



# Experiences of Siblings of Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)

Noam Ringer <sup>1</sup> · Rano Zakirova-Engstrand <sup>1</sup>

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## Abstract

Pediatric acute-onset neuropsychiatric syndrome (PANS) is a relatively new diagnosis, characterized by an abrupt and dramatic onset of obsessive-compulsive disorder together with neuropsychiatric symptoms. This sudden onset of symptoms that occurs within 24–48 h presents tremendous challenges for the affected children and their immediate family members. Currently, research on the experiences of siblings of children with PANS is lacking. This study explored siblings' perspectives on living with brothers and sisters with PANS, and their perceptions of own ability and available resources to manage challenging situations. Nine siblings of children with PANS, aged 10–17 years, participated in semi-structured interviews. Informed by Transactional Theory, a combined deductive-inductive approach to qualitative content analysis was used for analyzing the data. The findings illuminate that PANS has considerable impact on the lives of healthy siblings who experienced fear of aggression and unpredictability of their siblings' behavior; they felt that their basic needs as well as social and emotional needs were often neglected. The results also showed that siblings lacked formal knowledge about PANS and had only a limited number of strategies to cope with stressful situations. However, peers in similar situation were a source of emotional support. Practical implications include the need for development of community-based, family-centered support programs to reduce the impact of PANS on healthy siblings' well-being. Directions for further research are outlined.

**Keywords** PANS · Siblings' lived experiences · Stress · Coping

## Highlights

- Siblings of children with PANS live in fear of experiencing aggression and outbursts by their brother or sister.
- Siblings of children with PANS experience that their basic needs, as well as social and emotional needs, are neglected due to their sibling's needs.
- Siblings of children with PANS experience that they lack formal knowledge about the diagnosis, and that they have difficulties to understand, predict and manage their sibling's symptoms.
- Siblings experience that the resources in their surroundings to manage problems are limited, but that peers with a similar situation are a source of emotional support.

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These authors contributed equally: Noam Ringer, Rano Zakirova-Engstrand.

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✉ Noam Ringer  
noam.ringer@specped.su.se

<sup>1</sup> Department of Special Education, Stockholm University, Stockholm, Sweden

Pediatric acute-onset neuropsychiatric syndrome (PANS) is a chronic condition characterized by an acute – “lightning-like” – early-age onset of obsessive-compulsive disorder or severely decreased food intake (Swedo et al., 2012). Additional concomitant symptoms may include anxiety, emotional lability, irritability, aggression and/or oppositional behavior, sleep problems, enuresis or urinary frequencies, tics, visuomotor difficulties, worsened handwriting, and deterioration of academic performance at school (Murphy et al., 2015; Swedo et al., 2012). Children with PANS may also have other co-occurring conditions such as autism, attention deficit hyperactivity

disorder (ADHD), or intellectual disability (Gromark et al., 2022). The underlying mechanism or etiology of PANS is still unknown (Pfeiffer et al., 2021), and the syndrome has been described as “a diagnosis of exclusion” after causes of other illnesses, e.g. autoimmune or metabolic conditions, infections, trauma, and toxins, have been eliminated (Thienemann & Murphy, 2017, p. 744). 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 symptoms (Gromark et al., 2022).

The sudden and dramatic onset of symptoms that occurs within 24–48 h presents tremendous challenges to both the child and their immediate family members. Existing research has shown that parents of children with PANS reported significant disruptions in family functioning, fear due to behavioral changes in their child, fear for their child’s well-being and safety, social isolation, financial strain, and lack of support from school and healthcare professionals (Dolce et al., 2021; McClelland et al., 2015; Ringer & Roll-Pettersson, 2022). Parents described feelings of uncertainty around their child’s condition and frustration at the lack of knowledge about PANS among healthcare professionals (Dolce et al., 2021; McClelland et al., 2015; Ringer & Roll-Pettersson, 2022). Dolce et al. (2021) also reported that parents had concerns regarding the impact their child with PANS had on their unaffected siblings: Parents described that they often asked them to make accommodations for their brother or sister with the condition, and also felt guilty and concerned about violence and conflicts that the healthy siblings could experience, fearing this would negatively affect the siblings’ relationship.

Although these findings are important, they reflect parents’ perspectives and thus provide only limited knowledge on the lived experiences of siblings of children with PANS. Currently, research on how this group experiences their everyday life and well-being in relation to their sibling’s condition is lacking. For instance, the meta-synthesis of primary qualitative research on the well-being and needs of siblings of children with mental health problems (Ma et al., 2015) did not include any studies on siblings of children with PANS. Included studies that specifically focused on siblings’ perceptions were limited to such conditions as ADHD (Kendall, 1999), obsessive-compulsive disorder (OCD) (Barrett et al., 2000), eating disorders (Garley & Johnson, 1994), and emotional mental health problems (Litzelfelner, 1995). A review of these studies revealed that all siblings of children with the above-mentioned conditions experienced a profound impact of their brother’s or sister’s condition on their everyday lives (Ma et al., 2015). The siblings in these studies shared similar experiences, such as poor understanding of their sibling’s disability, increased

levels of distress – e.g. feeling anxious and sad – and negative influence on family relationships. For instance, the interviewed siblings felt that their parents favored their brother or sister with the chronic condition, which negatively affected their sibling relationship. Some siblings reported that their parents expected them to care for their brother or sister with ADHD or an eating disorder (Garley & Johnson, 1994; Kendall, 1999). Siblings of children with ADHD described their everyday family life as chaotic and filled with conflicts due to their sibling’s disruptive behavior. They often experienced physical violence and verbal aggression from their sibling with ADHD (Kendall, 1999). Similar findings were reported by siblings of children with emotional disabilities (Litzelfelner, 1995). These studies also showed that the siblings used various ways of adjusting to their affected sibling; for instance, brothers and sisters of children with OCD reported high levels of accommodation to their sibling’s symptoms by assisting them in their rituals (Barrett et al., 2000), whereas siblings of children with eating disorders and ADHD coped with their sister’s or brother’s condition through avoidance (Garley & Johnson, 1994; Kendall, 1999). Nevertheless, in Garley and Johnson’s (1994) study, some siblings also reported a range of positive experiences, such as increased feelings of empathy and tolerance toward others and valuing friendship.

A quantitative study conducted by Maleki-Tehrani (2006) examined patterns of sibling and family relationships from the perspective of 55 siblings of children with Tourette Syndrome. The findings demonstrated the importance of communication between the healthy siblings and their parents in understanding and managing their family member with this chronic condition. As Maleki-Tehrani (2006) noted, effective discussions with parents could help healthy siblings not only to gain knowledge about the symptoms of their sibling with Tourette Syndrome but also to correct possible misunderstandings about their parents’ behavior, as well as giving them opportunities to discuss their feelings and concerns with their parents. This type of communication was associated with family cohesion and warmth in sibling relationships. However, the study also revealed that siblings of children with severe forms of Tourette Syndrome and with co-occurring ADHD and OCD felt less close to their brother or sister with the disability. A recent systematic review of empirical literature that investigated the psychological impact of disability on siblings of individuals with various types of disabilities (e.g., mental, neurological, or genetic disorders), found that sibling relationships was the most frequently studied psychological construct with varying results (Levante et al., 2024). For example, evidence gained from the quantitative studies ( $n = 37$ ) showed warm and loving sibling relationships in some families, while in other – poor and conflictual. A literature review by Knecht and colleagues (2015) on perspectives of siblings of children

with chronic illness highlighted siblings' internalizing and externalizing behaviors as emotional reactions to situation of growing up with the ill brother or sister. This review has also revealed that healthy siblings often experienced information about their siblings' chronic condition as inadequate or insufficient. None of the studies included in these reviews, however, investigated experiences of siblings of children or adolescents with PANS.

## Theoretical Framework

The present study was guided by Transactional Theory, originally suggested by Lazarus and Folkman (1984) and further developed by Folkman (2008). This is a cognitive-perceptual perspective that connects between psychological stress and how individuals appraise their environment (Lazarus & Folkman, 1984). The theory suggests that people constantly engage in interpreting events in their environment in order to evaluate the threat or potential harm the events pose to their well-being, as well as their resources to manage the threat (Lazarus & Folkman, 1984; Biggs et al., 2017). The interpretation stage is based on two types of appraisals: *primary* and *secondary*. Primary appraisals are evaluations that allow the individual to assess the potential harm the event may constitute (Lazarus & Folkman, 1984). These appraisals are related to the nature and characteristics of the event; i.e., how familiar or ambiguous the event is to the individual (*What is going on?*). Primary appraisals can be related to the individual's personal agenda, values, goals, beliefs, wishes, expectations, and personal needs (*Is it in conflict with my beliefs and needs?*) (Lazarus & Folkman, 1984).

Based on the nature of the event and the individual's personal agenda, they evaluate the event as insignificant, positive, or threatening. Interpreting the event as threatening will lead the individual to engage with secondary appraisals, which are related to one's resources for managing the threatening event (Lazarus & Folkman, 1984). As such, the secondary appraisals are evaluations of one's personal abilities and skills for decreasing or eliminating the threat, as well as evaluations of social and practical resources in the environment (Biggs et al., 2017). According to Transactional Theory, if an event is perceived as threatening while the resources to manage the potential threat are perceived as limited, the individual may experience psychological stress (Lazarus & Folkman, 1984).

## The Current Study

In Sweden, the country where this study was conducted, there are currently no data available on the prevalence and

incidence of PANS in children (Johnsson et al., 2020), although preliminary prevalence estimates of 0.1% have been mentioned (Eberhard et al., 2022). Descriptions of the first two cohorts – 23 and 45 cases – were provided by researchers at the Child Neuropsychiatry Centre (CNC) at the Sahlgrenska University Hospital (Johnson et al., 2019) and Karolinska Institutet (Gromark et al., 2019), respectively. In this context, very little is known about the impact children with PANS have on their family members and on family functioning. A pioneer study by Ringer and Roll-Pettersson (2022) reported elevated parental stress and parents' perceived reduced ability to function as parents to their well children.

To date, no studies have elicited the experiences of siblings of children with PANS. The present study therefore aimed to fill this knowledge gap, and thus contributes to the literature. A deeper awareness about everyday experiences of siblings living with a brother or sister with PANS can contribute to our understanding protecting and risk factors to potential development of emotional and behavioral difficulties in non-affected siblings. For example, previous research with siblings of children with psychiatric disorders demonstrated that healthy siblings had a significantly higher risk to develop anxiety and depression (Koukouriki et al., 2021; Popovic et al., 2018). Beyond the genetical vulnerability that the typically developing siblings may have, the psychosocial adversity of having a brother or sister with mental illness may be a part of the explanation for this high risk (Palacio-Ortiz et al., 2024).

Among other risk factors for developing emotional or behavioral problems in healthy siblings is lack of knowledge about conditions that affected their siblings (Ross & Cuskelly, 2006). As PANS is a relatively recently described diagnostic concept – still being highly controversial within the biomedical scientific community (Leonardi et al., 2024) – an investigation of siblings' experiences can illuminate and contribute to our understanding of the role of having knowledge about the diagnosis that their affected siblings have. Moreover, the episodic characteristic of PANS in which symptoms come and go unpredictably allows us to explore the meaning of predictability for the siblings. Knowledge about experiences of siblings to children with PANS can, therefore, help develop intervention strategies to provide support to these siblings in order to reduce possible negative effects of distressing experiences that may be associated with PANS, increase their resilience, and develop warm family relationships. Guided by Lazarus and Folkman's Transactional theory of stress and coping, we asked the following research questions to address the study's aim:

- (1) How do siblings of children with PANS describe the impact of their brother's or sister's condition on their everyday lives?

- (2) What are the siblings' perceptions of their own ability to manage challenging situations in relation to their brother or sister with PANS?
- (3) What are the siblings' perceptions of resources available in their environment to manage challenging situations?

## Method

### Study Design

This study is part of a broader research project designed to investigate the experiences and perceived stress of families of children diagnosed with PANS including parents and siblings. In the current study, we explored perspectives of healthy siblings of children with PANS, using a qualitative, cross-sectional research design with a semi-structured interview format. The study was approved by the Swedish Ethical Review Authority (reference number: 2020–06554).

### Recruitment and Participants

Inclusion criteria for participating in the study were (1) children and youth, aged 10 to 18 years, who (2) had a sibling, aged 3 to 18 years, with a formal diagnosis of PANS. Participants were recruited via advertisement on the websites of patient organizations, and in waiting rooms at child and youth outpatient clinics. Contact between the participants and the first author was made when their parents replied to the advertisement. Eleven parents initiated contact, and they and their child received further written information about the study and terms of participation. Informed consent forms were sent home to each family; both parents needed to give the signed consent, as well as participants older than 15 years. Younger participants gave their consent to participate verbally. The signed forms were collected prior to the interview. Although all parents gave their consent to their child's participation, two of the approached children declined participation because they did not want to be interviewed. A total of nine ( $n = 9$ ) siblings of children with PANS participated in the study. Six girls and three boys in the ages of 11 to 16 years (average age 13 years) were interviewed. Table 1 describes the participants' characteristics.

### Measures

The first author created a semi-structured interview guide to obtain rich descriptions of the participants' experiences, emotions, and appraisals in relation to having a sibling with PANS. The interview guide was built upon the first author's

**Table 1** Participants' characteristics

Characteristic	Mean/median age or number of participants
Male sibling to male with PANS	2
Male sibling to female with PANS	1
Female sibling to female with PANS	1
Female sibling to male with PANS	5
Older/Younger than child with PANS	4/5
Have other siblings /No other siblings	3/6
Age at time of interview	
Mean age $\pm$ SD (years)	13 $\pm$ 0.8
Age at time sibling fell ill	
Mean age $\pm$ SD (years)	10 $\pm$ 1.1
Family living arrangements	
Two-parent home	7
Single-parent home	2
Parents' level of education (16 parents)	
Primary education	2
Secondary education	2
Vocational education	4
Higher education	8
Parents' occupations (16 parents)	
Managers	2
Teaching professionals	2
Technicians	2
Service and sales workers	5
Skilled agricultural	1
Homemaker	4

clinical experiences, as well as previous research findings on the implications of other chronic psychiatric conditions on siblings, and with consultation with other clinical psychologists in the field.

The interviews' point of departure was the participants' everyday life within the family, with friends, and at school and leisure activities. In the interview the participants were asked to describe daily activities in which their sibling's PANS played a role and had a meaning. Focusing on the different situations that the participants described they were asked about their thoughts, emotions, and behaviors related to what is happening. Focusing on everyday experiences in order to understand the participants' experiences of living with a sibling with PANS is both in line with the aim of the study and also an effective interview technique to receive rich descriptions when interviewing children (Greene & Hogan, 2005). Table 2 outlines interview questions included in the interview guide. The following are the examples of questions asked to the siblings: *Tell me about a regular day in your life/your family/friends/Is there any activity you like to do? In what ways has your sibling's PANS affected your life? School? Being with family/friends? What do you*

**Table 2** Sample of interview questions*Initial Questions*

- Tell me about a regular day in your life/your family/friends/Is there any activity you like to do?
- Can you tell me what your sibling's PANS means/what PANS looks like?
- How do you know he/she has PANS?
- How long has he/she had PANS?
- Does it come and go? Is it the same? What do you think/feel about it?

*Intermediate Questions*

Tell me about how you experience your sibling's PANS in (different everyday situations that the participants talked about in the initial questions). What happens? What do you think/do/feel? What do you think/feel about your sibling's behavior? Is there anything you do to manage challenges? How do you think and feel about how others can help you in these situations? Do you talk to someone? How do you feel/think about your ability to manage challenges?

In what ways has your sibling's PANS affected your life? School/being with family/friends/What do you do/feel/think in such situations? How do others react? Is there someone who gives you support in these situations? How? How do you think/feel/react then?

Tell me about a specific situation in which you think your sibling's PANS doesn't have an effect or doesn't matter to you? What does it look like? What do you do/think/feel?

Are there good things about having a sibling with PANS? Tell me about it. How do you think and feel about it?

*Concluding Questions*

- How do you think the future will be?
- Is there something else you think I should know in order to understand what it's like to be the sibling of someone with PANS?

*do/feel/think about in such situations? Is there anything you do to manage challenges? Is there someone who gives you support in these situations?*

The effectiveness of interview questions was not piloted with siblings of children with PANS. However, clearness and conciseness of the included interview questions had been previously tested on three siblings to children with ADHD. The formulation of the questions was revised based on comments from these children. When evaluating interview's clearness and conciseness we investigated how they understood the questions, how they experienced the formulations and the tone of the questions, as well as the number of them. Nevertheless, it is important to note that in the present study, the conducted interviews were semi-structured and the interview guide was used in a flexible way.

**Procedure**

The data collection took place from May 2021 to March 2022. The interviews were conducted at the participants' homes. All participants were interviewed at the weekends, in a quiet environment, in a separate room from their parents

and siblings, who were at home at the time of the interview. Interviews lasted 15–75 min, and were audio-recorded. Participants were not offered compensation for their participation. The first author – a clinical psychologist with an extensive experience in the field of neurodevelopmental disorders – conducted and transcribed all the interviews.

**Data Analysis**

In analyzing the interviews, we applied a combined deductive-inductive approach to qualitative content analysis, suggested by Elo and Kyngäs (2008). The analysis process involved two stages. In the first, a deductive stage, we deductively analyzed the interviews by categorizing the material into predefined categories based on the core concepts of Transactional Theory. In the second, an inductive stage, we inductively analyzed data under each category to create subcategories. We found this method of analysis to be appropriate as it enabled us to use Transactional Theory as a guiding framework without compromising on the aim to understand the siblings' experiences as expressed from their perspectives. We used QSR International's NVivo software (2022) as support during the analysis.

At the beginning of the deductive stage of the analyses, we formed a preliminary categorization matrix using three pre-defined categories corresponding to core concepts of Transactional Theory. Table 3 outlines the categorization matrix and operational definitions of these core concepts.

In order to test the categorization matrix, deductive coding was conducted by both authors independently of each other on one interview transcript ( $\approx 11\%$  of all data). This transcript was selected because it was considered to have covered the main aspects of the phenomenon under study. After this coding round, the two authors met and discussed the results of their coding, which led to a refinement of the operational definitions of the categories outlined above. Subsequently, we applied the coding scheme independently of each other to a random subsample of three interviews ( $\approx 33\%$  of all data). We met and discussed the individual coding decisions as well as the reasons for any disagreements. For instance, siblings' appraisals of a lack of the parents' involvement in their life could be categorized as both as a personal consequence of their sibling's PANS and as appraisals of resources found in their near environment.

During the second stage of the analysis, the inductive stage, meaning units under each category were sifted, organized, and synthesized inductively to form subcategories that together composed the category. During the inductive analysis the two authors met repeatedly and discussed emerging subcategories. In this context, it is important to note that boundaries between the two stages – the deductive and inductive content analyses – were not

**Table 3** Categorization matrix

Core concept of Transactional Theory	Operational definition
Primary appraisals	The meanings and significance the sibling lends to a specific situation or event in relation to the sibling with PANS in everyday life; the impact of the situation or event on the sibling's everyday life and well-being; the consequence of PANS in relation to their own needs, values, and interests.
Secondary appraisals of own ability	The sibling's judgement of what can be done to manage the challenging situation or event; the sibling's assessment of his or her own abilities to manage the situation or event.
Secondary appraisals of situational variables	The sibling's judgement of what can be done to manage the challenging situation or event using the resources available for help in his or her environment.

always clear-cut and could overlap. We jotted down any emerging subcategories during the deductive stage and discussed this with each other. Due to the iterative nature of the data analysis, the authors decided not to perform inter-coder reliability (ICR) for two coders when conducting the deductive content analysis.

In order to increase the trustworthiness of the analysis, the following strategies were used: Firstly, we applied ongoing reflexivity throughout the study, reflecting on how our professional backgrounds as a clinical psychologist and a special educational teacher might have affected the research process (Brantlinger et al., 2005). In addition, we repeatedly discussed and negotiated our interpretations of the data with each other during the analysis process. Thirdly, we presented and discussed the preliminary findings at a seminar with five researchers with extensive experience of qualitative research methods and the field of families of children with disabilities. Previous to the seminar, the members were given a description of each subcategory along with the quotes that constitute them. During the seminar, the members gave feedback regarding the clarity of each subcategory – whether it represented the quotes that underlie it, or whether subcategories overlapped with each other.

## Results

In line with the aim and research questions, the findings were divided into three main categories: (1) Consequences of having a sibling with PANS; 2) Own ability to manage; and 3) Resources in the environment. In the following section we will describe the content of these categories and the subcategories that constitute each of them. Figure 1 describes the results schematically. To protect the identity of the study participants, all quotations are shown with no personal details.

### Consequences of Having a Sibling with PANS

This category covers the participants' experiences regarding the consequences of PANS on their everyday life

functioning and well-being. The results indicate that having a sibling with PANS is perceived as an adverse event with substantial negative consequences in various arenas of everyday life. All participants experienced their sibling's illness as a source of difficulties and threats, lacking any positive value. Two subcategories of negative consequences were identified: Fear of sibling's aggression and Unsatisfied needs.

#### Fear of Sibling's Aggression

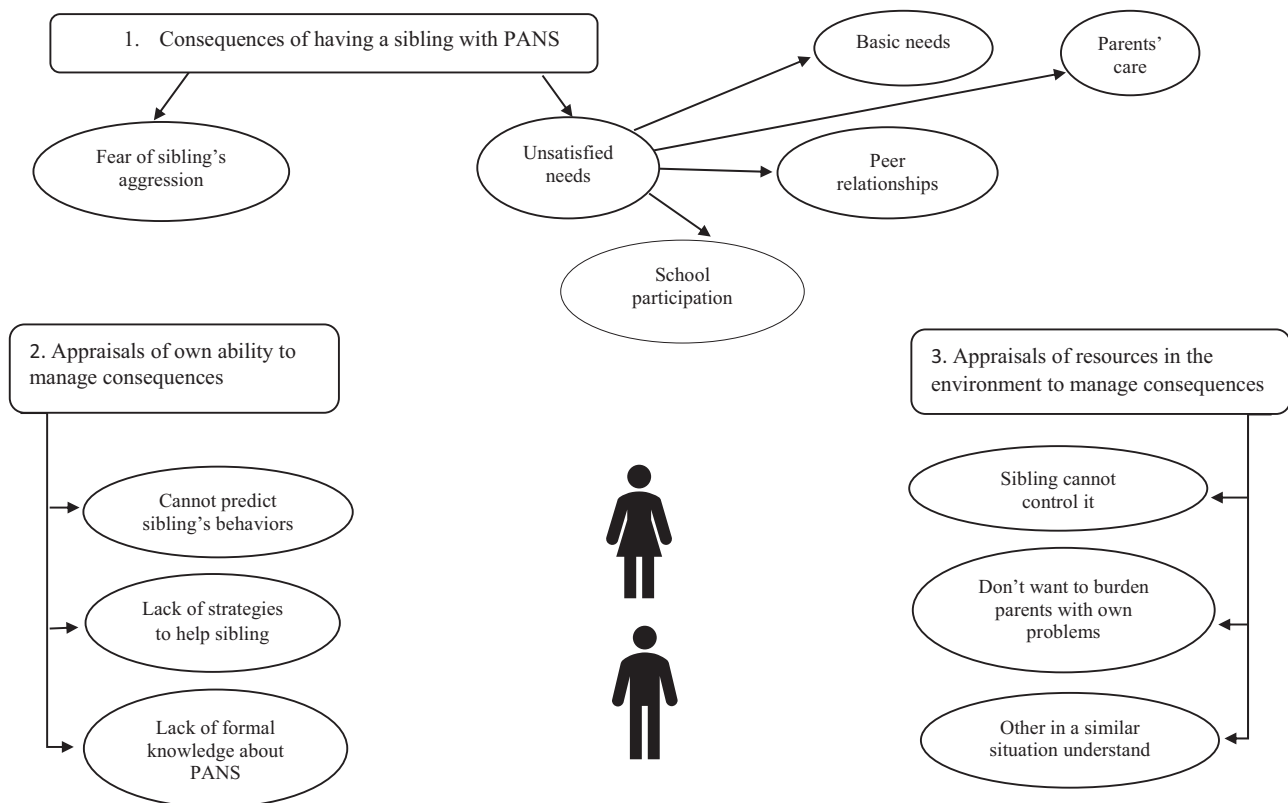
Many participants expressed a fear of their sibling's physical and verbal aggression, outbursts of violence, and screaming. They expressed a fear of their sibling's aggression toward them, toward the sibling him or herself, toward their parents, and toward items in the house. This experience is described in the following quote:

*For my sister, it means that she gets really mad really easily; she can get stressed out by things and stuff like that. And sometimes, for example if she has homework she forces Mom to do it, and if Mom says 'No, I don't have time', she gets really mad. Then she usually cusses a lot at Mom and raises her voice. It's really annoying. I try to just stay in my room then, and watch YouTube. She gets mad and does things I don't want her to do. I'd rather she yell at me because she always yells at Mom. She could take it out on me instead of Mom, because she always takes it out on Mom. Then I'd know that Mom didn't have to have it done to her.*

Many described often being anxious and alarmed when they were at home, due to the risk of being exposed to violence.

#### Unsatisfied Needs

This subcategory is comprised of experiences related to difficulties the participants had in fulfilling their needs. All participants perceived that their sibling's illness caused their own needs to be prioritized less by their



**Fig. 1** Categories and subcategories

parents. They also perceived that they were expected to adjust their own needs, or ignore them, to those of their ill sibling. These experiences were categorized into four groups of needs: basic needs, the need for parents' care, the need for peer relationships, and the need to participate at school.

**Basic Needs** All participants experienced having difficulties satisfying their basic needs at home, such as eating when hungry, having access to the toilet and shower, or getting sleep. The sibling's symptoms, mainly their OCD and aggressive behaviors, were the reasons for these difficulties. In some cases, it was the parents themselves who clearly asked the participant to wait or to adjust to their sibling's needs. In other cases it was the participants themselves who put their needs aside, and waited until it was possible to satisfy their needs in relation to their sibling's well-being, as described in the following quote:

*If he's going to, like, eat I have to adjust to that and eat before or after him. I can't eat when he's going to eat. There was this one time I got home from school and was going to eat something; I sat there and waited for two hours. I was really frustrated and hungry. And I couldn't eat for two hours. Because you can't sit there and eat when he's eating.*

**Parents' Care** A repeated experience that the participants expressed was that their parents were not available to see to their needs. This was related to both instrumental care, such as driving them to places or bringing them things they needed, and emotional care, such as participating in important events, sharing happiness with them, encouraging them when they experienced challenges, and comforting them in times of failure. This experience is illustrated in the following quote:

*I've played handball for four years and my Mom was at one of my matches for the first time, like, a year ago. She's only been to one match. Because she's had to stay home with my brother instead.*

Another consequence of their sibling being ill involved limitations they experienced in engaging in leisure activities with their parents. Many of the participants experienced that their weekends and school vacations were less active and that they were limited to staying at home, to adjust to their sibling's needs. Some experienced that plans for fun activities with their parents were often cancelled at the last minute due to their sibling's condition. In cases in which the whole family participated in a leisure activity, it was experienced as stressful and unpleasant due to the sibling's behaviors.

In some families, there was a division between parents so that one of them always took care of the sibling with PANS while the other took care of the rest of the children in the family. In these cases, the participants experienced that they had a problematic relationship with the parent who took care of their ill sibling.

**Peer Relationships** All participants experienced that having a sibling with PANS had negative consequences on their relationships with peers. One specific consequence was the difficulties they had in inviting peers to their home. In some cases, the participants themselves believed that having peers at home would worsen their sibling's mental health, while in other cases it was the parents who did not allow them to have peers over, in order to protect the ill sibling from the risk of distress. Furthermore, some participants avoided inviting friends over because they were afraid their sibling would behave in a way that would make their friends feel uncomfortable or would cause them to be judged negatively by their friends. The fear of being negatively judged by invited peers is illuminated in the following quote:

*You don't want to talk about it because they can talk crap about you. You want to just keep it secret. If I invited friends [over], they wouldn't understand why it's like that. I think about what they're going to think of me, or something like that. Like they'd think I was weird, they wouldn't like me anymore, things like that.*

Many participants shared that having difficulties inviting friends over put them in situations in which they felt excluded. To avoid questions about the reason they were not able to have friends over they made up various excuses, or tried to avoid situations in which friends would ask to come over. One of the participants described how she managed to have friends over without her parents' knowledge:

*I get irritated and mad because I don't get to have anybody over. But I've gone to my friends' houses or snuck them in instead...they went up through the yard and I opened the window in my room. And we were only in my room. But my friends asked 'but why don't you get to have anybody over?'; they didn't know it was like this. I told them my Mom works. I wanted to prove that they could be at my house, that there was nothing wrong. No, we came home after school and went right to my room. We went in through the balcony so nobody knew we were home. We were only in my room.*

**School Participation** All participants experienced daily that their sibling's illness made it difficult for them to carry

out their school assignments. Firstly, the distress over their own, their parents', and their sibling's well-being made it difficult to concentrate on their studies. Secondly, the sibling's outbursts created a destructive study environment that was inappropriate for schoolwork. Moreover, participants who attended the same school as their sibling experienced difficulty participating in school activities as they needed to take responsibility for managing their sibling's problems at school. Such an experience is exemplified in the following quote:

*It was when I was just about to go into a class and she saw me in the schoolyard and she ran right up to me and said hi and wanted to talk, and I told her I had to go to class but she didn't want that; she was like 'no, you have to stay here with me because I don't want to be by myself'. And I told her I had to go to class. But then she held onto my arm.*

### Appraisals of own Ability to Manage Consequences

This category entails participants' perceptions related to their abilities and skills for managing the negative consequences of having a sibling with PANS. Three subcategories of perceptions were identified in relation to their difficulties in predicting their sibling's behaviors, their lack of strategies for helping their siblings, and their lack of formal knowledge about PANS. These subcategories illuminate that the participants perceive inability to manage the negative consequences of PANS rather than strengths and competencies.

#### Cannot Predict Sibling's Behaviors

All participants perceived their sibling's behaviors as unpredictable, saying they never knew how their sibling would react in different situations:

*She gets so angry because of such small things that don't work. She likes to tinker and stuff like that and she builds Lego. If some Lego part is missing, she gets very-very angry just for a small piece of Lego that is missing. (...) If I don't stay away from, it can be so that she becomes even more angry with me. I am also more careful before that, I am very careful. If I go far with something, she gets really angry, so I think all the time about not to do this or not to say that as she might be very angry. If, for example, if we are just talking or we are doing some handcrafting, and I maybe I should say something about how she does that, then I must rethink whether I should say that [or not] – otherwise she might be very angry.*



Furthermore, the participants appraised that there was no logic or pattern in their sibling's behaviors as their reactions were too intense, radical, and disproportionate to the triggers that elicited them. For example:

*When he is in good mood, then one can do almost anything. [I] can ask him whether I can borrow his things and he just says 'yes, of course'. But when he is in a bad mood, then he just yells. And I don't know sort of ... this is kind of... I don't know what exactly makes him be in bad mood. He just becomes like that. I don't know what makes him be like that.*

Additionally, many of the participants expressed unfamiliarity with their sibling's behavior, describing it as unique, and said they could not recognize it in other children.

### **Lack of Strategies to Help Sibling**

With regard to their own ability to mitigate their sibling's symptoms, the participants expressed helplessness and a lack of effective strategies for helping their sibling during flares. This is expressed by one of the participants as follows:

*And I see how Mom and Dad help her, but as for me I don't know how to handle it and I don't really know what I'm supposed to do...the way she feels is so bad, and not being able to help her; it feels so hopeless. You, like, can't do anything.*

Perceiving an inability to help led the participants to leave the management of their sibling's well-being to their parents, and to avoid their sibling by going to their room, leaving home, or distracting themselves. Older participants experienced that they felt particularly distressed when they were responsible for taking care of their sibling when their parents were not nearby.

### **Lack of Formal Knowledge about PANS**

The participants perceived that they had little, if any, formal knowledge about what PANS is. Such a lack of knowledge could entail the formal meaning of the diagnosis, its causes, or its treatment. In addition, many participants experienced a lack of words to describe the condition to others, and compared PANS to more familiar conditions such as ADHD and dyslexia, as illustrated in the following quote:

*(...) if she'd had ADHD, then I could just say 'my sister has ADHD' and everybody knows what that is. But if I say 'my sister has PANS' then I have to explain what PANS is and that can be hard. It's hard to explain what PANS is.*

## **Appraisals of Resources in the Environment to Manage Consequences**

This category involves the participants' appraisals regarding the availability of social resources to manage the negative consequences their sibling's PANS had for them. Appraisals in this category were divided into three subcategories in relation to the inability of the ill sibling to control their symptoms, the participants' unwillingness to place an additional burden on their parents, and the source of support they found in other children in similar situations. Similar to the previous category involving one's own ability, this category also illuminates that the participants perceived a lack of available and supportive resources in their environment rather than social support.

### **Sibling Cannot Control it**

All participants perceived that their sibling lacked the ability to control and manage their own symptoms, and was thus not seen as a resource for managing threats. However, some of the participants believed their sibling might be able to control their symptoms better with the help of effective medications. As two siblings expressed it: *"When she gets angry or yells, it [feels] like as if another person that entered in her, she can't control it."*

*For my sister it means like this: that she has compulsion, she must feel things, that she very quickly gets very sad, [that] she gets stressed by things. She must be able to do things now-now-now, [and] you must do that, Mom must do that – you understand – this kind of stuff. She just must do things. She cannot control it.*

### **Don't want to Burden Parents with own Problems**

Many participants perceived that their parents were already overloaded and burdened by taking care of their ill sibling, which made them avoid asking the parents for support. Besides, participants also perceived that there might be a risk that their parents would feel guilty or sad if they asked them for help. This meant that parents were perceived as a limited source of support, as illustrated in the following quotes:

*I've also been scared. I didn't want to let on in front of Mom and Dad. I was scared that they won't have the energy. That both my sister and I feel bad. It would feel weird if both of them had to be engaged with us all, all the time. Then they wouldn't have any free time. And then it feels mean to them in some way. Even though I need help too.*

*If there's something that I just want to talk to someone, and I know that Mom and Dad are busy with [sister's name], then I go to my [maternal] grandma and grandpa – they live very close to us. I use to be there and talk to them. I talk to them, for example, how the school has been and things like that, or [discuss] the TV program that we watch together.*

### Other in a Similar Situation Understand

Although the common perception among participants was that they had limited possibilities to receive support from others, some experienced that peers with a similar situation were a source of emotional support, mostly in the form of compassion. It is important to note that it was not the participants themselves who searched for sibling support groups; contact with other siblings in the same situation was often organized by the healthcare system or help organizations. The siblings themselves developed and continued this support after the organized activities, however, by creating support groups in social media.

*I have also been in a sibling group with other siblings of someone with PANS. We sat at dinner and we just talked for two hours not only about PANS but also about us as siblings. It was easier because they, they don't ask a lot of questions about, they already know, because they also have siblings. It is much easier because I can say this, if I have problems at home, then they understand because they also have siblings with PANS. We still write to each other in case something has happened at home, you just want to talk like this with someone who really knows how I feel. I could write to my closest friends if I feel bad, but they don't understand in the same way as another sibling. If I write to my other close friends who don't have a sibling with PANS they might say 'I understand you' and that may feel good but a person who has a sibling with PANS says 'I understand you', and I know they understand for real because they've been through the same thing too. And then I know I'm not alone in that.*

## Discussion

This study reported findings from interviews with nine siblings of children diagnosed with PANS – a condition that is characterized by a sudden and dramatic onset of various behavioral, cognitive, emotional, motoric, and somatic symptoms (Swedo et al., 2012) and that entails tremendous

challenges for the affected child and their family (Murphy et al., 2015). PANS is a relatively new diagnosis and scientific knowledge regarding the condition, its etiology, typical course, and treatment is still unclear (Calaprice et al., 2017). Several authors pointed to the concept of PANS as an inflammatory disease with anti-inflammatory and immunomodulatory therapy as suggested treatment strategies (Gagliano et al., 2023; Melamed et al., 2024). Yet, these medical treatment approaches are presently viewed as controversial due to lack of strong evidence base (Gagliano et al., 2023; Leonardi et al., 2024). Currently, the PANS diagnosis is based on timeline or history as well as physical examination with a focus on symptom manifestation (Gagliano et al., 2023).

To our knowledge, this is the first study to investigate how siblings of children with PANS experience their everyday life and well-being in relation to their sibling's condition. Our results illuminate that PANS has tremendous consequences for the siblings of the ill child. Siblings live in fear of experiencing aggression and outbursts by their brother or sister, an experience they share with siblings of children with ADHD (Kendall, 1999). In addition, siblings of children with PANS also experience that their basic needs, as well as social and emotional needs, are neglected due to their sibling's needs; such experiences have also been reported by siblings of children with anxiety disorders (Litzelfelner, 1995). Interestingly, two main consequences of PANS that the siblings in this study expressed as being particularly significant to their well-being were the difficulties they had in inviting friends to their home and spending leisure time with their family. These results can be understood with regard to the cultural context in which the study was conducted, as international comparisons have shown that recreational and social leisure activities are frequent among Swedish children's everyday life (Ullenhag et al., 2012; Santaliestra-Pasías et al., 2014). At the same time, these findings corroborate the results from the earlier studies with siblings of children with chronic illnesses indicating that compared to general population, this group of siblings reported significantly lower levels of relationships with friends and leisure activities, thus affecting negatively siblings' social quality of life (Berbis et al., 2015; see also Gan et al., 2017).

Furthermore, the results show that siblings of children with PANS perceive that their own ability, as well as that of the resources they have in their surroundings, to manage their problems is limited. Their lack of ability is related to difficulties predicting their sibling's symptoms, as well as a lack of formal and practical knowledge about the illness. Particularly, the results reveal that one difficulty is related to the perception that the diagnosis is unfamiliar to others, compared to diagnoses such as ADHD and dyslexia. This finding may be unique to the experience of siblings of

children with PANS, as the syndrome has been fairly recently described and knowledge about it is lacking not only among healthcare professionals but in schools and the general community. This difficulty is exacerbated by the experience of not knowing how, and lacking the words, to explain the diagnosis to others. However, having social contact with other siblings of children with PANS is perceived as a source of emotional and social support. Studies have searched to identify protecting and risk factors related to siblings' mental health (Ferraioli & Harris, 2009). In the case of siblings to a child with autism, research has showed that siblings who have more knowledge about autism, showed significantly lower levels of internalizing and externalizing problem behaviors (Ross & Cuskelly, 2006). In addition, research has showed that girls siblings are more affected than boys, and those who share their problems with friends and are able to invite friend home experience significantly less behavioral and emotional problems (Caner et al., 2024). Social support and parents' guidance are the types of social support with the strongest protecting effect regarding depressive symptoms (Koukouriki et al., 2021). Support group programs, however, have only moderate effect on emotional and behavioral difficulties (Roberts et al., 2016). Since PANS is a relatively newly described condition, insufficient knowledge about it as well as limited access to support groups at healthcare settings can present a risk factor for healthy siblings. Nevertheless, findings in the present study suggest that the siblings could utilize formal and informal support available to them in their near environment in order to be able to handle negative consequences of living with their siblings with PANS, for example, they could visit their grandparents or participate in sibling support groups. Moreover, it seems that some siblings in our study were able to develop and use mechanisms of self-control to deal with unpredictable situations during their interaction with ill siblings (e.g., as one sibling reflected: "I am very careful... I think all the time about not to do this or not to say that"). Self-control has been described as "a variable representing the coping phase when individual implements the planned response by thinking or doing something to cope with the stressful situation" (Hamama et al., 2008, p.123). This is in line with Lazarus and Folkman's (1984) Transactional Theory of stress and coping that proposed an activation of person's coping actions, that are process-oriented and dynamic in nature, in response to stressful events (Biggs et al., 2017).

### Practical Implications

Understanding the results from the perspective of Transactional Theory (Lazarus & Folkman, 1984) suggests that siblings of children with PANS experience daily chronic psychological stress, as while the negative impacts of PANS

on their life are significant, they perceive that their resources for managing them are limited. These results have implications for practice. As with other conditions, even in the case of PANS health and support interventions should take a family perspective and include all family members alongside the affected child. In the Nordic countries, the proposed clinical guidance for managing PANS includes recommendations for the provision of psychoeducation to the child and his or her parents (Pfeiffer et al., 2021). In Sweden, there is a long tradition of taking a family-centered approach to the provision of habilitation services to families of children with various conditions, including neurodevelopmental ones (Hedberg et al., 2010). For example, alongside psychoeducational interventions for parents, habilitation units also provide support programs for siblings as well as grandparents of children with autism (Zakirova-Engstrand et al., 2021). Considering the documented evidence on pre-existing neurodevelopmental or psychiatric disorders in several PANS cohorts (Gagliano et al. 2023), it is desirable that non-pharmacological, family-centered interventions be offered to family members of children with PANS, including their siblings, based on existing psychoeducational treatment protocols. In connection to this, there are two aspects that need to be emphasized. Firstly, it is important that psychoeducational interventions include siblings, in order to increase their general understanding of and knowledge about the condition. It is also important that such psychoeducational interventions acknowledge the current lack of scientific knowledge about the condition. Secondly, based on the results and the fact that PANS is a rare diagnosis, it is recommended that community-based support groups of siblings of children with PANS be organized to enable siblings to establish contact and offer each other social and emotional support. School-based Pupil Health Teams (PHTs) with multi-professional expertise could also provide timely support to siblings of children with PANS, given these teams' preventive approach to pupils' health problems (Education Act 2010:800).

### Study Limitations

There are several limitations in this study that are important to highlight. Firstly, despite our attempts to achieve variation among participants there was no variation in terms of cultural background, as all participants lived in families from a Swedish cultural background; this may limit the generalizability of the results. It is thus recommended that future studies include participants from different cultural backgrounds in order to understand how culture may be important in regard to the consequences of PANS as well as participants' perceived resources and support.

Another limitation is that the number of participants was limited, and that they were mainly recruited via a user organization, a main task of which is to collect and spread knowledge about PANS. The small number of participants and the recruitment method may decrease the generalizability of the results. Moreover, the small sample size did not allow us to investigate influence of families' financial situation on daily lives of siblings of children with PANS to get a more nuanced understanding of siblings' well-being. However, this methodological challenge is a consequence of conducting research on a rare diagnosis. With the present study having employed a qualitative, cross-sectional design, there is a need to conduct a longitudinal study to follow the siblings' life trajectories over time to understand their patterns of resilience. Future studies could also investigate availability and access to support services in order to understand how these contribute to the siblings' quality of life.

## Conclusion

The present study contributes to the growing body of literature by reporting everyday life accounts of the siblings of the children diagnosed with PANS in Sweden. The findings strongly indicate that healthy siblings experienced tremendous difficulties when growing with their brothers or sisters with PANS: they felt living in fear of experiencing aggression, and that they could not predict their siblings' behaviors. Healthy siblings lacked knowledge about PANS and had only a limited number of strategies to cope with stressful situations in relation to their siblings with PANS. Peers in a similar situation and extended family members were a source of emotional support. There is an urgent need to develop community-based support programs to reduce the impact of PANS on healthy siblings' well-being by helping them acquire knowledge about PANS and equipping with strategies to meet the complex needs of their chronically ill siblings.

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## Compliance with ethical standards

**Conflict of interest** The authors declare no competing interests.

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