

# SELF-HARM AND SUICIDALITY IN PEDIATRIC ACUTE-ONSET NEUROPSYCHIATRIC SYNDROME (PANS) AND IMMUNOPSYCHIATRIC DISORDERS

## TECHNICAL REPORT

Gunilla Gerland

SANE SWEDEN

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Gerland, G. (2023) Self-Harm and Suicidality in Pediatric Acute-Onset Neuropsychiatric Syndrome (Pans) And Immunopsychiatric Disorders. SANE Sweden. 1:2023

*SANE is a Swedish parental and patient society for Pediatric Autoimmune Neuropsychiatric Syndrome (PANS) and related immunopsychiatric disorders such as Autoimmune encephalitis (AE) and Sydenham's Chorea (SC). SANE has supported individuals with PANS and their families since 2013. It was observed that suicidality, including suicide attempts and self-harming behavior, was not uncommon. Moreover, there is literature supporting the idea of suicidal ideation and self-harming behavior occurring in PANS (e.g., Hesselmark and Bejerot, 2019; Frankovich et al., 2015a). However, knowledge about the extent and characteristics of self-harming behavior and suicidality in PANS has been lacking. In light of the known links between self-harming behavior and suicidality (Whitlock and Knox, 2007), the lack of knowledge in the field, and the fact that children's and adolescents' mental health, as well as suicide prevention, are priority areas in society, SANE applied for and received project funding from Folkhälso-myndigheten, the Swedish Public Health Agency, to conduct a survey. The results of the survey are presented in this report which was first published in Swedish 2021.*

*The report author and SANE Sweden would like to thank all parents and relatives who took the time to fill out the survey. We also would like to thank the Public Health Agency for the project funding that made this report possible. Special thanks to Professor Susanne Bejerot for her invaluable assistance with the report.*

*We hope that this exploratory study will generate avenues for future research using both quantitative and qualitative methods.*

*Gunilla Gerland, author*

*Katrin Pettersson, chair SANE Sweden*

<https://sane.nu/>

[info@forbundetsane.se](mailto:info@forbundetsane.se)

## **Abstract**

This study aimed to gain a better understanding of self-harming behavior and suicidality among individuals with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and other immunopsychiatric disorders by surveying 240 mainly parental respondents. The results showed that a significant number of individuals with these disorders exhibit severe self-harming behaviors that include high frequency, violent methods, onset at a young age, and/or overlap with suicidal behaviors. Suicidal ideation and communication were also found to be common in this population, and suicide attempts appear to occur at a young age. Furthermore, a subgroup of individuals reported extensive suffering including unbearable symptoms, hopelessness, and social isolation.

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# 1. Introduction

Pediatric Autoimmune Neuropsychiatric Disorder associated with streptococcal infection (PANDAS) was first described in the 1990s (Swedo et al., 1998) and is now considered a subgroup of PANS. Therefore, the latter term is mainly used in this report. PANS is a medical condition characterized by a rapid onset of often severe obsessive-compulsive symptoms and/or restricted eating, in combination with other symptoms. Several psychiatric and neurological symptoms are common, such as anxiety, aggression, sensory or motor abnormalities, sleep disorders, enuresis, and urinary frequency. Psychotic symptoms such as delusions and hallucinations can also occur but are less common. In most cases, the condition has a relapsing-remitting course. Often, a connection between relapses and infections, mainly but not exclusively streptococci, is observed (Frankovich et al., 2015b).

PANS mainly affects children before puberty, but older adolescents and young adults can also become ill, and children with PANS may remain ill in adulthood. The exact disease mechanism is not yet known. Neuroinflammatory and immunological mechanisms have been discussed. Animal models have found signs of the immune system (Platt et al., 2020), and one study showed that IgG antibodies bind to a certain type of interneuron in the brain, which could be part of the disease mechanism (Xu et al., 2021).

In Sweden, the term immunopsychiatric disorder is used as an umbrella term for the group of disorders, including PANS, that have a mainly psychiatric presentation but are suspected to be immune-mediated. There is no exact definition of this term, but it has been suggested that an immunopsychiatric disorder should be suspected when a patient presents with one or more of the following signs: the debut of (or extremely aggravated) severe multiple psychiatric symptoms in combination with physical symptoms; a loss of previously established functions (such as in terms of language, motor skills, cognition, and activities of daily living); an atypical onset or course.

## **Distinguishing PANS from Other Disorders**

Delimitations between immunopsychiatric disorders are not always clear (Cellucci et al., 2020). Clear differences between PANS and SC have been found in one study (Gamucci et al., 2019), while the results of another study suggest that SC and PANS could be two manifestations of a common mechanism, namely dopamine receptor-mediated encephalitis of the basal ganglia (Chain et al., 2020). In addition to distinguishing PANS from SC and autoimmune encephalitis, the distinction from obsessive-compulsive disorder (OCD) has been discussed. One study found that 5% of 136 children and adolescents with OCD met the criteria for PANS and/or PANDAS, and those in this subgroup more often had autoimmune illnesses, were less likely to report symmetry symptoms, and experienced greater OCD-related family impairment during their worst OCD episode (Jaspers-Fayer et al., 2017).

Since the most prominent symptoms of PANS are often psychiatric, it can be mistaken for other conditions such as OCD, eating disorders, or autism (Stanford Medicine, 2020; Goncalves et al., 2018). This may contribute to the difficulty in obtaining a diagnosis and treatment that has been reported (Calaprice et al., 2017).

## 2. Method

This report aims to increase knowledge about self-harming behaviors and suicidality in PANS and immunopsychiatric disorders. We gathered information through a survey addressed to parents or other adult relatives (such as an adult sibling) of individuals who have or have had PANS or another immunopsychiatric disorder (such as autoimmune encephalitis and SC).

The questionnaire was broadly designed as there is essentially a lack of previous knowledge on this topic. We formulated the questionnaire with the following questions in mind:

- How common are self-injurious behaviors, suicide attempts, and other expressions of suicidality in people with PANS and immunopsychiatric disorders?
- Do these groups differ from what is known about self-injurious behavior and suicidality in the general population and/or in other psychiatric conditions?

The survey was created using the online service SurveyMonkey and analyzed using its built-in tools.

The survey was designed so that respondents were directed to different parts of the questionnaire depending on their responses. For those who reported no suicide attempts or self-harming behaviors, the questionnaire took about 5-10 minutes to complete, while for others it could take up to 30 minutes. Because the questions could potentially affect respondents emotionally, we included recurring information about the option to contact SANE's helpline. All data collected was completely anonymous.

The survey was advertised via email to the members of SANE and in the support groups online run by SANE. The invitation was, as well as the survey, in the Swedish language. To ensure we received responses from a range of parents, we stated that we were interested in respondents whose children were at any stage of PANS or immunopsychiatric disorders, from severely ill to full recovery. To avoid only attracting parents whose children had self-harming behavior, we presented the survey as being about 'severe symptoms that may occur in PANS and immunopsychiatric disorders.'

We chose to include other immunopsychiatric disorders due to the overlap in symptoms and our experience that a PANS diagnosis may be changed to another diagnosis over time, for example if the individual develops choreatic movements indicating SC (Frankovich et al., 2015) or if a patient develops seizures or other findings indicating autoimmune encephalitis (personal communication with parents).

Of the 287 respondents, 47 were excluded due to incomplete answers. Ten answers were somewhat incomplete but were retained as they only lacked answers to certain parts.

Ninety-seven percent of the respondents were parents, with 90% being mothers and 7% being fathers. Only 3% were 'other relatives,' such as adult siblings.

Parents with more than one child with PANS/immunopsychiatric disorder were asked to complete one questionnaire for each child. However, it is unclear how many respondents followed this request. Fifteen respondents indicated that they had more than one child with

PANS/immunopsychiatric disorder in their family. The majority of the respondents (n = 233) were based in Sweden, while a small number (n = 7) lived abroad.

Table 1.

The survey responses were provided for 240 individuals born between 1977 and 2016 (as shown in Table 1). Of these individuals, 59% were male and 41% were female.

Distribution of age groups (N=240)	% (n)
Born 1977-1979 (older than 25 years of age)	12% (29)
Born 1995-2000 (20-25 years of age)	10% (24)
Born 2001-2005 (15-19 years of age)	29% (69)
Born 2006-2010 (10-14 years of age)	32% (77)
Born 2011-2016 (4-9 years of age)	17% (41)

Most of the responses referred to children, adolescents, or young adults, with 195 out of the 240 individuals being under the age of 21. This result is expected given that PANS is a relatively new area of research and the majority of cases occur in childhood.

When asked if the individual had recovered, 37% stated that they are “still ill”, 30% reported “better but not recovered”, and 12% stated that the individual is “symptom-free right now, but uncertain whether there may be new relapses”. A further 17% described the individual as “fully or to some extent recovered” and 4% described the person as “fully recovered”.

That only a minority is said to be to some extent or fully recovered should not be taken to reflect a prognosis. Rather, when an individual is recovered, many families leave the association and thus have not been reached by information about the survey and/or are less motivated to participate.

Among the members of SANE, there are parents of children with immunopsychiatric disorders other than PANS, such as autoimmune encephalitis and Sydenham's chorea. Additionally, since obtaining a diagnosis of PANS can be difficult, we have included the group of individuals with ‘suspected PANS,’ where the family strongly suspects PANS but the patient has not yet received a diagnosis.

The majority of responses were from individuals with Confirmed PANS (n = 162), meaning they received the diagnosis from a medical professional. Suspected PANS was a smaller group (n = 55). An even smaller group consisted of individuals with other Confirmed or Suspected Immunopsychiatric disorders (n = 23), including autoimmune encephalitis (n = 11), Sydenham's chorea (n = 2), as well as other diagnoses (n = 10), such as Myalgic encephalomyelitis (ME) and PANDAS, Variable immunodeficiency (CVID) with PANDAS-like symptoms, and Neuroborreliosis with encephalitis.

In this report, the term “PANS and immunopsychiatric disorder” will be used for the entire group of responses (N = 240), but the responses will be reported separately according to each group where relevant.

The survey results are limited by the fact that they are based on information provided by close relatives (mainly parents), meaning that they rely on the respondents' memory, and that the information, such as diagnosis, cannot be objectively confirmed. As PANS and immunopsychiatric disorders are relatively unknown, emphasis has been placed on relating the results to relevant research to provide context.

### 3. Introduction:

## Suicidality in PANS and Immunopsychiatric Disorders

#### **Suicidality and Self-harm in PANS and Immunopsychiatric Disorders**

As previously mentioned, suicidality and self-harming behaviors have been noted to occur in PANS. One study reported that 10 out of 33 children with PANS (aged 6–18 years) “checked suicidal items on the CBCL, including ‘talks about killing self’ and/or deliberately harms self or attempted suicide” (Murphy et al., 2015). Another report on symptoms in 47 PANS patients (aged 5–17 years) found that 44% had suicidal ideation, 14% had “suicidal gestures”, and “life-threatening violence” occurred in 14% (Frankovich et al., 2015a). However, these concepts have vague definitions, and the term ‘suicide gesture’ has been criticized for its ambiguity, arguing that ‘suicide attempt’ is a more proper term (e.g., American Academy of Child and Adolescent Psychiatry, 2001; Silverman et al., 2007; Posner et al., 2007b; Heilbron et al., 2010).

A Swedish study examined symptoms in patients with PANS and compared them with a control group who had psychiatric symptoms but did not meet the criteria for PANS (*never-PANS*). The individuals with PANS were divided into two groups: *Confirmed PANS* (the subjects met all the criteria) and *Suspected PANS* (the subjects lacked the criterion of rapid onset of symptoms). The three groups reported similar rates of suicidal ideation after onset of their respective symptoms. However, those with confirmed PANS reported suicidal ideation more frequently at onset than the other groups, suggesting it could be part of the disease mechanism (Hesselmark and Bejerot, 2019). In a case report describing obsessive suicidal ideation in a nine-year-old girl with PANS, the authors conclude that the sudden onset of suicidal ideation may indicate underlying somatic disease and that one should be aware of this in acute suicidality in children (Rozatkar and Dingra, 2015).

Suicidality is also described in autoimmune encephalitis, for example, anti-NMDAR encephalitis. In a study of 133 patients, 13% had suicidal symptoms (Zhang et al., 2017). Furthermore, suicidality has been reported in Lyme and associated diseases (Bransfield, 2017). Although psychiatric symptoms such as OCD, depression, and anxiety are common in Sydenham’s chorea (Moreira et al., 2014; Pudukollu et al., 2016; Peall et al., 2017) information on suicidality and self-harming behavior in SC is lacking in the literature.

#### **Overlapping Symptoms between PANS and Disorders with Increased Risk of Suicide**

Obsessive-compulsive disorder (OCD) is the most common symptom of the two main criteria for PANS. In a report on symptoms in 47 patients, OCD was present in 94% of cases (Frankovich et al., 2015a). OCD is a known risk factor for suicide. For example, a large Swedish registry study involving over 35,000 people showed that OCD is associated with an increased risk of death by suicide (Fernández de la Cruz et al., 2016).

Psychotic symptoms occur in approximately one-third of PANS patients. Hallucinations have been reported to occur in 36% of patients (Hesselmark and Bejerot, 2019; Silverman et al., 2019; Calaprice et al., 2017), and an observational study of 23 patients with PANS reported psychotic symptoms (hallucinations, delusions) in 26% (Johnson et al., 2019). In autoimmune encephalitis, psychotic symptoms occur in 60% of patients according to one study (Herken and Prüss, 2017). Although it is unknown to what degree these psychotic symptoms share mechanisms with known psychotic disorders, it is well known that the risk of suicide is



elevated in disorders such as schizophrenia (Fenton et al., 1997; Pompili et al., 2007). Additionally, psychotic symptoms without a conventional psychotic illness can increase the risk of suicidal behavior, as shown in a study of 1,100 Irish schoolchildren aged 13–16 years, where psychotic symptoms were associated with a high risk of suicide attempts (Kelleher et al., 2013).

Furthermore, eating disorders are associated with an increased incidence of suicide attempts (Udo et al., 2019), and restrictive food intake has been reported in 53% of patients with PANS (Calaprice et al., 2017).

### **Relationship Between Self-Harming Behavior and Suicidality**

Although most individuals who engage in self-injuring behavior do not have suicidal intent, the possibility of a connection to suicidality cannot be entirely ruled out on an individual basis. This connection is particularly true in cases of frequent and severe self-harming behaviors (Whitlock and Knox, 2007). Grandclerc et al (2016) argue that self-harming and suicidal behavior share the same risk factors, such as psychiatric comorbidities, substance abuse, and posttraumatic stress disorder. The authors conclude that “Because suicidal behavior short-circuits thought, it is difficult to conceive an intention to die during adolescents’ acts of self-injury.”

Suicide attempts are often linked to prior self-harming behavior, which may be partly explained by Joiner's interpersonal theory of suicide (Andover and Gibb, 2010). In brief, Joiner theorizes that the desire for suicide arises when three factors interact: the individual perceives themselves as burdensome, socially alienated, and has an acquired capability to overcome the natural fear of death. According to the theory, the acquired capability primarily eliminates the inherent mechanism of pain avoidance in humans. This ability can be acquired in different ways, such as repeatedly exposing oneself to painful or frightening experiences, including self-starvation and self-harming behavior, or violence/abuse from others (Joiner, 2005; 2009).

### 3.1. Results: Suicidality in PANS and Immunopsychiatric Disorders

Table 2. Overview.

	All % (N)	Females % (N)	Males % (N)	Confirmed PANS all ages % (N)	Confirmed PANS Today ≤ 14 y.o % (N)	Confirmed PANS Today ≤ 10 y.o. % (N)
Suicidal communication*	57% (235)	62% (100)	54% (135)	61% (161)	57% (90)	42% (40)
Suicidal ideation	41% (233)	44% (98)	39% (135)	40% (159)	33% (90)	20% (40)
Suicidal plans	18% (233)	22% (98)	14% (135)	14% (159)	10% (90)	10% (40)
Assessed as at risk for suicide	13% (233)	15% (98)	16% (135)	12% (159)	4% (90)	5% (40)
Inpatient care due to suicide risk	7% (233)	10% (98)	5% (135)	5% (159)	1% (90)	0 (40)
Suicide attempt	14% (235)	17% (100)	13% (135)	12% (161)	9% (90)	10% (40)

The number of respondents (N) varies due to a few participants not answering all questions. The headings "All", "Females" and "Males" refer to both Confirmed and Suspected PANS, as well as other Immunopsychiatric disorders (for definitions, see the previous section). The heading "Confirmed PANS, all ages" refers to individuals born between 1979 and 2016.

\* For the purposes of this survey, suicidal communication is defined as verbal expressions of not wanting to live or wanting to die that were perceived by parents as serious and a cause for concern.

#### Suicidal Ideation and Plans

According to the respondents, suicidal ideation had occurred in 41% (n = 96) and suicidal planning in 18% (n = 41), as far as they knew. These results were consistent across both the entire sample and only confirmed PANS cases.

Suicidal ideation and planning were found to be common in younger age groups, with 33% (n = 30) of individuals under 15 years of age (all confirmed PANS, born 2006 or later) reporting suicidal ideation and 10% (n = 8) reporting suicide plans. Some of these cases involved children younger than 11 years old, with 8 cases of suicidal ideation and 4 cases of suicidal planning reported in this age group (Table 2).

#### Suicidal Communication

Based on the survey responses, 135 participants (57%) explicitly expressed a desire to die or not to live in a way that the respondent considered concerning (Table 2). More than half of these individuals (n=72) were under 10 years old when they first expressed this wish, while around a third (n=40) were aged 11-14.

The majority of those who expressed suicidal communication did so frequently, with many (n=60) or countless times (n=26). Additionally, 21% (n=28) of those with suicidal communication reported having attempted suicide.

When asked if the individual had verbally expressed a wish to die, 25 respondents selected the "other" option and provided examples of how the individual expressed resignation with

more or less suicidal communication. Some examples included statements such as “It doesn't matter if I live or die,” “I can't stand this, it's not a life,” and “It wouldn't have mattered if I had been there and died during the terror attack on the news.” Other comments described the individual expressing despair and hopelessness in different ways, such as feeling that life is meaningless and that symptoms are too frightening or unbearable to live with. (Quotes were translated from Swedish to English.)

### Suicide Risk Assessments

The results indicate that 13% (n = 31) of the entire sample (N = 240) had been assessed as at risk for suicide at some point. The first time they were assessed, they were aged between 5 and 24 years, with an average age of 12.8 years. Of these individuals, more than half (n = 17) had been hospitalized for suicide risk, with 7 being hospitalized once and 10 on several occasions.

Among the youngest group in the entire sample, i.e., those who are currently 10 years or younger (born in 2010 or later, all confirmed PANS), 5% (n = 2) had been assessed as at risk for suicide. The corresponding figure for all ages in the confirmed PANS group was 12% (n = 19) (Table 2).

Half of all respondents, 51% (n = 116), answered yes to the question “had they ever been worried that the individual will take their life intentionally”. Of these, 17% reported feeling such worry “often” (n = 19) or “very often” (n = 20).

Table 3.

Groups	Suicide attempt % (n)	Suicide (n)
Confirmed PANS (N=161)	12% (19)	0
Suspected PANS (N=55)	18% (10)	1
Other suspected or confirmed immunopsychiatric disorder (N=23)	22% (5)	0

### Suicide and Suicide Attempts

We found that 14% (n = 34) of the entire sample had attempted suicide, and one individual had completed suicide. Among the confirmed PANS group, 12% (n = 19) had attempted suicide (Table 3). There was a small gender difference, with 17% (n = 17) of females and 13% (n = 17) of males reported to have made suicide attempts (Table 2). The majority of those who attempted suicide (n = 23) had made more than one attempt (Table 4).

The material also revealed that suicidal ideation and attempts were not uncommon among younger individuals with confirmed PANS. Specifically, 33% had experienced suicidal ideation and 9% had attempted suicide among those who were 14 years or younger.

Table 4.

Characteristics	Individuals who made suicide attempts All (N=32-34*)	Individuals who made suicide attempts Confirmed PANS (N=17-19*)
Multiple suicide attempts	23	11
First suicide attempt, ≤ 10 years of age	8	6
First suicide attempt, 11-14 years of age	10	8
Self-harming behavior	28	14

\* Two respondents did not answer all questions

### Age at First (or Only) Suicide Attempt

The average age for the first suicide attempt was 13.9 years (median 13.5). Nearly a quarter (n = 8) of the 34 individuals who attempted suicide were under the age of 11 on their first attempt. Among them, the majority were boys (n = 7), and confirmed PANS (n = 6). All 8 had made multiple suicide attempts, and most (n = 7) are still children today (between 8 and 14 years old). More than a quarter (n = 10) of those who had attempted suicide made their first attempt at the age of 11-14 years. The majority of them had confirmed PANS (n = 8) and are currently between 13-21 years old.

### Self-Harming Behavior in Individuals Who Attempted Suicide

Self-harming behavior was common among individuals who attempted suicide (see Table 4). Those who attempted suicide had used more self-harming methods on average than those who engaged in self-harming behavior but never attempted suicide.

Among those who attempted suicide and engaged in self-harming behavior (n = 28), the average number of methods per individual was 3.2, whereas those who only engaged in self-harming behavior (n = 76) used an average of 1.8 methods per individual. More than half (n = 15) of those who attempted suicide and engaged in self-harming behavior had used one or more violent methods (see Table 12 and page 27 for a definition of violent methods).

### Planning and Injury from Suicide Attempts

When asked whether the suicide attempt was planned or impulsive (in the case of multiple attempts, the most serious one), 14 respondents reported it as impulsive, 9 were unsure, and 7 stated it was planned. Most of those who made impulsive attempts were male (n = 13), while the majority who had planned their attempt (n = 5) were female. Two respondents selected the “other” option and commented that the attempt seemed both planned and impulsive.

The majority of suicide attempts did not result in serious physical injury, 22 individuals had no or minor physical injuries (Table 5). The six who had the most serious injuries (required hospitalization, intensive care, or resulted in death) had all made multiple suicide attempts.

Table 5.

<b>Did suicide attempt lead to physical injury?</b>	<b>All N=32</b>	<b>Females N=15</b>	<b>Males N=17</b>
No or very minor injury, e.g., scratches.	17	6	11
Minor injury, e.g., mild bleeding; small burn.	7	3	4
Moderate injury where medical attention was needed, e.g., second-degree burns; severe bleeding.	2	1	1
Moderately severe injury requiring hospitalization, e.g., extensive blood loss; major fractures.	2	1	1
Severe injury requiring hospitalization with intensive care, e.g., extensive blood loss, major damage to vital organs, comatose.	3	3	0
Death	1	1	0

### **Symptoms and Number of Symptoms in Individuals Who Attempted Suicide**

There was no significant difference in the number of symptoms between those who attempted suicide and those who only had self-harming behavior (Table 6). However, self-punishing behavior (such as denying oneself something desired) was more common in those who attempted suicide (62%) and/or had self-harming behavior (67%), compared to those who never had self-harming behavior and never attempted suicide (27%).

Aggression, including physical aggression directed towards others, was also more common in those who attempted suicide and/or had self-harming behavior than in those who never had self-harming behavior or attempted suicide (Table 6). Those who had not attempted suicide nor ever had self-harming behavior (n = 100) reported an average of 18.6 symptoms. Those who attempted suicide and/or had self-harming behavior (n = 110) reported a higher number of symptoms, with an average of 24.8. Those who made their first suicide attempt before the age of 11 (n = 8) had a significantly higher number of symptoms, with an average of 33.8.

Table 6 (continued on next page.)

Symptoms	Never self-harming, never attempted suicide N=100	Self-harming, but never attempted suicide N=78	Attempted suicide N=32
OCD	79%	90%	90%
Restrictive eating	42%	60%	62%
Generalized anxiety	60%	86%	76%
Social anxiety	37%	58%	73%
Separation anxiety	80%	87%	73%
Panic attacks	54%	71%	69%
Depression/sadness	67%	86%	87%
Self-punishing	27%	67%	62%
Mood swings	72%	90%	83%
Irritability	72%	90%	76%
Oppositional behavior	29%	62%	34%
Aggressivity	57%	87%	72%
Physical aggressivity towards others	32%	62%	52%
Hyperactivity	42%	56%	31%
Impulsivity	30%	56%	41%
Sensory symptoms	72%	87%	79%
Motor tics	54%	61%	65%
Vocal tics	47%	62%	66%
Sleep disturbances	65%	81%	69%
Nightmares	39%	59%	55%
Extensive fatigue/exhaustion	65%	87%	79%
Confusion/brain fog	49%	69%	55%
Enuresis	40%	47%	24%
Frequent urination	34%	53%	31%
Behavioral regression	47%	56%	52%
Handwriting deterioration	50%	72%	69%
Loss/decline of math skills	32%	50%	48%
Muscle pain	45%	60%	72%
Joint pain	42%	60%	60%
Stomach pain	42%	58%	45%
Headaches	52%	71%	72%

Symptoms	Never self-harming, never attempted suicide N=100	Self-harming, but never attempted suicide N=78	Attempted suicide N=32
Specific phobias	36%	57%	58%
Bisarr thoughts or behaviours	47%	58%	69%
Hallucinations	37%	46%	48%
Delusions	29%	42%	59%
Manic episodes	22%	35%	34%
Catatonia	11%	16%	20%
Mutism (stopped speaking)	7%	6%	3%
Selective mutism	5%	7%	14%
Stuttering	9%	12%	7%
Involuntary movements	39%	43%	48%
Difficulties walking	30%	26%	34%
Unexplained recurring rashes	22%	33%	48%
Seizures/deviant EEG	10%	14%	10%

Table 6, continued.

### Symptoms and Environmental Factors Related to Suicide Attempts

Depression and anxiety were the symptoms most commonly perceived to be associated with suicide attempts (Table 7). In a quarter of cases (n = 8), respondents reported that both aggression and impulsivity were related to suicide attempts. These individuals had all made their first suicide attempt before the age of 15 and had all made more than one suicide attempt.

The three most common factors in the life situation that respondents considered to be related to suicide attempts were a lack of hope that the situation could be changed or improved, unbearable symptoms, and perceiving oneself as a burden to others (Table 8).

A few respondents (n = 5) chose the “other” option, and their comments were about extreme levels of anxiety leading to suicide attempts. One respondent mentioned that the child not only wanted to die but also threatened and acted homicidal towards a parent by trying to strangle them, putting plastic bags over their head, or suffocating them with a pillow.

Table 7.

Symptoms respondents felt were related to suicide attempts	All N=32 % (n)	Females N=15 % (n)	Males N=17 % (n)
Depression	72% (23)	73% (11)	71% (12)
Anxiety	59% (19)	67% (10)	53% (9)
Impulsivity	44% (14)	33% (5)	53% (9)
Aggressiveness	34% (11)	20% (3)	47% (8)
OCD (e.g., intrusive thoughts about suicide/self-harming)	31% (10)	33% (5)	29% (5)
Psychotic symptoms (e.g., demanding auditory hallucinations about dying/killing oneself)	25% (8)	33% (5)	18% (3)
Behavioral regression (e.g., didn't understand the consequences of their action)	19% (6)	13% (2)	24% (4)
Can't see any connection with symptoms	3% (1)	0	6% (1)
Unsure	3% (1)	0	6% (1)

Table 8.

Factors in the environment/life situation respondents felt were related to suicide attempts	All N=32 % (n)	Females N=15 % (n)	Males N=17 % (n)
Lack of hope that the situation could change	69% (22)	60% (9)	76% (13)
Symptoms felt unbearable to cope with	65% (21)	60% (9)	71% (12)
Symptoms felt unbearable to cope with	47% (15)	47% (7)	47% (8)
Alienation and social isolation	44% (14)	27% (6)	47% (8)
Resignation/sadness because of difficulties in receiving treatment/care	41% (13)	20% (4)	53% (9)
Resignation/sadness because of lack of understanding in everyday life, e.g., in school	34% (11)	20% (3)	47% (8)
Resignation/sadness because of lack of understanding in healthcare	31% (10)	20% (3)	29% (5)
Can't see any connection to factors in the environment	9% (3)	13% (2)	6% (1)



## 3.2. Discussion: Suicidality in PANS / Immunopsychiatric Disorders

### **Prevalence**

The estimated lifetime incidence of suicidal ideation among young people in the general population is 12–13% (Santesson, 2020). In psychiatric populations, the reported lifetime prevalence varies depending on the diagnosis and whether the population is outpatient or inpatient. However, patients with psychiatric disorders always have a higher incidence of suicidal ideation than the general population, which is consistent with the survey results presented here. In our survey, 41% of participants were reported to have suicidal ideation, which is in line with previous reports of suicidal ideation in PANS (Frankovich et al., 2015a). However, the reported occurrence should be interpreted in light of the fact that parents were the main informants, and children may not have disclosed their suicidal ideation. Suicide attempts in a PANS population have not been previously reported to our knowledge. The occurrence of attempted suicide in our sample (14%) may not seem alarmingly high compared to reports in psychiatric populations, but given the young age of the individuals in our sample, serious consideration is warranted.

### **Suicidality in Children**

There is a substantial lack of knowledge about suicidality in children under 12 years of age (Ridge Anderson et al., 2016; Ayer et al., 2020). It is mainly in the last decade that this issue has attracted attention, and a certain interest in research has arisen. According to our survey results, more than half (n=18) of those who had attempted suicide had made their first attempt before the age of 15. Nearly half of these (n=8) were under 11 years of age, several of whom (n=6) were 7 years or younger at the time of their first suicide attempt.

Although it is statistically unusual for children under the age of 15 to die by suicide, it does occur. When this is put into perspective with how rarely children die from other causes, it becomes clearer that it is a significant problem. Suicide is the most common cause of death in older teenage girls and the second most common cause of death in boys, according to Santesson (2020). In Swedish children and young people aged 10–14, suicide accounts for one-tenth of all deaths. While it is extremely rare for children under the age of 10 to complete suicide, one study showed that suicidal ideation and behaviors in younger children tend to persist until school age, and it has been suggested that an inability to identify and treat suicidality in younger children may be related to later suicide (Whalen et al., 2015; Ridge Anderson et al., 2016)

### **Suicidal Communication**

Our survey results indicate that a significant number of individuals have explicitly and repeatedly verbalized statements such as wanting to die or no longer wanting to live. These statements were in many cases perceived as worrying and serious by caretakers. However, it's essential to note that not all such statements indicate suicidal ideation or risk. Some experts have cautioned against over-interpreting children's statements about not wanting to live (Zeanah and Gleason, 2018).

Nevertheless, it's crucial for healthcare professionals not to assume that young children cannot be suicidal (Van Meter et al., 2018). A study on suicidality in children with depression aged 3-7 years revealed that 11% of them had suicidal ideation. The authors of the study suggested that suicidal statements and behaviors in children at this young age are strongly associated with psychological problems and suffering, irrespective of their level of understanding of death and suicide (Whalen et al., 2015).

Traditionally, it was believed that children only develop a perception of death and suicide at school age. However, children with depression and suicidal ideation aged 4-6 years were found to have a better and more advanced understanding of death compared to children of the same age with depression without suicidal ideation and healthy peers (Hennefield et al., 2019).

### **Suicide Risk Assessment**

Evidence for the validity of instruments used in suicide risk assessment in psychiatry is lacking (SBU, 2015), and assessing suicide risk in younger children can be particularly challenging (Odlind, 2020). Our survey results showed that children aged 11-14 were more likely to be assessed as being at risk of suicide than those aged 10 or younger, among those who had attempted suicide. One respondent noted that they felt their concern for their child's life was not taken seriously, saying "The concern has been noted, but it feels as if they think that such a young child cannot mean this and that I as a parent am exaggerating this" (translation from Swedish). Gleason (2019) has pointed out that due to a lack of knowledge about younger children's suicidality, suicide risk assessments for young children may depend more on the assessing physician's perceptions of children's suicidality. Acute child psychiatry units may not be tailored to the developmental needs of younger children, and there is a need to develop age-appropriate interventions.

### **Differentiation Between Suicide Attempt and Self-Harming Behavior**

Differentiating between a suicide attempt and a self-harming act with a high risk of mortality can be challenging, leading to both overreporting and underreporting of suicide attempts. Non-suicidal self-injurious behaviors and suicide attempts can differ in several ways, such as method and frequency. However, the most critical difference is the intention to die. Santesson (2020) defines a suicide attempt as an intentional injury with *any* intention of dying, regardless of the intention's severity. In a smaller study, younger children who attempted suicide had a low intention to die, despite using methods with high mortality (Stordeur et al., 2015). Respondent comments suggest that in some cases, a sudden and impulsive suicide attempt can occur during strong symptom relapse. This could mean that suicidal intent in PANS can be sudden and high, but then decrease or disappear, making suicide risk assessment more challenging.

### **Factors in the Environment**

The survey identified four environmental factors that were most commonly associated with suicide attempts: hopelessness, unbearable symptoms, feelings of being a burden to others, and social isolation. Previous research has consistently found that hopelessness is a known risk factor for suicidal behavior (Klonsky et al., 2012; Kuo et al., 2004; Steeg et al., 2016), although some studies have found weaker relationships (e.g., Qiu et al., 2017). It is important

to distinguish between temporary feelings of hopelessness and more lasting conditions (Burr et al., 2018).

The feelings of burdensomeness and social isolation are consistent with Joiner's interpersonal theory of suicide. However, it is important to note that caregiver burden can also be a complicating factor. One study found that PANS caregivers experience high levels of caregiver burden (Frankovich et al., 2018). The same study also found that a shorter time between PANS onset and entry into a multidisciplinary clinic predicted a lower caregiver burden.

To our knowledge, there are no studies on how PANS affects an individual's quality of life. However, Frankovich et al. (2015a) reported that in addition to psychiatric symptoms, individuals with PANS often experience severe and life-impairing somatic symptoms, such as sleep disturbances, urinary symptoms, sensory amplification, and generalized pain. Given the severity of these symptoms, as well as those reported in our own material (including severe obsessive-compulsive symptoms, severe anxiety, pain, loss of skills, hallucinations, and more, see Table 6), it is likely that PANS greatly affects an individual's quality of life.

### **Summary**

The survey results indicate that suicidal ideation and communication are common in PANS and immunopsychiatric disorders, and that suicide attempts may occur at a young age. The results also suggest that there is a subgroup of individuals with extensive suffering, including unbearable symptoms, hopelessness, and social isolation.

According to the Swedish national program for suicide prevention, early implementation of medical, psychological, and psychosocial interventions is crucial for preventing suicide in individuals with mental illness. The Strategy for Suicide Prevention in the Stockholm Region emphasizes the importance of reducing suffering by treating the underlying conditions and reducing the difficulties that cause the suffering. This highlights the need for better awareness, diagnosis, and treatment of PANS and immunopsychiatric disorders.

Although the risk of completed suicide in children under the age of 11 is statistically very low in Sweden, it is important to consider the following facts: previous suicide attempts increase the risk of future attempts (Santesson et al. 2017); early-childhood suicidal ideation confers significant risk for continuation into school-age (Whalen et al., 2015); and the use of violent self-harming methods in individuals who have not attempted suicide increases their risk of future suicide (Bergen et al., 2012).

From a suicide prevention perspective, several areas for improved or new initiatives for patients with PANS are conceivable, including efforts to reduce suffering through treatment of both the disease mechanism and symptoms, increased knowledge about PANS and other immunopsychiatric disorders in healthcare, and measures to reduce social exclusion and isolation. These initiatives can help prevent the development of risk factors such as hopelessness and perceived burdensomeness.

## 4. Introduction: Self-Harming Behavior

Self-harming behavior is a broad term that includes a range of behaviors, from scratching or tearing the skin without causing serious injury to more dangerous behaviors like poisoning or jumping from heights that can result in severe harm or death. It generally excludes self-destructive behaviors such as substance abuse or self-starvation. However, how to classify and name different types of self-harming and self-destructive behaviors has been debated for a long time (e.g., Hamza et al., 2012; Muehlenkamp et al., 2012; Liljedahl and Westling, 2014). In research, three primary terms are used: deliberate self-harm (DSH), self-injurious behavior (SIB), and nonsuicidal self-injury (NSSI). DSH and SIB do not exclude suicidal intent, while NSSI does.

Nonsuicidal self-injury disorder (NSSID), introduced as a condition requiring research in the latest DSM edition, is defined as the intentional, non-suicidal destruction of body tissue for non-socially sanctioned reasons (APA, 2013). However, individuals with NSSID may have suicide plans or have attempted suicide, even though they do not intend to die during self-harm (Zetterqvist et al., 2020). Some argue that the difference between SIB and NSSI is a matter of degree rather than nature, and that keeping them separate makes it difficult to grasp the full picture. Others contend that focusing on suicidal intent is problematic since many individuals who self-harm may be uncertain about their intentions (Kapur et al., 2013; Orlando et al., 2015). Nonetheless, some believe that categorizing NSSI as a separate entity from suicidality can aid research and the development of treatment methods (Hooley et al., 2020).

### **Demarcation of Suicide Attempts**

Self-harming behavior that is carried out with the intention of dying should be considered as a suicide attempt. However, some individuals may have mixed feelings, younger children may have a lower degree of intent, and individuals with PANS may experience sudden and short-term intent to die during flares of symptoms. Assessing intent can therefore be challenging, and in the case of children, it's risky to assume that those who use a non-lethal method to harm themselves have no intention of dying as they may have a limited understanding of the fatal consequences of their actions (Posner et al., 2007a).

### **Prevalence**

In the general population of adolescents, the estimated incidence of self-harm without suicidal intent is between 13% to 28% (Westling et al., 2016). Self-harming behaviors are more prevalent among psychiatric patients. In a Swedish survey of self-harming behaviors in psychiatric patients, 47.2% of women and 34.9% of men reported engaging in at least one self-harming behavior in the last six months (Odelius and Ramklint, 2014).

### **Self-Harming Behavior in PANS and Other Immunopsychiatric Disorders**

Self-harming behavior is common in PANS, although deeper knowledge about it is lacking. A report on the characteristics of the first 47 patients at a specialized PANS clinic found that "injury/damage from violence" directed towards "self" occurred in 36% of patients, and that

“impulsive dangerous behavior, such as attempting to jump out of moving cars and out of windows, was common” (Frankovich et al., 2015a).

In a survey answered by 698 parents of children with PANS, 40% stated that their children had self-harming behavior (Calaprice et al., 2017). The incidence of “harm to self and others” (listed in the category “obsessive-compulsive symptoms”) was reported to occur in 40% of 43 children with PANS aged 4-14 years in a report of symptoms (Murphy et al., 2015). Self-harming behavior is also mentioned in case reports of PANS. Lawrence and Baggot (2017) describe a boy whose symptoms included self-harming behaviors. His symptoms were successfully treated with antibiotics. Another case report describes a 15-year-old girl with a progressive course of the disease and a number of severe symptoms, including self-harming behavior. She was previously diagnosed as schizophrenic but did not respond to treatment for psychosis. When she was assessed to meet the criteria for PANS and treated with plasmapheresis, this led to a dramatic resolution of her psychosis, OCD traits, and anxiety (Barzman et al., 2018).

A treatment study in which intravenous immunoglobulin (IVIG) was evaluated for patients with PANS mentions self-harming behavior as one of several symptoms in those who received the treatment. However, it is unclear whether the self-harming behavior was improved by the treatment (Pavone et al., 2020). In autoimmune encephalitis, self-harming behavior is reported in case reports (Chen et al., 2020; Engen et al., 2020), but data on self-harming behavior in Sydenham's Chorea are lacking in the literature.

### **Relationship Between Self-Harming Behavior and Suicidality**

As mentioned previously, self-harming behavior can occur without the intention of dying, but it is widely recognized that it carries an increased risk of both suicidal ideation and behaviors (Hamza et al., 2012; Klonsky et al., 2014; Franklin et al., 2017).

Moreover, self-harming behavior can increase the risk of suicide. For instance, one study showed that children and adolescents who sought emergency care for self-harm during the years 2000–2013 had an annual incidence of suicide that was 30 times higher than what would be expected in the same age group in the general population (Hawton et al., 2020). Other studies have observed an increased risk of suicide associated with certain self-harming methods (Beckman et al., 2018), repeated self-harming behavior (Zahl and Hawton, 2004), and the use of violent self-harming methods (Bergen et al., 2012).

## 4.1 Results: Self-Harm in PANS / Immunopsychiatric Disorders

Table 9. Overview Self-Harming Behavior.

Self-harming	All % (N)	Females % (N)	Males % (N)	Females Today ≤18 years old % (N)	Males Today ≤18 years old % (N)	Females Today ≤14 years old % (N)	Males Today ≤14 years old % (N)
Self-harming in any form	51% (240)	50% (100)	51% (140)	36% (69)	50% (106)	34% (38)	51% (77)
Frequent self-harming	30% (240)	28% (100)	31% (140)	17% (69)	28% (106)	8% (38)	26% (77)
Use of one or more violent methods	18% (240)	16% (100)	19% (140)	13% (69)	20% (106)	3% (38)	21% (77)

### Occurrence

As for the occurrence of self-harming behavior, 51% (n = 121) of respondents reported that the individual intentionally had injured themselves, while 44% (n = 104) had never engaged in intentional self-harm. A few respondents (n = 14) were unsure whether the individual had intentionally harmed themselves.

The gender distribution of those who engaged in current or historic self-harming behavior was even, with 50% of females and 51% of males reported to have had such behavior. Among those who had never intentionally harmed themselves (n = 104), attempts to harm themselves had occurred but were stopped (n = 12), and/or they had made threats to self-harm (n = 28).

There was no significant difference in the occurrence of self-harming behavior when comparing the confirmed PANS group to the entire sample. Within the confirmed PANS group, there was also no significant difference in the prevalence of self-harming behavior between different age groups, with a prevalence of 47% among those currently under 15 years of age and 42% among those under 11 years of age (Table 9).

Of the 121 individuals who engaged in self-harming behavior, 65% (n = 79) were confirmed PANS cases, 16% (n = 31) were suspected PANS cases, and 6% (n = 7) had other confirmed or suspected immunopsychiatric disorders.

### Debut Age

In 78 respondents (64%) with self-harming behavior, the behavior debuted before the age of 12. The average age of onset of self-harming behavior was 10.9 years (median 9 years).

Self-harming behavior had typically debuted in close proximity to the onset of the disease. For 51% (n = 62) of respondents, self-harming behavior debuted at the same age as the onset of the disease, while for a further 23% (n = 28), it debuted within about one year after the onset of the disease.

Table 10.

How serious were the consequences of self-harm (on the most serious occasion)?	All N=120 % (n)	Females N=49 % (n)	Males N=71 % (n)
No or very minor injury, e.g., scratches, bruising	52% (62)	39% (19)	61% (43)
Minor injury, e.g., mild bleeding; small burn	34% (43)	41% (20)	32% (23)
Moderate injury where medical attention was needed, e.g., second-degree burns; severe bleeding.	7% (9)	10% (5)	6% (4)
Moderately severe injury requiring hospitalization, e.g., extensive blood loss; major fractures.	2% (3)	4% (2)	1% (1)
Severe injury requiring hospitalization with intensive care, e.g., extensive blood loss, major damage to vital organs, comatose.	2% (3)	6% (3)	0
Death	0	0	0

### Injury Caused by Self-Harming

Serious injury resulting from self-harming behavior was relatively rare. About half (52%) of respondents reported no or only very small physical injury resulting from self-harm, while 34% reported only minor physical injury. For 12%, the injury required medical intervention, and for a few (n = 3), it led to severe physical injury (Table 10). Females were somewhat more likely than males to experience serious injury resulting from self-harming behavior.

Table 11.

Frequency of self-harm	All N=121 % (n)	Females N=50 % (n)	Males N=71 % (n)
Innumerable times	21% (26)	6% (12)	20% (14)
Many times	38% (46)	32% (16)	42% (30)
A few times	37% (45)	36% (18)	38% (27)
One time	1% (1)	2% (1)	0
I don't know	2% (3)	6% (3)	0

### Scope and Duration

With the exception of one individual, all had engaged in repeated self-harming behavior. The behavior was often frequent, with individuals harming themselves many (n=46) to countless

times (n=26) (Table 11). Very frequent self-harm was reported more often in males than in females.

According to respondents, self-harming behavior had completely ceased in 74 individuals. For 41 individuals, self-harming behavior was still ongoing, and six respondents reported that they did not know whether the behavior had stopped or not. Among the 74 individuals where self-harming behavior had ceased, it lasted for a long time (more than 3 years for n=15 or more than 5 years for n=14) in more than a third of cases (n=29).

### Self-harm Methods

The most common self-harm methods were hitting oneself (n=90) and cutting (n=42). About a quarter of individuals had tried to strangle/suffocate themselves, and methods involving traffic were used by a fifth of individuals. Fewer individuals had used methods such as jumping/throwing themselves from heights, poisoning, or swallowing objects (see Table 12).

Table 12.

Methods	All N=121	Females N=50	Males N=71
Hitting (including banging head against objects)	74% (90)	58% (29)	86% (61)
Cutting	35% (42)	50% (25)	15% (17)
Strangling/Suffocation	25% (30)	22% (11)	27% (19)
Traffic-related (e.g., jumpinmg in front of moving vehicles)	19% (23)	18% (9)	20% (14)
Jumping from heights (e.g., windows, precipes)	11% (13)	6% (3)	14% (10)
Poisoning	10% (12)	12% (6)	9% (6)
Swallowing objects	4% (5)	6% (3)	6% (4)
Burning	6% (7)	6% (3)	3% (2)
Scratching/pulling skin*	7% (9)	12% (6)	4% (3)
Biting*	7% (8)	6% (3)	7% (5)
Pulling nails/hair (leading to damage to skin)*	5% (6)	6% (3)	4% (3)
Cutting/stabbing with scissors*	2% (2)	0	3% (2)
Multiple methods	53% (64)	62% (31)	46% (33)
Violent methods	34% (41)	32% (16)	35% (25)

\*Data volunteered in the category "other".

Respondents were also given the option to choose "other" and provide a comment, leading to additional methods that were commonly used (see Table 12). A few methods were mentioned in the comments and were used by only one individual each, and therefore are not included in the table. These methods were:

- Pushing needles into the skin (n=1)



- Crushing porcelain and walking on it (n=1)
- Digging oneself into a grave (n=1)
- Throwing a switched-on electrical appliance in the bath and attempting to jump in (n=1)

Strangling/suffocation was the third most common method, and a little over half of individuals (n=64) had used more than one method to harm themselves (see Table 12).

Among those with confirmed PANS and self-harming behavior (n=79), both strangulation/suffocation (n=24) and cutting (n=24) occurred in 30% of cases, making them the second most common methods after hitting oneself.

### Violent Self-Harm Methods

Methods with a risk of serious injury and/or mortality, such as traffic-related methods, jumping from heights, and trying to suffocate/strangle oneself, were categorized as violent. Several violent methods were found to be more common than less violent ones. Of those who had engaged in self-harming behavior, more than a third (n = 42) had used one or more violent methods (see Table 12). Anyone who used a violent method had also used multiple methods. Not surprisingly, the use of violent methods more often resulted in serious injury, with 6 out of 42 individuals experiencing injuries that required medical intervention, and half of those requiring hospitalization (2 of whom required intensive care).

Using violent methods was roughly equally common in both sexes, with 19% of males and 16% of females reporting the use of such methods. With confirmed PANS, the use of violent methods was as common in those who are currently younger than 15 years (born in 2006 or later) and in those who are currently younger than eleven years (born in 2010 or later) as in the group as a whole (see Table 9).

Table 13.

Suicidality	All who had self-harming behavior N=116 % (n)	Confirmed PANS + Self-harming behavior N=77 % (n)	Never had self-harming behavior N=103 % (n)
Suicidal ideation	56% (65)	57% (44)	23% (24)
Suicidal plans	29% (34)	23% (18)	4% (4)
Assesed as at risk of suicide	23% (27)	21% (16)	4% (4)
Hospitalization due to suicide risk	13% (15)	9% (7)	2% (2)
Suicide attempts	24% (28)	18% (14)	3% (3)

### Suicidality in Individuals with Self-Harming Behavior

Suicidal ideation was reported to have been present in more than half (n = 65) of those who had engaged in self-harming behavior, and 18% (n = 28) had made suicide attempts (see Table 13). One individual had completed suicide. In those with self-harming behavior who are currently under 15 years old (n = 50), the incidence of suicide attempts was 14% (n = 7), with

a number of those (n = 3) being under eleven years old. Of the 14 individuals who had engaged in both frequent self-harming behavior and violent self-harm methods, 6 had attempted suicide. In the group with confirmed PANS, almost one-fifth of those with self-harming behavior had attempted suicide. Those who had never engaged in self-harming behavior were reported to have had suicidal ideation and behaviors to a lesser extent (Table 13).

Table 14.

*Respondents could choose several options.*

<b>Symptoms respondents felt were related to self-harming behavior</b>	<b>All N=121</b>	<b>Females N=50</b>	<b>Males N=71</b>
Anxiety	66%	70%	63%
Depression	55%	54%	55%
Aggressiveness	51%	42%	58%
OCD (e.g., intrusive thoughts about suicide/self-harming)	41%	48%	37%
Impulsivity	32%	36%	30%
Psychotic symptoms (e.g., demanding auditory hallucinations about harming oneself)	25%	30%	21%
Behavioral regression (e.g., didn't understand the consequences of their action)	20%	16%	23%
Can't see any connection with symptoms	2%	2%	3%
Unsure	3%	2%	4%

Table 15.

*Respondents could choose several options.*

<b>Factors in the environment/life situation respondents felt were connected to suicide attempts</b>	<b>All N=121</b>	<b>Females N=50</b>	<b>Males N=71</b>
Lack of hope that the situation could change	55%	58%	54%
Symptoms felt unbearable to cope with	49%	48%	49%
Resignation/sadness because of lack of understanding in everyday life, e.g., in school	36%	30%	39%
Alienation and social isolation	34%	34%	34%
Perceived himself/herself as a burden to others	32%	26%	35%
Resignation/sadness because of difficulties in receiving treatment/care	27%	28%	27%
Resignation/sadness because of lack of understanding in healthcare	22%	24%	21%
Can't see any connection to factors in the environment	16%	16%	15%

**Symptoms and Environmental Factors Related to Self-Harming Behavior**

The majority of respondents saw a connection between self-harming behavior and more than one symptom. Anxiety and depression were the most commonly perceived symptoms associated with self-harming behavior (Table 14). Respondents also identified a lack of hope for change and unbearable symptoms as the most common environmental and life situation factors related to self-harming behavior (Table 15).

Several respondents left comments, indicating connections between self-harming behavior and self-punishment (such as feeling stupid, bad, or ugly), misunderstandings and setbacks, frustration over sudden symptoms, and physical pain.

**Measures to Prevent Self-Harming Behavior**

Most respondents (107 out of 121) had taken measures to prevent the individual from harming themselves. The most common measures were hiding knives, scissors, and sharp objects, comprehensive monitoring, and physically hindering the individual (Table 16). On average, respondents took 3.1 measures to prevent self-harming behavior, and several respondents took more than one measure. Some respondents (n = 14) also commented on additional measures taken, such as installing surveillance cameras in the home, having one parent stay at home full time, nailing windows shut, removing ladders, making fewer demands, and avoiding triggers.

Table 16.  
*Respondents could choose several options.*

<b>Measures taken to prevent the individual from self-harming</b>	<b>N=118</b>
Hiding sharp objects (e.g., knives, scissors)	63%
Comprehensive surveillance (e.g., not leaving the individual by themselves, around the clock)	52%
Physically holding the individual	52%
Some degree of surveillance	36%
Avoiding triggering environments	32%
Hiding poisonous substances	31%
Calling for an ambulance and/ or turn to an ER in hospital	30%
Psychiatric in-patient care	11%
No measures, as it was impossible to stop the individual from self-harming	9%

**Perceived Desire to Die and Concern for the Child**

According to respondents’ perceptions, in the majority of cases (61%, n = 74), there was a degree of desire to die associated with self-harming behavior. In most cases (n = 54), the individual had expressed this verbally, while the remaining respondents (n = 20) perceived it without the individual explicitly stating so. For 28% (n = 34) of cases, such a wish was not

perceived, and a few (n = 13) answered that they did not know if the individual had a wish to die.

Almost all respondents (98%, n = 118) expressed concern that the child could die from self-harming behavior, and about half (n = 50) were very or extremely worried about this (Table 17).

Table 17.

Had respondents been worried that the individual could die from self-harm?	Respondent N=118
No, not at all	28% (34)
A little worried	18% (22)
Somewhat worried	12% (15)
Very worried	26% (30)
Extremely worried	17% (20)

When asked about the level of stress/anxiety caused by the self-harming behavior, the majority of respondents (60%, n = 71) reported that it led to extensive stress/anxiety, and another 24% (n = 28) reported that it led to a lot of stress/anxiety. According to respondents, siblings were affected to a somewhat lower degree, but in 66% of cases (n = 66), it still led to a higher degree (very to extensive) of anxiety/stress for siblings (Table 18).

Table 18.

To what degree had self-harming been stressful to the family?	Parents N= 118	Siblings N=99
No stress/worry	2% (2)	7% (7)
Some stress/worry	14% (17)	26% (26)
A lot of stress/worry	24% (28)	32% (32)
Extensive stress/worry	60% (71)	34% (34)

### **Optional Comments on Support Needed for Self-Harming Behavior**

Respondents were given the option to leave comments on what support they would have wanted regarding self-harming behavior. The majority of the comments were about wishing that the individual would receive treatment for PANS, including immunological treatment, but many also mentioned psychological treatment such as CBT and counseling. Respondents also expressed frustration about the lack of knowledge about PANS in the healthcare system and the extended time it took to get a diagnosis and treatment. Bedside manners in healthcare were also often mentioned, with parents feeling that they were not understood or taken seriously. However, a few respondents did comment that they had received the help they needed and that healthcare responded with an immediate treatment plan, such as by prescribing intravenous immunoglobulin (IVIG).

## 4.2. Discussion: Self-Harm in PANS / Immunopsychiatric Disorders

### **Prevalence and Age of Onset**

Self-harming behavior was common according to respondents; it occurred in almost half with confirmed PANS (49%). This differs somewhat from what has been previously reported about self-harming behavior in PANS: 36% (Frankovich et al., 2015a), and 40% (Calaprice et al., 2017). According to research on self-harming behavior in the general population, it usually debuts in early adolescence (Hawton et al., 2012), although earlier debuts occur (Ross and Heath, 2002). According to Odelius and Ramklint (2014) in a report from the Swedish National Self-harm Project, few patients in psychiatric care report a debut of self-harming behaviors before the age of 12. The age of onset for self-harming behavior in PANS patients has not been previously reported, and in our material, it was quite low (average 10.9 years, median 9 years), and in almost three-quarters, it debuted in close connection to the onset of PANS symptoms. This may indicate that self-harming behavior is related to the disease mechanism itself.

### **Gender**

Research has often reported a higher incidence of self-harming behavior in females than in males, both in the general population and in psychiatric populations (Hawton and Harriss, 2008; Odelius and Ramklint, 2014). However, it has been suggested that the behavior may be underreported in males due to a lower rate of seeking care (Tengelin and Samulowitz, 2014; Kimbrel et al., 2017). In a survey of PANS characteristics, Calaprice et al. (2017) reported a relatively even distribution of self-harming behavior between genders, which is consistent with the results presented in this report.

### **Self-Harm methods**

Slightly more than a third of those who had self-harming behavior used violent methods. Violent methods were defined here as any method with a high risk of serious injury/mortality, such as traffic-related methods (e.g., jumping in front of moving vehicles); strangulation/suffocation; and jumping from heights (e.g., a precipice, window, balcony).

The term violent method has mainly been used in suicide research and it is not directly transferable to self-harming behavior. For example, a suicide attempt involving cutting can be considered using a violent method (Stenbacka and Jokinen, 2015), while cutting as a method of self-harming behavior often means superficially scratching the skin thus not considered violent. However, the term has been used in the area of self-harm, one study showed that those who needed hospital care after self-harm with a violent method had a higher risk of later suicide (Beckman et al., 2018).

Our material does not provide detailed information, making it difficult to make an absolute assessment of whether reported methods were violent or not. Nonetheless, among those who self-harmed, only 12% required medical intervention, and 3 (out of the total 6 in the entire study) who required hospitalization due to self-harm, of which 2 required intensive care, were found among those who used violent methods. Furthermore, the survey results indicate that those who used violent methods to a greater extent had made suicide attempts and that the combination of violent methods and frequent self-harming behavior increased the incidence of suicide attempts. This suggests that in the case of PANS/immunopsychiatric disorders, there

may be a subgroup with complex self-harming behavior and an increased risk of serious injury and suicide attempts, and that the self-harming method may be a factor that should be noted.

Studies on the prevalence of different self-harm methods have yielded varying results, which may depend on the population studied and the questions asked. In a Swedish survey of psychiatric patients, the three most common methods were beating, scratching, and cutting oneself, followed by skin-tearing, preventing wound healing, sticking sharp objects in the skin, biting, burning, and carving pictures/words in the skin (Odelius and Ramklint, 2014). This study did not mention any violent methods.

In studies of the general population, cutting is the most common method, followed by severe scratching, burning, and banging or hitting, without mutual order (Klonsky and Muehlenkamp, 2007). Our material is to some extent consistent with these results: hitting and cutting were the most common methods among those with PANS and immunopsychiatric disorders. However, there were also methods that according to the literature seem unusual among psychiatric patients and the general population. Notably, several violent methods (strangling/suffocating, traffic-related methods, and jumping from heights) were more common than less violent methods, such as burning oneself.

Deliberate foreign body ingestion (DFBI) is thought to be a very uncommon method of self-harm (Huang et al., 2010), although its occurrence is not well known. In addition to the obvious risks of swallowing objects like pens, batteries, and razor blades, DFBI poses a challenge to healthcare and is costly to society as it may require repeated medical intervention (Huang et al., 2010; Low Kapalu et al., 2020).

Knowledge of DFBI is still low, and the need for more research on DFBI and other complex self-harming behaviors has been highlighted (Low Kapalu et al., 2020; Navinés et al., 2013). The literature has mainly a gastroenterological/surgical perspective although there are occasional case descriptions (e.g., Navinés et al., 2013; Low Kapalu et al., 2020). In the scientific literature, DFBI is not described in PANS/immunopsychiatric disorders, although there is anecdotal evidence of successful immunological treatment of DFBI in a case of suspected PANS (Bejerot, 2019).

Swallowing objects was stated by our respondents to occur only in 4% but was almost as common as burning oneself which occurred in 6%. Given the rareness of DFBI and the challenges in connection with this method, the occurrence in our material, albeit rare, should warrant further research.

### **Symptoms and Factors in the Environment Perceived to be Related to Self-Harming Behavior**

As mentioned in the first part of this report, the reported symptoms and their number did not differ between those who had self-harming behavior but never attempted suicide and those who had attempted suicide: however, there were differences compared with those who had neither attempted suicide nor had self-harming behavior.

Respondents stated anxiety and depression as the most common symptoms related to self-harm, which were also most commonly related to suicide attempts in reverse order. However, self-harming behavior was more commonly associated with aggression and OCD symptoms (having obsessive thoughts about harming oneself).

Several studies have documented the prevalence of depression and anxiety in individuals with self-harming behavior (e.g., Zetterqvist, 2014; Boone and Brausch, 2016; Giner-Bartolome et al., 2017; Dixon et al., 2019), which is in line with our results. Studies have shown a higher incidence of aggression in people with self-harming behavior (Ross and Heath, 2003; Tang et al., 2013). Aggression and irritability are common symptoms of PANS, occurring in 64–79% (Frankovich et al., 2015; Johnson et al., 2019; Hesselmark and Bejerot, 2019). Violence and rages/meltdowns have also been described in PANS (Thienemann and Frankovich, 2017; Calaprice et al., 2017). In one report of five cases, a girl with PANS displayed self-harming behavior and suicide threats in connection with aggression and violent outbursts (Frankovich et al., 2015b).

Our results show that 41% perceived self-harming behavior to be associated with obsessions and compulsions, such as obsessive thoughts about harming oneself. Obsessions and compulsions are the most common main criterion (out of two possible) in the diagnostic criteria for PANS, but it is unclear whether these symptoms should be considered OCD when occurring in PANS. These symptoms may resemble OCD without PANS, presenting as e.g., contamination obsessions, repetition compulsion, and hoarding. However, obsessive-compulsive symptoms in PANS manifest differently by acutely debuting and the simultaneous onset of several other symptoms (Hesselmark and Bejerot, 2019). Although the differences are not extensively studied, one research study found that among individuals diagnosed with OCD and meeting the criteria for PANS, symmetry compulsion was less common compared to those with OCD alone. Additionally, the impact of compulsions on family functioning was greater in the group with both OCD and PANS (Jaspers-Fayer et al., 2017).

The distribution of factors that respondents considered to be related to self-harming behavior was similar to those who had attempted suicide, where the two most common factors were lack of hope that the situation could be changed/improved and that living with the symptoms was unbearable. However, it was more common for respondents to state that individuals who had attempted suicide perceived themselves as a burden to others. This is consistent with Joiner's interpersonal theory of suicide, mentioned earlier.

Hopelessness is a risk factor for repeated self-harming behavior and suicidality in the self-harming group (Steege et al., 2016; Kuo et al., 2004). Since the majority of respondents felt that both suicide attempts and self-harming behavior were associated with hopelessness, an awareness of this as a risk factor and the importance of conveying hope should be present in the treatment of patients with PANS.

Many individuals who had experienced self-harming behavior and/or attempted suicide reported their symptoms as unbearable to live with. As shown in Table 6, the number of symptoms can be extensive. Therefore, it is important to carefully map the individual's symptoms, including how difficult they are perceived to cope with, in addition to treatment aimed at the mechanisms of the disease, to reduce suffering.

Pain conditions are common in PANS and it has been noted that children with PANS rarely report pain symptoms unless specifically asked. Early treatment of pain is important to prevent it from developing into chronic pain and to improve the individual's overall functioning (Frankovich et al., 2015a; Thienemann et al., 2017). While symptoms causing the most suffering may vary among individuals, paying special attention to pain conditions, especially muscle and joint pain and headaches, seems important as these symptoms were

reported more frequently in those who had self-harming behavior and/or had attempted suicide.

### **Suicidality in Self-Harm**

Distinguishing between a suicide attempt and non-suicidal self-harm can be challenging (Runesson, 2020), and as previously mentioned, understanding of suicidality in younger children is lacking. Several respondents perceived a desire to die in connection with self-harming behavior, and some self-harming acts, such as digging oneself into a grave or throwing a switched-on electrical appliance in the bathtub, and trying to jump into the water, may be considered interrupted suicide attempts.

While it is well-documented that suicidal ideation and suicide attempts are more common among those with self-harming behavior, healthcare providers should be aware that in PANS and immunopsychiatric disorders, suicidality and complex self-harming behavior can occur at a very young age. The respondents' statements also strengthen the picture of serious self-harming behaviors, with 30% of those surveyed having called an ambulance or sought emergency room care due to self-harming behavior, and 11% requiring inpatient care.

### **Impact on Families**

According to a qualitative study on families affected by self-harming behavior, social isolation, stress, and guilt are common among parents and siblings (Ferrey et al., 2016). As previously mentioned, parents of individuals with PANS often experience a significant burden (Frankovich et al., 2018). In our study, self-harming behavior frequently caused high levels of stress for both parents and siblings. Moreover, several respondents reported taking extensive measures, such as camera surveillance and nailing windows, to prevent the individual with PANS from injuring themselves. The overall picture suggests an extensive parental burden.

The relative lack of knowledge about PANS and the absence of large-scale replicated treatment studies may contribute to increased vulnerability, which can be a contributing factor to why some respondents have reported a lack of understanding in healthcare encounters. Several respondents reported difficulties in receiving a diagnosis and treatment, which has been previously reported in PANS (Calaprice et al., 2017). A pilot study has suggested that a delay in identifying and treating PANS could lead to a more severe course of the disease with more serious symptoms (Harris et al., 2020).



## 5. Conclusion

Overall, the survey results suggest that a significant portion of individuals with PANS and immunopsychiatric disorders exhibit severe self-harming behaviors that are characterized by high frequency, use of violent methods, onset at a young age, and overlap with suicidal behaviors.

Given the known association between violent self-harm methods and suicide attempts (Bergen et al., 2012), as well as the fact that early onset of self-harming behavior is a risk factor for later suicide (Beckman, 2018), healthcare providers treating PANS and self-harm should be aware of these risks. As there is largely a lack of knowledge about suicidality in children under the age of twelve, this appears to be an important area for future research.

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