the pandemic, how is it now? If different: why is that?
- How do you feel about that?
- Do the restrictions have an impact on your child's health? If so, which ones?

Effect of the COVID-19 pandemic on parental well-being

The following questions are about the consequences of the COVID-19 restrictions on your well-being

- To what extent do you manage to combine your work with caring for your children?
- Are there financial consequences for your family?
- How do you assess your mood in general over the past 2 weeks?
- Is your mood different than before the COVID-19 pandemic?
- How do you assess your night's sleep?
- What was this like before the COVID-19 pandemic?
- What do you miss the most?

- What is the reason that it is not possible now: COVID-19 restrictions, extra care for the children, financially, otherwise

Effect of the COVID-19 pandemic on your child's well-being

The following questions are about the consequences of the COVID-19 pandemic on the well-being of your child

- How do you assess your child's mood in general over the past 2 weeks?
- What was this like before the COVID-19 pandemic?
- How do you assess your child's night's sleep?
- What was this like before the COVID-19 pandemic?
- Do you notice a difference in how your child with SMA experiences the COVID-19 pandemic and how his/her brothers and/or sisters experience this? (difference in fear of infection, difference in dealing with the restrictions to prevent infection)

Characteristics resilience in parents

Some parents feel that, no matter how difficult it is, they can handle the situation. Other parents have the feeling that they are completely overwhelmed.

- How's that like for you? To what extent do you feel you can handle the situation? What determines this?
- What are you doing to keep up?
- How good do you think you can keep it up?
- Does the COVID-19 pandemic give you something positive?
- What is important to you in life for yourself?
- What is important to you in life for your child?

Expectations of the hospital/healthcare providers

- Are you satisfied with the information you receive from your healthcare providers in the hospital?
- Are you satisfied with the care you receive from your healthcare providers in the hospital?
- Do you think things could be better?
- Would you appreciate an additional conversation with one of my colleagues to discuss your concerns? (social worker or psychologist)