

## Original Article

# Learning to live with nephrotic syndrome: experiences of adult patients and parents of children with nephrotic syndrome

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### ABSTRACT

**Background.** People living with nephrotic syndrome (NS) need to develop an in-depth understanding of their condition in order to participate in treatment decisions, develop self-management skills and integrate illness into daily life. However, the learning needs of adult patients and parents of children with NS are unknown. We therefore explored patient and parent perspectives on learning needs related to NS as part of a larger study to develop a shared learning tool for NS.

**Methods.** Qualitative data were collected using semistructured focus groups and individual interviews with adult patients ( $n = 22$ ) and parents of children with NS ( $n = 25$ ).

**Results.** The complexity of NS and its treatment made decision making challenging, as patients/parents often had to assimilate information about a condition that is poorly understood. Specific informational needs related to understanding the diagnosis and treatment approaches as well as learning to manage NS were identified. Difficulty in getting accurate information often made learning challenging. The importance of learning to monitor their condition, including understanding triggers that might precipitate a relapse, was highlighted, underscoring the need for individualized approaches to ensure unique learning needs are addressed.

**Conclusions.** Our findings reveal some of the unique concerns of people with NS given its uncertain course and the limited

information available specific to NS. These results suggest the need for shared communication between the patient/parents and providers to elicit the patient's/parents' understanding of NS and to support them in meeting their unique learning needs.

**Keywords:** focus groups, interviews, learning needs, nephrotic syndrome, qualitative approaches

### INTRODUCTION

Primary nephrotic syndrome (NS) represents a group of rare glomerular diseases, including minimal change disease (MCD), focal segmental glomerulosclerosis (FSGS) and membranous nephropathy (MN) that are frequently characterized by disabling edema due to heavy proteinuria. Recent research in these conditions highlights their detrimental effect on physical and mental well-being [1, 2], emphasizing the potential negative impact of NS on quality of life. Thus NS represents a significant burden for patients and parents of affected children who are faced with an overwhelming task of learning to live with a chronic relapsing and remitting condition that often has an uncertain course and requires management of complex medication regimens, ongoing monitoring and symptom management.

While limited attention has been given to the experiences of people with NS, qualitative research reveals that people with chronic kidney disease (CKD) face numerous challenges in learning to manage their illness. Unfortunately, information and guidance specific to CKD and tailored to a patient's unique situation are often lacking, making it challenging for them to participate in management decisions [3–6]. Others have described a lack of understanding about CKD among the public and primary care providers [7, 8], which can make it challenging to provide education to patients and families. This may also be true in NS, given the lack of common understanding about the syndrome and the many diseases that cause it. Given the link between level of knowledge and health outcomes [9, 10], there have been calls to prioritize patient-centered approaches to information exchange in CKD that address basic knowledge as well as providing specific information about prognosis, treatment and the expected clinical course [7, 11].

Patient-centered communication (PCC) is an essential aspect of patient-centered care and includes making decisions, exchanging information, fostering healing relationships, managing uncertainty, recognizing/responding to emotions and enabling self-management [12]. PCC facilitates shared learning and requires an exchange of information between the provider and the patient; thus understanding these perspectives is a critical first step to providing patient-centered care. We therefore explored patient, parent and provider perspectives on health-related decision making in NS as part of a larger study to develop a shared-learning decision support tool for NS. In this article we report specifically on patient and parent perspectives about their learning needs.

## MATERIALS AND METHODS

The larger study was conducted in two phases using a sequential mixed-methods design [13]. In Phase 1, qualitative approaches were used to elicit patient, parent and provider perspectives on health-related decision making in NS, which informed the creation of a shared-learning tool in Phase 2. Data reported here were generated in Phase 1 and reflect patient and parent perspectives.

Our study was informed by a model for understanding patient-centered chronic disease management. Our model integrated aspects of the Ottawa Decision Support Framework that facilitates identification of treatment-related decisions from patient and provider perspectives [14, 15], with an inclusive approach to patient-centered communication [12]. This study model guided the development of interview questions, helped to frame analysis and supported tool development.

### Participants

Adult patients and parents of children diagnosed with NS for  $\leq 4$  years were invited to participate. Participants from nephrology programs in four North American cities were provided with study information by mail, phone or in person by their nephrologist or study staff. Information about the study was also made available in partnership with NephCure Kidney International (<http://nephcure.org/>) through a posting on

**Table 1. Interview questions<sup>a</sup>**

Part 1: Experiences with health decisions in managing NS
(1) Let's start the discussion by talking about the kinds of decisions that you have to make to manage nephrotic syndrome. At this time, what are some of the health decisions you make in managing nephrotic syndrome?
(2) You have described a number of different types of decisions you make related to nephrotic syndrome. If you had to rank these decisions in terms of importance, which decisions would be at the top of your list?
(3) What has helped support you in making decisions about managing nephrotic syndrome?
Part 2: Decisions people have to make about medications when they are first told they have NS.
(4) Thinking back to when you first learned that you had nephrotic syndrome, and the discussion you had with your doctor about medications, how were the options presented to you?
(5) What were the important treatment decisions you had to make when you were first told about nephrotic syndrome?
(6) Imagine you were making a decision about different medications to treat nephrotic syndrome. What kinds of things would you want to know about each medicine before you made your decision?
(7) What might get in the way of making decisions about medication selection?
(8) Thinking about what we talked about, imagine you had the opportunity to participate in an online program about making treatment decisions for nephrotic syndrome. This online interactive program could be completed at home or in the doctor's office waiting room at the first visit.
(a) What information would you want to see included in the program?
(b) How long would you want to spend doing the program?
(9) Is there anything else that you think would help people with nephrotic syndrome make decisions about their treatment?

<sup>a</sup>Adapted from Jacobsen *et al.* [14].

their website and via their patient contact registry in Toronto and North Carolina. All potential participants were invited to contact the study research coordinator at their respective site, who assessed their eligibility and arranged interviews.

Institutional Review Board approvals were obtained from all participating institutions.

### Data collection

After obtaining informed consent, separate focus groups ( $n = 7$ ) and individual interviews ( $n = 7$ ) were held with adult patients and parents at the participating sites. While most participated in focus groups, individual interviews were offered to those who were unable or preferred not to join a group discussion. All interviews were guided by trained facilitators using a semistructured interview guide that included questions about the types of health decisions patients and parents faced in managing NS, informational needs related to key decisions and barriers/supports for the decision-making process (see Table 1).

### Data analysis

Audiotapes of focus groups and interviews were transcribed verbatim and uploaded into the NVivo 10 software (QSR International, Melbourne, VIC, Australia) for coding and analysis. A coding scheme was developed inductively with participation of team members from three sites (H.B., M.M., E.H., C.P.). Reviewers independently read a transcript from each of the

stakeholder groups and then participated in teleconferences for consensus building around the coding scheme. Two team members (H.B., M.M.) coded subsequent transcripts using this scheme, which was revised as new categories emerged from the data. This iterative process was repeated until a comprehensive coding framework was developed and all transcripts were coded. Analysis of coded transcripts was undertaken using a qualitative content analysis approach [16, 17]. While a number of themes were identified, findings related to the needs of patients and parents learning to live with NS are the focus of this article.

## RESULTS

Twenty-two adult patients and 25 parents participated (see Table 2). Patients were predominantly Caucasian (69%), included equal numbers of women and men and had a median

**Table 2. Demographic characteristics of patients and parent participants**

	Patients (n = 22)	Parents (n = 25)
Age (years), median (25th, 75th percentiles)	52.5 (41, 64)	35 (33.3, 40.5)
Female, n (%)	11 (50)	18 (72)
Married/common law, n (%)	18 (82)	22 (88)
Employment status, n (%)		
Full time	12 (55)	16 (64)
Part time	0 (0)	3 (12)
Unemployed	1 (5)	4 (16)
Retired	7 (32)	0 (0)
Student	2 (9)	0 (0)
Missing	0 (0)	2 (8)
Race, n (%)		
Caucasian	15 (69)	19 (76)
Black	1 (5)	5 (20)
Asian	2 (9)	1 (5)
American Indian	1 (5)	0 (0)
Multiracial	1 (5)	0 (0)
Other	2 (9)	0 (0)
Ethnicity		
Hispanic	0 (0)	3 (12)
Non-Hispanic	14 (64)	11 (44)
Missing	8 (36)	11 (44)
Education level, n (%)		
High school	2 (9)	6 (24)
Associates degree	2 (9)	6 (24)
4-year college degree	7 (32)	6 (24)
Graduate degree	9 (41)	7 (28)
Missing	2 (9)	0 (0)
Duration of NS (months), median (25th, 75th percentiles)	24 (17, 36)	25.5 (12, 36)
Self-reported diagnosis, n (%)	Adult patients	Children
MCD	4 (18)	15 (60)
FSGS	6 (27)	5 (20)
MN	9 (41)	0 (0)
Steroid-sensitive NS	1 (5)	1 (4)
Steroid-resistant NS	0 (0)	2 (8)
NS, NOS	1 (5)	0 (0)
Unsure/missing	1 (5)	2 (8)

NS, nephrotic syndrome; MCD, minimal change disease; FSGS, focal segmental glomerulosclerosis; MN, membranous nephropathy; NOS, not otherwise specified. Steroid-sensitive and steroid-resistant NS was collected when the diagnosis is known only by the steroid treatment response pattern in the absence of a biopsy-confirmed diagnosis.

age of 52.5 years. The most common self-reported diagnosis was MN (41%) followed by FSGS (27%) and MCD (18%). The majority of parents were female (72%) and Caucasian (76%). The median age for parents was 35 years, while the mean age for their children was 7.5 years. The most common diagnoses parents reported for their children were MCD (60%) and FSGS (20%). The educational background of participants varied, with more patients reporting having obtained a college degree or higher (73%) when compared with parents (52%).

Participants described a process of learning about a condition that is often poorly understood by the general public. This entailed 'understanding the diagnosis and approach to treatment' as well as 'learning to manage NS', both of which required 'getting the right information' (see Figure 1).

### Understanding the diagnosis and approach to treatment

Nephrotic syndrome ... it's not that common, right?

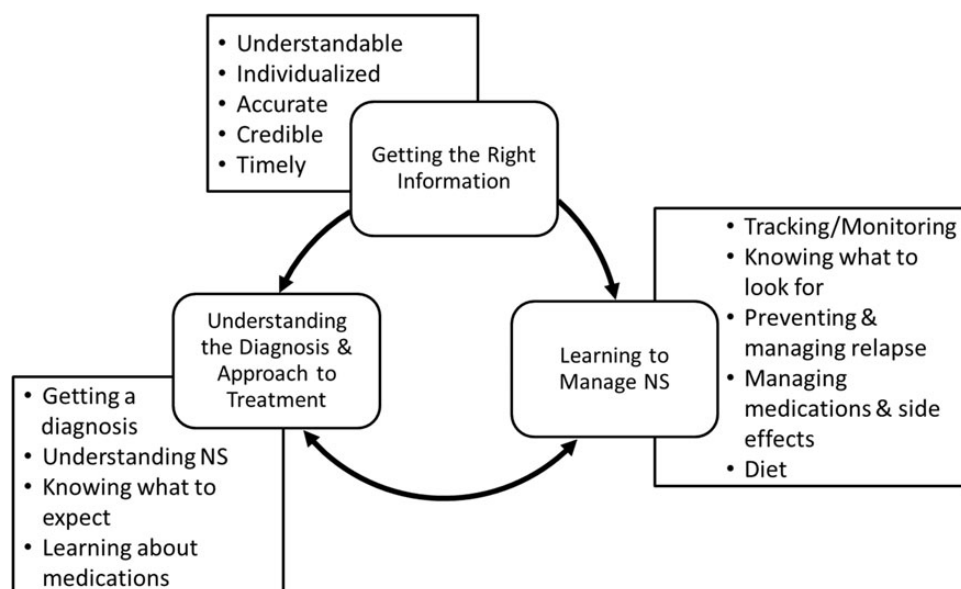
Patients and parents described a range of experiences when they first found out they had a kidney problem or had symptoms of NS. However, a consistent theme was the lack of public awareness about NS that made understanding the diagnosis difficult. Many participants described uncertainty about what was wrong with them [their child] and recounted the difficulties they experienced in finding out 'what was going on'. The severity of their [child's] symptoms (i.e. swelling) prompted many to seek help. However, some recalled initial medical encounters where doctors were unable to diagnose the cause of their symptoms or attributed them to other problems such as heart disease or allergies, which delayed the diagnosis.

I ... went to ... emergency three or four times. I have that swelling on my feet ... Nobody actually told me to do a urine test. They don't know. (patient)

The lack of a diagnosis was not only stressful for patients/parents but also made participation in treatment decisions and self-management difficult. Even with a diagnosis, the lack of general knowledge often meant that patients/parents had no frame of reference for making sense of it. Many described learning about NS as being fraught with unknowns and uncertainties, and identified the need for basic information about NS, its potential causes and long-term prognosis that was understandable to them and their families.

... one of the issues that's been a problem for me with the nephrotic diagnosis is it's really nebulous and ambiguous and you don't really know what caused it or where it came from or where it's going ... (patient)

Getting a diagnosis of NS evoked a variety of emotions and many described how they were unprepared for its abrupt onset and long-term nature. Many described a sense of disbelief when they found out that they [their child] had a chronic condition. In particular, some patients described how not having physical symptoms made it difficult to accept they had a serious problem.



**FIGURE 1:** Learning about NS: common learning needs.

I was in my denial stage because I don't feel any pain. I don't feel anything before that biopsy happened. I was like 'do I really have this disease?' (patient)

The experiences of others reinforced how the emotional struggle of getting a diagnosis of NS might interfere with their ability to take in information.

... all of us struggled with the emotional component of this far greater than I think physicians would know ... I didn't want to talk to anybody about it, I didn't want to know anything ... (patient)

Despite the initial difficulties that some patients/parents experienced with accepting the diagnosis, all participants discussed the importance of understanding the approach to treating NS in order to facilitate decision making. Many emphasized the importance of learning about medications and highlighted that information specific to NS would be helpful to support their decision making. This ranged from a desire for 'basic information about the different medication types and choices' to a preference for more detailed information on 'the efficacy of the drug and the chances of it being successful in treating nephrotic syndrome'.

Information about short- and long-term risks and benefits of medications was identified as important. Specifically discussed were common side effects and the likelihood that they [their child] would experience these, as well as knowing how to manage them. In addition, some participants indicated it was helpful for them to get information about remission and relapse rates for the various medications to support their decision making and give them some hope for a positive outcome.

... it's nice to know like in their studies out of this group of people, how many went into partial remission, how many

went into complete remission, how many relapse after ... (patient)

Finally, participants indicated that it would be important to have information about treatment duration when making decisions. The process of discontinuing a medication was raised by some participants who had questions about 'tapering' (e.g. 'how long you have to taper off of prednisone') as well as concerns about the consequences of tapering, including ongoing side effects and the risk of relapse.

### Learning to manage NS

I became a urine watcher.

Participants were also interested in information that would help them understand and manage NS and its consequences. Many learned to monitor their [child's] condition (i.e. urine protein, blood pressure, swelling) and discussed the importance of knowing the meaning of their assessments. A concern for some, early in the course of the disease, was knowing what to look for, what was important to report and how to respond. In particular, participants stressed the need to know when to be concerned about changes in their [child's] condition and when to ask for help.

One of the things I don't even understand is ... I know okay the strips told me number 4 is more than 2000 milligrams, but who do you call when it's 15 000? (parent)

Being vigilant in monitoring helped patients and parents gain experiential knowledge about how they [their child] experienced symptoms and responded to treatment. Over time many developed an awareness that allowed them to notice subtle changes in their [child's] condition. A particular concern was understanding and preventing relapse, which entailed learning about their [child's] unique triggers and ultimately

trying to prevent or manage them. To help make sense of their [child's] condition and response to treatment, some participants developed strategies for tracking clinical information, as well as medication dosing and side effects, which they often shared with providers.

We now have a spreadsheet where we put protein results, prednisone dosage, and then we have a comments. A fever, yes or no.... 'Every time he has a fever, he relapses.' Whether he has a fever and any other comments that could be complained of—tummy illness or whatever—just something so that we can maybe over time look back and make correlations. (parent)

Many patients/parents described being vigilant in monitoring and controlling the environment, including limiting exposure to communicable diseases. However, the need for constant monitoring, coupled with the persistent, uncertain nature of NS, contributed to an emotional roller coaster for many.

... it's forever, so it's not just the physical. It's also thinking about it all the time, losing sleep, wondering if you're going to wake up and dip the stick and have protein on it. (parent)

Other self-management behaviors participants discussed involved adherence to recommendations, including managing complex medication regimens and potential side effects. Participants highlighted informational needs related to diet and 'figuring out what's right to eat'. A number of misperceptions or questions about diet were identified, particularly early in the disease experience. Some reflected how the dietary information they accessed was intended for people in later stages of kidney disease, reinforcing the importance of getting the right information.

... in the beginning, we were keeping my son off of a lot of potassium-rich foods ... and they said, well, you only do that if he goes into kidney failure. (parent)

### Getting the right information

Don't start telling me something until you tell me what applies to me.

Participants highlighted the importance of having information that was accurate, timely and specific to them. A lack of accessible, understandable and reliable information was repeatedly described as a barrier for patients and parents in learning about NS. While most agreed that there was 'not a lot of information out there', health care providers, particularly nephrologists, were identified by many as a primary source for credible information. Access to their nephrologist was important in terms of feeling they had sufficient time to get information and to have their questions addressed.

I think the key for me has been the willingness of health care providers to take ... all the time that they need to

describe and discuss the disease and the medications and all the ramifications. (patient)

For many, the lack of general knowledge about NS made it difficult for them to get information from both lay and scientific resources. In some instances, patients/parents felt they did not have adequate information to 'really totally understand' or 'have the whole picture' about what was going on with them or their child. Time constraints made it difficult for many to get the information they felt they needed to make an informed decision, either because they felt they had insufficient time at the doctor's visit or they felt they had limited time to inform themselves about options.

You feel so, not necessarily rushed, but you feel like you have to make a decision right then and there, and you don't have a chance to look into ... how long the drug has been around, or ... what the studies are on the drug. You just feel like you have to do it right then. (parent)

The Internet was commonly identified as a source for information. Some used the Internet as a tool to gather information about NS and treatment options or to verify their understanding of information they had received from other sources such as health care providers. Many described how they sought information early on to help make sense of what they were experiencing and, in some instances, to give them hope.

The first year, I was on every night hoping that I would find this glorious page that said, oh, it's not a big deal. (patient)

A number of participants discussed a desire to connect with and learn from the experience of others, because as one patient put it, 'initially, you feel incredibly alienated'. Another participant recalled,

You get diagnosed with this thing and you don't know anybody that's had it, you don't know anybody you could talk to, and I like to go on [a chat room] just to know there's somebody else there like me ... (patient)

Although a few participants located sources they felt were reliable, success in finding credible sources was variable. Some described how they stopped using the Internet either of their own accord because the information was incomplete, inaccurate or frightening or because their physician recommended it.

I got on there and it was fairly depressing to see—and in the blogs too ... My doctor said, 'I can tell you've been reading, but that's not a good thing to do because you won't understand what we're trying to get accomplished ...' (patient)

While a number of participants discussed the importance of understanding the various treatment options, there was no agreement as to how much information was desired or when. Some felt that it would be important to have initial treatment

options laid out for them in a way that allowed them to consider risks and benefits. Others felt it would be helpful to have information about longer-term options to help them anticipate or plan for the future.

I feel like I get half a story. And every time I get to another visit I get a little bit more information. I kind of want the whole book instead of getting chapters. (parent)

Some participants preferred to have the information offered in smaller doses and found it overwhelming to be presented with this information all at once.

When I took [child] in there they said we're gonna try these medications, if that don't work we're going to dialysis, if that doesn't work kidney transplant. I was like whoa. ... Let's slow down and do ... some baby steps as we go. Let's not jump to dialysis so soon. (parent)

Some participants described being faced with too much information that was frightening, confusing and often not specific to them. Hence many participants highlighted the importance of individualized approaches where they received information specific to their unique situation and learning needs.

## DISCUSSION

Our findings suggest a number of priority needs for patients and parents learning about NS, which include the need to better understand their condition, what it means to their life now and in the future and how to optimize management in a way that is sensitive to individual needs. These findings are consistent with research in other chronic conditions that suggests patients and families seek out information about diagnosis, prognosis and treatment to help them understand their disease, participate in decision making and manage uncertainty [18]. However, our findings highlight that it may be particularly challenging to meet these needs in NS given the general lack of understanding and limited information specific to NS available to patients and families.

The remitting and relapsing nature of NS distinguish it from many chronic conditions and our participants revealed the importance of being vigilant in monitoring their condition as well as learning about and mitigating the triggers that might precipitate a relapse. Participants described a process of experiential learning and development of self-awareness that is consistent with research in other chronic diseases [19, 20] and highlights the importance of acknowledging the various sources of knowledge people draw on when learning to live with a chronic condition. Providers working with individuals affected by NS could facilitate the development of this experiential knowledge by educating patients and parents about risks for relapse and by supporting their efforts to identify and track personal triggers by eliciting this information when planning care.

A key principle of patient-centered care is providing clear and reliable information [21]. Consistent with the findings of others [22], our participants identified providers as a primary

source of credible information. Given their essential role, it is important that providers convey information in a clear and meaningful way. Providers can foster meaningful information exchange with patients and families by first eliciting their perspective about the problem and understanding their specific concerns, as well as their goals [12, 23]. Strategies such as active listening, using open-ended questions, clarifying and repeating key points and summarizing information can be useful approaches [12, 23]. Information exchange can also be enhanced by using uncomplicated language and avoiding jargon, encouraging questions and addressing barriers to understanding such as language, health literacy and communication challenges [23].

In our study, accessing meaningful, relevant information about NS was an identified challenge. The majority of participants accessed the Internet, which is consistent with reported Internet use among patients with advanced CKD [24]. However, many raised concerns about the accuracy, relevance and applicability of such information to NS in general or to their unique circumstances. Our findings suggest some patients/parents accessed information about treatments used in other populations that may not apply to them, which placed them at risk of generalizing information that may confound decision making. Some participants also mentioned that their physicians voiced concerns about information they were obtaining from the Internet, signaling a need for better communication between providers and patients about reliable sources of information online. A recent evaluation of websites providing information about CKD substantiates some of these concerns [25]. The authors evaluated 40 publically accessible websites and noted that more than half were rated as difficult to read and those that ranked higher in terms of quality of content tended to be more challenging to understand. The authors highlighted the need for the development of better, more accessible websites and recommended that providers direct patients and families to credible websites. This may be particularly important given that others have reported the Internet is commonly used by patients for medication information and is often rated as a relatively credible source [22].

A lack of information about the diagnosis or disease severity, the complexity of the treatment and the unpredictability of disease course can all contribute to uncertainty in chronic illness [26–28]. Assessing and addressing sources of uncertainty are central to PCC, and providers could help patients/families by exploring their specific concerns, providing clarification and attending to the emotions around them [12]. Similarly, providers can help mitigate the emotional impact of NS by creating opportunities for patients/families to express the emotions they are experiencing, acknowledging these and assessing for distress and offering tangible help [12, 23].

As others have reported and our findings support, the desire for information and readiness to learn may vary across individuals [18, 29]. In our study, patients and parents described not getting enough or the right information, or getting too much information, highlighting the importance of individualizing education to address the informational needs of each patient. As learning needs and abilities may be related to educational background, providers should take this into consideration

when discussing treatment options and providing educational resources. This may be particularly important, as participants in our study had a higher educational status than the general population in the USA [30]. Those with overall lower socioeconomic status or education levels may have unique learning needs that require further exploration and attention when providing educational support. Further, although we focused on common learning needs of patients and parents, it is likely that these groups have some unique concerns that should be further explored and considered when individualizing health teaching.

Our results should be interpreted in the context of study limitations. We recruited a purposive sample of patients and parents who were interested and willing to participate in focus groups and interviews, but their views may not reflect all perspectives. Participants had to be English speaking; thus, the learning needs of those who are non-English speaking may not have been captured. Further, participants in our study were more educated overall than the general population, and their experiences may not be reflective of those with less education or with overall lower socioeconomic status. Finally, while we invited participants who were within 4 years of diagnosis, recall bias may have affected their responses.

## CONCLUSIONS

Collaboration between patients, parents and providers is needed to identify credible sources of information about NS and novel approaches to shared communication. Optimizing communication and support for patients and parents is essential to facilitate understanding and support self-management that is central to patient-centered care. Building on these findings, our team developed a health information technology platform, iNSider ([www.MyKidneyGuide.org](http://www.MyKidneyGuide.org)), that offers one approach to supporting shared learning among NS patients, parents and providers. In addition, iNSider incorporates patient/family vignettes that illustrate strategies to integrate NS into everyday life, as well as addressing emotional responses by helping patients and parents normalize their experiences.

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## DISCLAIMER

All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

## CONFLICT OF INTEREST STATEMENT

None declared.

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