



Gaining Knowledge of a New and Contested Diagnosis – A Qualitative Examination of Swedish Parents of Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)

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Abstract

Background: Pediatric acute-onset neuropsychiatric syndrome (PANS) is a symptom-based and clinically heterogeneous condition characterized by an abrupt and dramatic onset of symptoms such as loss of motoric and cognitive abilities, anxiety, compulsion, tics, and eating disorders. PANS is a new diagnosis and the condition has gathered controversy in research and clinical practice. **Aim:** We aimed to investigate the process by which parents of children with PANS acquire knowledge about the condition; the causes that lead parents to search for knowledge; the ways in which they search for knowledge; and the manner in which this knowledge is received by medical care professionals. **Method:** The study employed in-depth semi-structured, individual interviews with 13 parents of children diagnosed with PANS. An inductive qualitative thematic analysis was used as a guide for analyzing the data. **Results:** Challenges to understand their child's illness and receive effective care led the parents to search for knowledge about PANS and provide an explanation for their child's symptoms. They used personal and social resources to search for knowledge. They felt trusted and encouraged when clinicians endorsed their knowledge. On the other hand, when they were dismissed as a source of knowledge, they experienced a lack of trust towards professionals. **Conclusions:** A driving force for parents' search for knowledge is a perceived incapacity to give meaning to their experiences. Another reason is mistrust of healthcare staff's existing knowledge.

Keywords Pediatric acute-onset neuropsychiatric syndrome · PANS/PANDAS · Contested diagnosis · Qualitative study · Knowledge construction · Parents

Highlights

- PANS is a new diagnosis and the condition has gathered controversy in research and clinical practice, particularly with regard to the role of autoimmune and infectious diseases at the onset of PANS.
- Parents of children with PANS manage challenges to understand their child's illness and receive effective care by searching for knowledge about PANS. They used personal and social resources to search for knowledge. They felt trusted and encouraged when clinicians endorsed their knowledge. On the other hand, when they were dismissed as a source of knowledge, they experienced a lack of trust towards professionals.
- The results illustrate a need for in-depth knowledge of PANS in mental healthcare and enhanced person-centered care where parents are regarded as valuable carriers of knowledge.

Introduction

Pediatric acute-onset neuropsychiatric syndrome (PANS) in children is a clinical diagnosis defined by the abrupt onset –

“lightning-like” – early-age onset of obsessive-compulsive disorder or severely decreased food intake (Swedo et al., 2012). In addition, the condition manifests itself through symptoms such as loss of motor and cognitive abilities (Endres et al., 2022; Howes et al., 2021). PANS is distinguished from pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS), a subgroup of a broader PANS construct that requires the presence of a streptococcal infection – a specific etiological cause – temporally linked to the onset of

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symptoms (Gromark et al., 2022). For the children affected and their families, PANS entail tremendous challenges for everyday functioning (Calaprice et al., 2018; Gagliano et al., 2020).

The diagnosis of PANS is relatively new. The condition has gathered both attention and controversy in research and clinical practice (Frånlund & Talani, 2023) due to the lack of a clear scientific explanation of its causes and how it should be treated (Wilbur et al., 2019). The role of auto-immune and infectious diseases at the onset of PANS, and the role of symptom and disease-modifying therapies such as antibiotics, immunotherapy, and psychoactive drugs, are issues that have been a target of debate (Endres et al., 2022; Howes et al., 2021).

Previous research illustrates how parents of children with PANS are negatively affected by the lack of relevant support and knowledge from medical care (Dolce et al., 2022; Ringer & Roll-Pettersson, 2022). Parents have reported that one of their main strains was a lack of support from the medical community and experiences of being turned away by doctors and other medical professionals who had not heard of PANS. These parents also experienced that having a doctor listen and acknowledge PANS was often the most important step of their journey to manage their child's illness (Dolce et al., 2022). Similar results have been found in another study with parents (Ringer & Roll-Pettersson, 2022) reporting that a common experience of parents is that the initial explanation for their child's symptoms provided by clinicians often did not include PANS, and it was the parents themselves who initiated the diagnosis of PANS as a possibility (Ringer & Roll-Pettersson, 2022).

Experiences of being dismissed or delegitimated are also reported among patients suffering from other contested diagnoses where the evidence is complex, such as chronic fatigue syndrome (Pilkington et al., 2020), multiple chemical sensitivity (Seppälä et al., 2022), and burnout (Heinemann & Heinemann, 2017). Studies have reported individuals' experiences of professional scepticism, of being questioned by health professionals whether they were genuinely ill and whether they were doing their best to recover, and of being blamed for their failure to recover, so much so that they felt their personal credibility was being threatened (Seppälä et al., 2022; Pilkington et al., 2020).

Experiences of this kind illustrate an epistemic injustice (Fricker, 2007) between the individuals suffering from contested illness and the treating clinicians, which may be due to distrust towards the patient or the patient's parent, and causes a lack of recognition or discredit of experience-based knowledge (Blease et al., 2017; Buchman et al., 2017; Fricker, 2007). Fricker's theory of epistemic injustice can be used to understand the moral dimension of two seemingly simple practices: to convey knowledge to others (epistemic justice); and to give meaning to own experiences

(hermeneutic justice) (Fricker 2007). Fricker's theory is an analytical framework for studying power structures and the subtler mechanisms of who is believed and who is dismissed.

The current study draws from previously published work exploring parental stress when parenting a child with PANS (Ringer et al., 2022). Using this same sample, the present study intends to deepen the understanding of the process by which parents acquire knowledge about PANS and make it known to healthcare professionals. More specifically, we aimed to explore: (1) the causes that lead parents to search for knowledge about PANS as an alternative explanation for their child's symptoms; (2) the ways in which parents acquire knowledge about PANS; and (3) the ways in which knowledge about PANS is received by medical care professionals. We believe that an enhanced understanding of parents' knowledge-seeking processes will provide relevant information to help clinicians develop their communication skills around PANS and promote better involvement of informal family caregivers in the treatment process of their ill relative.

Methods

Design

The present study employed in-depth semi-structured, individual interviews with parents of children diagnosed with PANS, to explore individual experiences as expressed by the parents themselves (Cohen et al., 2018).

Recruitment Procedure and Participants

The study was approved by the Swedish Ethical Review Authority (case number 2021-06902-02). Inclusion criteria were parents of children aged 7–19 years who had been clinically diagnosed with PANS. Participants were recruited via an announcement on the websites of patient organizations, and in waiting rooms at child and youth medical clinics. In the announcement, in addition to the provision of general information about the study, parents were encouraged to contact the first author via email or telephone. Interested parents received further written information about the study and terms of participation. A total of 13 parents contacted the first author to receive information about the study, and all of them agreed to be interviewed. Participants were not offered compensation for their participation. All participants volunteered to take part in the project after being informed in writing and orally about the aims and method of the study. Participants were also informed that they could at any time withdraw their consent to participate. The researchers

deliberately aimed for a friendly and relaxed atmosphere during the interviews and asked the participants to talk about their experiences in a way that they could feel comfortable with. Table 1 describes the participants' characteristics.

Table 1 Characteristics of Participants

| Characteristics | Value |
|---|-------------|
| Gender of parents (M/F) | 5/8 |
| Education | |
| Undergraduate level | 3 |
| University level | 10 |
| Parents' living arrangement | |
| Two-parents home | 7 |
| Single-parent home | 4 |
| Joint physical custody | 2 |
| Child's age at illness onset (Mean age \pm SD years) | 7.2 \pm 2 |
| Child's age at diagnosis (Mean age \pm SD years) | 9.9 \pm 3 |
| Child's treatment experiences | |
| Antibiotics | 13 |
| Cognitive behavioral therapy (CBT) | 13 |
| Anti-inflammatory medications | 12 |
| Psychiatric medications | 12 |
| Intravenous immune globulin (IVIG) | 9 |

Table 2 Sample of Initial Interview Questions

| Type of Questions | Sample of Questions |
|------------------------|--|
| Initial Questions | <p>Can you tell me about your family situation?</p> <p>Can you tell me about your child's PANS?</p> <p>Can you tell me your work situation?</p> <p>Can you tell me about a regular day in your family life?</p> |
| Intermediate Questions | <p>Tell me about the first time your child showed symptoms. What was it like? What have you thought and how have you felt? What did you do?</p> <p>Tell me about when your child received the PANS diagnosis. What led to the diagnosis? How do you feel and what do you think about it?</p> <p>When have you heard about PANS for the first time? How? In what context? What have you done?</p> <p>How have you learned about PANS?</p> <p>Have you talked with the healthcare professions about what you have learned about PANS? How did they react then? How do you feel and think about their reaction?</p> |
| Concluding Questions | <p>Is there something else you think I should know in order to understand what was that that made you to search knowledge about PANS? What triggered you? What were the reasons for you to look for another explanation?</p> <p>Is there something else you think I should know in order to understand how you have gotten your knowledge about PANS? What ways you had?</p> <p>Is there something else you think I should know in order to understand how doctors, psychologist, nurses or other healthcare professions reacted when you told them about PANS?</p> |

Data Collection and Data Analysis

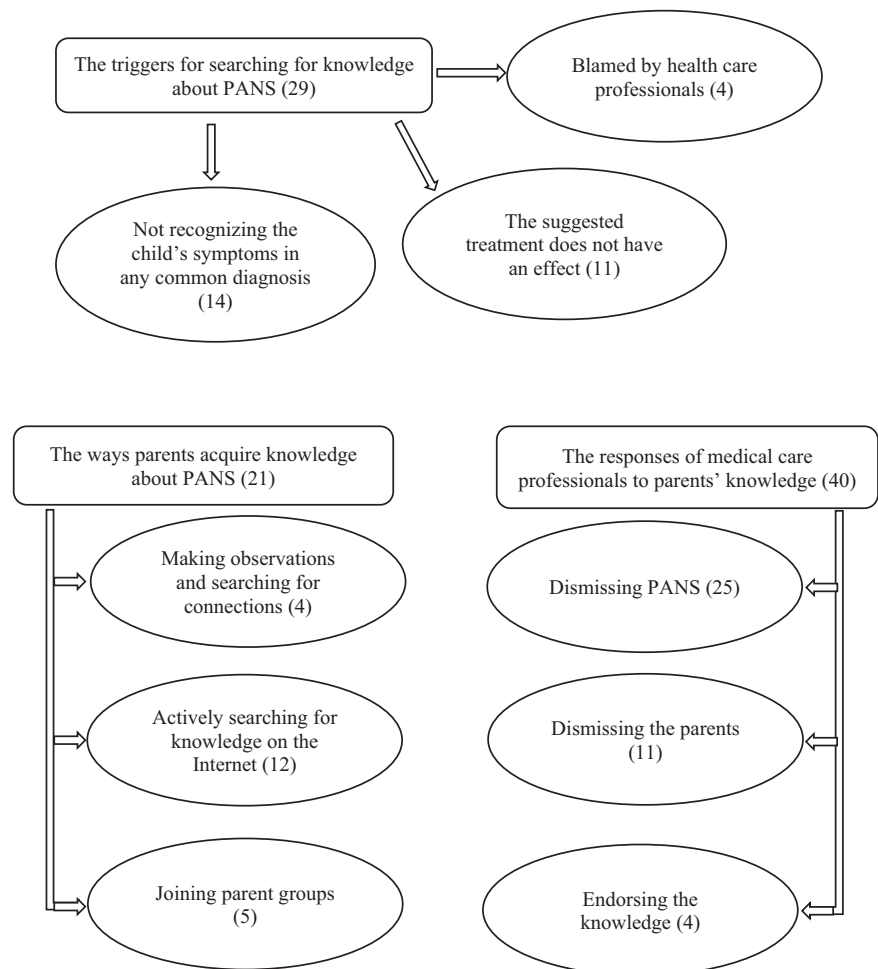
A semi-structured interview guide was created based on previous studies and discussions within the research group, to reach knowledge about parents' experiences of having a child with PANS. Table 2 provides a sample of interview questions. The guide was treated as a flexible tool, and follow-up probing questions were used to further explore, and deepen the understanding of, identified aspects.

Data collection took place between February and July 2021. The interviews, conducted at the participants' homes, lasted 40–100 min. All interviews were conducted, audio-recorded, and transcribed by NR.

To analyze the transcriptions of the interviews, we conducted thematic analysis using an inductive approach (Braun & Clarke, 2006). Thematic analysis was an appropriate method as it supported us to systematically search for and identify patterns (themes) in the large qualitative data (Braun & Clarke, 2006). With an inductive approach, the themes identified are strongly linked to the data itself, rather than to a redecided theoretical concept (Braun & Clarke, 2006). The themes were identified within the explicit meanings of the data, without looking for meanings beyond what a participant has said (Braun & Clarke, 2006).

In line with Braun & Clarke (2006, 2019), the data analysis involved six stages: (1) familiarizing ourselves with the data by reading and rereading the interview transcriptions, while noting our thoughts and impressions; (2) generating initial codes by coding manifest contents of the

Fig. 1 Themes and Subthemes and Number of Comments for Each Theme and Subtheme



data that are relevant for answering the research questions, and defining their underlying meanings; (3) selecting significant codes and organizing and synthesizing them in order to propose themes, where each theme captures something important about the data in relation to the research question; (4) reviewing the themes by checking whether they reflect and represent both the initial codes and the entire data set; (5) defining and naming the themes and subthemes; and (6) applying a ‘scholarly analysis’ (Braun & Clarke, 2019, p. 594) to the results, in which the results are interpreted through the lenses of Fricker’s theory of epistemic injustice (Fricker, 2007). This last stage of analysis allowed us to understand the inductively drawn themes and subthemes from a theoretical perspective. The data analysis was performed using the qualitative data analysis software NVivo 12 (QSR International, Burlington, MA, USA).

Results

Three themes emerged from the analysis of interviews: (1) The triggers for searching for knowledge about PANS; (2)

The ways parents acquire knowledge about PANS; and (3) The responses of medical care professionals to parents’ knowledge. Several subthemes emerged for each theme as noted below and in Fig. 1.

The Triggers for Searching for Knowledge About PANS

The analysis identified three reasons why parents search for knowledge about PANS as an alternative explanation to the one they have received from the medical staff, for their child’s symptoms. The first two reasons are related to the parents’ experience of the symptoms themselves, and the third reason is related to the parents’ experience of the interaction between themselves and the health care professionals.

Not recognizing the child’s symptoms in any common diagnosis

This subtheme describes the experience of not being able to recognize their child’s symptoms in other, more well-

known diagnoses. Some parents experienced that when they were requested to complete questionnaires about their child's symptoms they had difficulties to identify any similarities between their child's symptoms and the suggested symptoms, of the more established conditions. Several parents experienced that the symptoms that were assessed in the questionnaires were not relevant or were qualitatively different from their child's symptoms.

I thought, this isn't the typical OCD [obsessive compulsive disorder] they talk about. It must be something else. We had to do all those assessment scales, but hardly any of the questions matched.

Other parents noted that psychiatric diagnoses, such as neurodevelopmental disorders and anxiety disorders, matched some aspects of their child's symptoms. Many other characteristics, however, such as the unpredictability, the varying character, and the intensity of the symptoms, as well as the accompanying infections or other somatic conditions, were not included in these diagnoses.

The experience of not being able to recognize their child's symptoms in the diagnosis initially made by the medical staff was strengthened when they met parents of other children with the diagnosis. It was accompanied by feelings of loneliness, as well as the need to be able to recognize their own life situation in other parents' situation.

I started going to different forums and reading about OCD. I tried to be attentive and understand, but I couldn't relate, I just couldn't find it, like, 'Your child sounds like my child.' I never found it.

Finding information about the diagnosis of PANS with its underlying assumption that the symptoms are related to infections, and about the rapid manifestation of the symptoms, was described by many of the parents as an Aha! moment and an eye-opener experience. It also enabled the parents to recognize their situation in other parents' situation, and develop affinity with them.

The suggested treatment does not have an effect

Another reason for searching for an alternative to the initial diagnosis the child had received was that the treatment provided did not have the desired effect. When treatments, mostly psychopharmacological treatments and Cognitive Behavioral Therapy (CBT), in the parent's opinion, had no effect or worsened the child's condition, the parents started to doubt the validity of the treatment and searched for alternative treatments.

When we went to the child and adolescent psychiatric unit, he received CBT, but the treatment had no effect.

You hope it gets better, but the treatment does nothing. In comparison to other children. He actually got worse from the anxiety medication. And it was very frustrating. The psychologist adjusted the treatment to make it work better, but it didn't help. How he felt had nothing to do with the treatment itself. When he felt good, it didn't matter which method the psychologist used; when he felt bad, he felt bad. So it didn't matter in any case. That's why it felt strange; it felt completely wrong. And then my wife and I thought it has to be something else.

Blamed by healthcare professionals

Several parents experienced that being blamed for their child's symptoms, as well as feeling disrespected by the care professionals, encouraged them to gain further knowledge about alternative causes for their child's behaviors. Knowledge about PANS, and understanding the causes of the symptoms in terms of corporal mechanisms, allowed them to free themselves from the blame.

It's always that questioning. If she had worn long socks, she would have slept better. If you had disconnected the WiFi she might have been happier. It's always about questioning. We never get out of there without being lectured about what we could or should have done. When your child is so ill, it's very difficult to be blamed. They do not focus on the child, do not take care of her. They focus on us. You two, what are you doing wrong? And if the child is so sick, you can't bear to be questioned. You need to learn as much as you can about what it could be.

The Ways Parents Acquire Knowledge about PANS

This theme describes how parents acquire knowledge about PANS and about the meaning of the diagnosis, the treatments, and the underlying etiology. Three strategies parents apply for searching for knowledge were identified. The first strategy is personal and involves own observations and searching for connections. The other two are social and include contact with others to gain knowledge.

Making observations and searching for connections

One way to learn about PANS, particularly about the possible connection between the child having somatic symptoms, such as infections or dermatological irritations, and her or him having psychological symptoms, was by making observations and paying particular attention to this connection. Some

parents looked back at photos, read diaries they had written, and interviewed family members to investigate the connection. In this way, they themselves constructed their knowledge about their child's illness via self-reflection.

Then, almost exactly 1 year after the first episode, it happens almost exactly the same again. And what I noticed then, which I hadn't noticed before, is that she had some kind of infection. She had it the first time too, but I didn't think about it then. But this time I thought, 'Strange, she has that infection again at the same time.' Could there be a connection between them?

Actively searching for knowledge on the Internet

All parents used different Internet sources to actively search for knowledge about possible explanations for their child's symptoms, and specifically about PANS. They got information from both popular sources and more professional scientific sources.

What could it be? I didn't at all think that there could be a connection between the infection he had and the compulsion. And then I started reading and found some article in a neuroscience journal that mentioned some infection-inhibiting medication.

Joining parent groups

A third way to learn about PANS was by joining local and national parent groups for parents of children with suspected or diagnosed PANS. This strategy was relevant after the parents started becoming aware of the diagnosis. By joining a parent group, parents received general and theoretical knowledge about PANS, but also specific and practical information such as the treatment possibilities in their region, which clinics were recommended and which should be avoided, as well as strategies that may help their child.

We felt that we wanted to learn everything we could. We joined parent groups and learned a lot from other people's experiences. We are part of Facebook groups and read what others write.

The responses of medical care professionals to parents' knowledge

This theme describes parents' experiences of how medical care professionals responded to their knowledge about PANS. Three types of responses were identified: dismissing

the diagnosis of PANS itself; dismissing the parents as a trustworthy source of knowledge; and endorsing their knowledge.

Dismissing PANS

Many parents experienced that clinicians often dismissed the validity of PANS as a genuine diagnosis, responding that PANS was only an urban legend, an entity not recognized by the medical community. This invalidation concerns the existence of the diagnosis and the view that the psychiatric symptoms are related to autoimmune, infectious, and inflammatory states, and can be treated with antibiotics, anti-inflammatory medications, and intravenous immunoglobulin.

I asked the Child and Adolescent Psychiatric Clinic about PANS, and they just said, 'No, PANS don't exist, it's just popular science.' And then half a year later I brought it up again, and they just said, 'No, you have to give up and leave this PANS thing.'

Dismissing the parents

This subtheme considers the experiences of medical care professionals dismissing the parents as a legitimate and valuable source of knowledge. In this type of response, the parents perceived that the dismissal was regardless of the knowledge itself, but revolved around the role of the parents in relation to the medical staff. This experience led to frustration and helplessness.

We got to see a new doctor and I felt that he was mostly focused on showing us that, 'You parents, you shouldn't tell me what to do. Here, I am the expert,' and it didn't matter what we parents were going to say. – And it gets very, very weird.

Endorsing the knowledge

Some parents experienced that some healthcare professionals met their knowledge about PANS with interest and respect. In these cases, their knowledge was seen as valuable, trustworthy, useful, and had direct practical implications for the treatment. When parents experienced that their knowledge was endorsed, they felt hopeful and encouraged.

I called her doctor and asked, 'Could it be PANS she has?' – 'Yes, perhaps,' she replied. And she listened and took samples, and even though I could tell it was

new to her, she was responsive, and tried to give her antibiotics and followed up with her. And it felt good to be able to trust her and to receive trust from her.

Discussion

The diagnosis of PANS is relatively new and scientific knowledge about the condition, its etiology, typical course, and treatment is still largely lacking (Calaprice et al., 2017). In addition, there is no consensus within the medical community regarding the validity and legitimacy of the diagnosis (Wilbur et al., 2019). This qualitative study aimed to explore causes that lead parents to search for knowledge when their child is suddenly affected by this severe illness with complex psychiatric manifestations, the strategies they employ in their search, and the ways in which this knowledge is received by health care professionals.

The reasons why parents in this study searched for knowledge about PANS as an alternative explanation to the initial diagnosis their child had received were difficulties in recognizing the initial diagnosis in their child, and/or mistrust in the effectiveness of the treatment. It was clear from most parents' descriptions that the care their child received was not person-centered; rather, they described risking being blamed by healthcare staff for their child's illness. This triggered the need to seek explanations that would end the blame.

The participants in this study were parents in crisis, who sought information about their child's suffering in several ways: by making observations, searching for knowledge in medical journals and on professional platforms, and joining parent groups.

The remaining controversies about the nature of and treatment for PANS, as well as the lack of knowledge on the condition (Wilbur et al., 2019), were related to the negative response parents received from the medical profession. Negative responses such as being blamed, dismissed, or mistreated were described as moral oppression and can be understood as an epistemic injustice (Fricker, 2007).

These experiences are in line with other research on contested illnesses, illustrating an interplay of lack of evidence, lacking organizational readiness, and staff attitudes (Hayes et al., 2010; Mengshoel et al. 2018; Seppälä et al., 2022). But it is not only patients (or, in this case, parents) who are dismissed as worthy carriers of knowledge. The statements and diagnoses by health professionals are often dismissed by patients (parents). Likewise, our results illustrate a mutual distrust of competence, with physicians questioning the parents' information, and the parents simultaneously questioning the authority of professionals. The latter happens especially in psychiatry, because of

parents' perception that these professionals cannot effectively diagnose their child's condition or prescribe effective treatments. In the process of finding out more about the condition, they withdraw from mainstream medical services, seeking alternative services to give meaning to their experiences and be respected for their knowledge (Fricker, 2007). Through user organizations and web forums, they receive knowledge from others and simultaneously convey knowledge to others. This can be seen as a power shift, where the possibility of both creating meaning around PANS (hermeneutic justice) and being respected for having knowledge (epistemic justice) is renegotiated (Fricker, 2007). Nevertheless, this study shows that parents of children with PANS often experience non-participation and delegitimization in relation to the medical profession.

There are several limitations in this study. Although our aim was to achieve variation among participants, all participating parents were Swedish-born and were relatively familiar with both how the Swedish healthcare system functions and its procedures. In addition, the participants had a relatively high educational background, with the majority having a higher education. It is most likely these factors that influenced the parents' knowledge construction, as well as their search for knowledge in scientific journals. Fricker (2007) talks about epistemic justice as social justice. It can, of course, be challenging to assert your value as a subject of knowledge if you have a limited ability to search for and understand medical information. There may also be a cultural aspect where built-in hierarchies can mean that the doctor's knowledge is not questioned by the patient or her or parents (Giuliani et al., 2020). When health perceptions differ or when health care staff and patients and their parents do not (literally or figuratively) speak the same language the practice of person-centered care and the opportunity to be heard and respected for having knowledge is challenging, a process that Fricker refers to as 'hermeneutic injustice' (Giuliani et al., 2020; Fricker, 2007).

This study includes a limited number of participants, who have mainly been recruited via a user organization. One of the main tasks of the organization is to collect and spread knowledge about PANS/pediatric autoimmune neuropsychiatric disorders with streptococcal infections (PANDAS). Within the organization, there is a consensus on how PANS/PANDAS should be treated, which in part deviates from the more complex picture presented by other actors. This may have affected the knowledge position of the parents.

Also, the fact that this study focuses solely on parents excludes the experience and needs of care workers. Including healthcare professionals would certainly have given a more complete picture of knowledge generation, knowledge sharing, legitimacy, and responsibility in a new field of care. Nevertheless, the focus of this study was to examine parents'

search for knowledge, which we know relatively little about in general, and when it comes to PANS/PANDAS, the knowledge is non-existent. The results of this study illuminate the need for patients with contested illnesses and their families to receive good treatment that spans several medical specialties. In addition, the results emphasize the need for health workers to create collaboration with the patient and her or his caregivers to ensure that all important knowledge is considered to achieve high-quality services.

Conclusions

The analysis of interviews indicates that challenges to understand their child's illness and to receive effective care led parents to search for knowledge about PANS as a possible explanation for their child's symptoms. When searching for knowledge, parents used personal and social resources. When clinicians endorsed parents' knowledge, parents felt trusted and encouraged. When parents were dismissed as a source of knowledge parents experienced lack of trust toward professionals.

Data Availability

All authors share responsibility for the final version of the work submitted and confirm that they have full access to all the data in the study and take responsibility for the integrity of the data in the study and the accuracy of the data analysis.

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Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

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