

Supplementary Online Content

Understanding Caregiver Experiences with Disease-Modifying Therapies for Spinal

Muscular Atrophy

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eMethods 1. Semi-structured interview guide for family caregivers of children diagnosed with spinal muscular atrophy and receiving disease-modifying therapies

This supplementary material has been provided by the authors to give readers additional information about their work.

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Thank you for taking the time to speak with us today. I am going to ask you some questions about your experience as a parent caring for a child with Spinal Muscular Atrophy. There are no right or wrong answers. Your valued feedback will help us understand how we can better support children with Spinal Muscular Atrophy and their families. The interview is expected to take approximately 45-60 minutes and your answers are confidential.

Do you have any questions before we begin?

1. Can we start off with you telling me a little bit about your child?
 - a. Can you tell me about the period of time leading up to the diagnosis?
 - b. Can you tell me what it was like when you were told your child had SMA?
 - c. Can you tell me how you feel about caring for a child with SMA?
 - d. What were your expectations for caring for a child with SMA?

2. Can you tell me about your child and your family's experience with the disease modifying treatment they received (ie nusinersen [Spinraza], onasemnogene abeparvovec [Zolgensma], risdiplam [Evrysdi])?
(Interviewer note: let them talk before asking the subsequent questions. If child has been on multiple medications, please ask 2a, 2b, and 2c for each specific medication.)
 - a. Tell me about your understanding of the use of these medications.
 - b. What are the challenges? What are the benefits?
 - c. Do you have any worries about the treatment?
 - d. What are your hopes?
 - e. Any suggestions for how we could better prepare future children and their families that are going to be receiving these treatments?

3. Let's talk now about the members of your child's care team. *(Interviewer note: review case report form in advance)*
 - a. Can you tell me about the members of your child's care team?
 - b. Do you have one main person that you can call about everything?
 - c. What works well? What doesn't work as well? *(prompt: communication? Frequency of visits? Too many appointments?)*
 - d. Any suggestions or thoughts for how we could make this experience better for patients and families?

4. Can we talk now a little bit about your life at home with your child?
 - a. What is an average day like?
 - b. Can you tell me about the community supports you have in the community? (family and social, homecare nursing etc) *(prompt: Tell me about the resources you need on a day to day basis to be able to provide care to your child)*
 - c. Can we talk about what it is like to access those supports? *(prompts: any barriers to accessing these?)*
 - d. How do you stay organized with all that you have to handle?
 - e. What causes you stress, if anything, on a daily basis? *(prompt: what do you worry about?)*
 - f. Are finances a source of stress for you and your family? *(prompt: if yes, can you tell me about how this may have affected your child's care)*

5. Can we talk now about the respiratory technology that your child has been prescribed?
 - a. How did you feel when you were first told that your child needed to use a respiratory machine at home?
 - b. Can you talk about what it was like getting your child to first use the respiratory machine? *(prompts: barriers? challenges?)*
 - c. How is it currently going with your child using the respiratory machine?
 - d. What works well?

- e. Any suggestions or thoughts for how we could make this experience better for patients and families?
6. Can we talk now more generally about your child and your family.
 - a. Can you tell me about your care goals for your child?
 - b. Do you feel that these are understood by the healthcare team? (*prompt: barriers such as language/communication*)
 - c. Religion and spirituality may be important values for families when making medical decisions for their children. Can you tell me about the role these have played in your decision making?
 - d. Do you have a community that you draw from for support?
 7. Many families consider family-related factors (working outside the home, impact on other children) in the care of their child. It can be hard to talk about these things, because you of course want to focus on your sick child. But many families also have to think about other family members, about money, their work, and other things that may be difficult to talk about.
 - a. Are there some things that sometimes compete for your attention?
 - b. How do you feel about that?
 - c. How do you manage these competing priorities while also caring for your child?

Concluding questions:

1. Are there any other questions I should ask you that will shed light on your experience with caring for a child with SMA?
2. Do you have anything else to tell me about how we could be doing a better job to help support children with SMA and their families?
3. Do you have any other thoughts that you would like to share about things we did or did not speak about?