

A Systematic Review of Family Caregivers' Perspective on Psychogenic Non-Epileptic Seizures in Children and Adults

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Abstract

This review paper provides a comprehensive review of existing literature on the experiences of family caregivers of patients with psychogenic nonepileptic seizures (PNES). PNES is a challenging condition that often requires extensive caregiving support. Understanding the distinct challenges faced by family caregivers is crucial for the development of effective support systems. This review explores the physical, emotional, and psychological impacts of PNES on family caregivers, their coping mechanisms, and potential interventions and support strategies to improve their well-being and enhance patient care.

Keywords: Caregivers, Psychogenic Non-Epileptic Seizures, Children, Adults, PNES

Introduction

The main distinction between epileptic seizures and psychogenic non-epileptic seizures (PNES) is that electrophysiological alterations are not present in PNES. PNES are obvious changes in a person's awareness or behaviours (Reilly et al., 2013). Although this illness has been described using as many as 15 distinct names (Reilly et al., 2014), PNES will be used throughout this systematic review. According to Reuber, 2009, the best way to understand these seizures is through the prism of a biopsychosocial, etiological model, in which cooperating risk factors are understood to have a role in the eventual development of PNES. Incidence rates for referrals to neurological settings for adult PNES diagnosis have been reported as 1.5 per 100,000 annually (Sigurdardottir, & Olafsson, 1998) with these rates allegedly being lower in children (Reilly et al., 2013). According to one study, PNES in pediatric patients was linked to a successful result in 76.5% of instances (Rawat et al., 2015). PNES, as the name implies, is thought to be psychological in nature (Reilly et al., 2014). Although there is acceptance about the psychological foundation of PNES, Brown and Reuber (2016), stress that there is still little agreement regarding the precise processes behind this disorder, underlining the need for more study. However, a review of 24 studies conducted by Reilly et al. (2013) revealed that the most frequently reported precipitating factors to the onset of PNES in pediatric populations were physical and sexual abuse, interpersonal and familial conflicts, and school-related issues like bullying and poor academic performance. According to some reports, it might take up to seven years to diagnose PNES (Reuber et al., 2002). PNES may be misdiagnosed as epilepsy before receiving the proper diagnosis, subjecting those who present to needless treatments and potentially harmful antiepileptic drug treatment as a result (Reilly et al., 2013; Reuber & Elger, 2003). According to Dunne, et. al., (2019), the importance of understanding the perspectives of individuals affected by PNES, as it can provide valuable insights into the nature of the condition. It mentions that while there is existing research on the perspectives of adults with PNES, there is a need to explore the perspectives of pediatric patients and compare them to those of adults. Exploring the perspectives of children and young people with PNES may be crucial in learning more about the nature of this condition so that diagnosis and subsequent treatment are more streamlined and tailored to their needs. This is because PNES diagnosis can take a long time and there are distressing precipitating factors associated with seizure onset. Evidence from the literature shows that there have been fewer studies on adolescents' PNES than have been done on adults who have this condition (Reilly et al., 2014). There are several research studies examining the adult population's perspectives on PNES. 'Symptoms all in the mind' and 'hysterical seizures' were deemed to be highly offensive, whereas 'functional seizures' and 'stress-related seizures' were found to be significantly less offensive, according to research by Stone et al. (2003) on 102 adult

general neurology patients. The identification of PNES may be particularly crucial since data from 84 adult patients in the Carton et al. (2003) research suggested that a negative response to the diagnosis may be a sign of a bad prognosis.

Five adult subjects with PNES in the study by Dickinson et al. (2011) gave information that extended the findings of Reilly et al. (2013) within adult populations and emphasized experiences of stressful life events such as marital problems, workplace disputes, and bereavement. Prior to their seizures, these individuals described feeling exhausted, overcome with emotion, and stressed. They also underlined their irritation and discontent with the time-consuming and stressful procedure of getting a diagnosis (Dickinson et al., 2011). Studies involving adults have focused on isolation, loss of normalcy, and loss of independence as three key detrimental effects of PNES (Dickinson et al., 2011; Fairclough et al., 2014). Across studies, dissatisfaction with postdiagnosis information and assistance has also been found. Adults with PNES have complained of having trouble locating information and being abandoned by services after being diagnosed (Dickinson et al., 2011; Fairclough et al., 2014), which has led to limited awareness of the condition. Adults with PNES expressed a desire for validation in their thoughts and preferences on treatment results because they questioned the veracity of their disease, sought understanding from others, and sought solutions (Fairclough et al., 2014).

Although the viewpoints of adults with PNES are widely known, further study is still needed to determine how much has been done to examine the perspectives of juvenile PNES patients and whether or not they are similar. This systematic review's objective is to summarise the research on the viewpoints of children and adolescents with PNES as well as the perspectives of their families, parents, and caregivers.

Methods

The current systematic review was carried out using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) standards.

Searching Style

The need for an extensive and thorough search approach was brought on by the vast range of terms used in the nomenclature of PNES throughout the literature. The following databases' title and abstract fields—or title and subject fields in the case of Web of Science—were searched until the moment of searching to find all pertinent studies: CINAHL Complete, Medline (Ovid), PsycINFO, PubMed, Google Scholar and Web of Science.

All the above databases were searched using the following keywords:

(Family or families or children or teen or teens or carer or carers) and (perspective or perspectives or experience or lived experience or lived experiences or view or views) or perspective or attitude or attitudes or impact) and (stress-related seizure or stress-related seizure or functional seizure or psychogenic seizure or psycho seizure or pseudo-epileptic attack or pseudo epileptic attack or pseudo-epileptic seizure or pseudo epileptic attack or nonepileptic seizure or nonepileptic seizure or non-epileptic event or non-epileptic event or NEE).

Selection Style

Prior to completing the searches, inclusion and exclusion criteria were created to satisfy the objectives of this systematic review.

Inclusion Standards

Original study, written in English, examined PNES in a paediatric population, examined the viewpoints of the child or teenager with PNES, or the perspectives of their parents, carers, or family.

Exclusion Criteria

Studies exploring non-epileptic seizures of organic origin or non-epileptic seizures where a psychogenic origin was not clearly stated were excluded. Reference to the perspectives of the child or adolescent with PNES, or the perspectives of their parents, carers, or families, was too limited to warrant inclusion in the current systematic review.

Utilising the standards stated in the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018) as advised by Hannes (2011), each paper included in the systematic review was evaluated. This checklist was somewhat modified for use in this systematic review, and a system of low, moderate, and high-quality categories was also used as an approximated indicator of study quality. The CASP qualitative checklist was applied to the articles that used qualitative research techniques. This checklist's questions were graded using the following responses: "Yes" (3), "Can't Tell" (2), and "No" (1). An overall score of 1–10 indicated a low-quality study, 11–20 a moderate quality research, and 21–30 a high-quality study when the replies to the 10 questions were added together.

Features of the study

A summary of the general traits from the eight included researches. These traits include the principal author and the year of publication, examples of features, the methodology, and the main conclusions.

The characteristics and findings of eight studies that examined the psychosocial aspects of pediatric psychogenic non-epileptic seizures (PNES). The studies included different sample sizes, ranging from 10 to 146 participants, and different proportions of female and male participants, with females being more prevalent in most studies. The mean age of the participants varied from 13.82 to 15.5 years, and some studies did not report the age range or the standard deviation. The studies used either quantitative or qualitative methods, or both, to collect and analyze the data. The studies reported various themes and factors related to the onset, impact, and perception of PNES in children and adolescents, such as:

- Traumatic histories of violence, abuse, and domestic tension
- Delegitimizing experiences and concealing the diagnosis
- Threatened self-image and being believed.
- Upset, afraid, confused, and uncertain feelings.
- Missing out on school and social activities
- Feeling misunderstood and less than epilepsy
- Getting an explanation that makes sense and moving on.
- School performance, independence, and attendance impairment
- Familial and interpersonal distress and conflict
- Stressful situations such as bullying, assault, adjustment failure, and academic failure.

Key conclusions

Validity and the Significance of Comprehension

In three studies (Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016), the idea of legitimacy and how it relates to PNES was a recurrent subject. In the research by McWilliams et al. (2016), several individuals described unpleasant interactions with friends, instructors, and physicians in which it was implied that their seizures were faked.

In two investigations (Karterud et al., 2015; McWilliam et al., 2016), comparisons between PNES and other somatic diseases were drawn. Participants expressed concern that PNES would be seen as a less serious condition than others that were considered to be more somatic (Karterud et al., 2015), and both children with PNES and their families stated that persons with epilepsy received significantly more social and educational assistance (McWilliam et al., 2016). In the study by Karterud et al. (2015), young people reported feeling delegitimized by coworkers and employers who told them it was up to them to recover as well as snide remarks made by teachers that highlighted their belief that the PNES were under their control.

The universal need of young people to comprehend their condition and to be understood by others is incorporated within the significance of PNES being recognised as a legitimate illness. In the research by Karterud et al. (2016), eight of the 11 individuals refused their PNES diagnosis because they believed they were mentally sound and believed that a PNES diagnostic was connected to mental disease. Some young people also had difficulties comprehending whether their seizures really were beyond their conscious control, and young people virtually

universally anticipated being disbelieved or taken seriously by healthcare professionals (Karterud et al., 2015). Some people said that their friends and peers understood them better than their employers and teachers, and they also mentioned that how much information they revealed about their illness to others relied on how much they thought the other person could tolerate (Karterud et al., 2016). One reason why young people are more forthcoming with those who are closest to them appears to be their need to be understood and believed (Karterud et al., 2016). The majority of persons that young people with PNES and their families encountered showed a fundamental lack of awareness of this condition, and they noted that healthcare workers in non-specialist settings were unclear about how to examine and manage PNES (McWilliam et al., 2016). In fact, the relatives of young individuals with PNES themselves exhibited a lack of understanding of the condition's nature (McWilliam et al., 2016).

Impact of PNES on Social and Emotional

Young people with PNES were observed to have a history of personal and familial distress across a number of studies. According to Lancman, Asconapé, Graves, and Gibson (1994), 14 participants had a history of family conflict, three had a history of drug usage, and five had a history of sexual abuse. Adolescents with PNES were found to have a history of sexual and physical abuse that was much more prevalent than that of epileptic adolescents and healthy controls (Say et al., 2014). According to Yi et al. (2014), experiences of interpersonal or familial distress were regarded as PNES precipitants in their sample. In the study done by Irwin, Edwards, and Robinson (2000), such traumatic histories were also categorised as possible triggers for PNES onset, with experiences of marital conflict, bullying, dysfunctional maternal relationships, violence, and physical and sexual abuse being described.

PNES were discovered to significantly affect young people's lives in several areas. Both the young people and their families expressed concern about how this diagnosis would affect their present and future selves; the young people felt guilty about the strain their illness might be putting on their families, while the family members felt angry that they were powerless to do more to help when a seizure occurred (McWilliam et al., 2016). Young individuals saw receiving a diagnosis that contradicted their perceptions of mental health as alarming and felt alienated when medical experts emphasized the diagnosis' psychogenic nature (Karterud et al., 2015). PNES were found to have a significant effect on social, behavioural, and academic functioning in addition to their emotional effects. Families in the McWilliams et al. (2016) research said that the diagnosis caused them to stop working and avoid going on vacations and daily activities. Across studies McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; & Lancman et al., 1994, young people reported a loss of independence and friendships, challenges in interactions with parents, siblings, and instructors, academic underachievement, and reduced school attendance. In order to prevent stigmatisation, some young people have resorted to concealing their illnesses. At the extreme, this desire to remain hidden has led to a lack of attendance at job and school, a lack of friend interaction, and a complete avoidance of public spaces (Karterud et al., 2016).

Numerous research covered topics that could be crucial for helping a young person cope with their disease. In two studies McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; Lancman et al., 1994; Morgan et al., 2012, the question of correctly identifying the syndrome received particular focus. In contrast to terminology associated with fabrication, such as pseudoseizures, most families chose titles that highlighted the association with epilepsy, such as non-epileptic seizures (McWilliam et al., 2016). However, they did observe that a label emphasising that it is not epilepsy might be good, particularly in school settings, to convey that the therapy is not the same (McWilliam et al., 2016). Young people in this research looked more apathetic to the naming of their condition. In the Morgan et al. (2012) study, parents uniformly felt that the phrase "all in his/her head" was the most objectionable, followed by "hysterical seizures" and "psychogenic seizures." Non-epileptic events, non-epileptic attack disorder, and functional seizures were the least objectionable terms overall. Contrary to McWilliams et al. (2016) findings, the word "pseudoseizures" was classified as "moderately offensive" rather than "most offensive," along with "stress-related seizures" and "paroxysmal seizures" (Morgan et al., 2012).

Some young individuals believed that boredom, emotional tension, and exhaustion may cause the development of a seizure and that these factors could be prevented by relaxing or removing oneself from a stressful setting

(McWilliam et al., 2016). To avoid or stop seizures, families tried using distraction methods or displays of affection (McWilliam et al., 2016). When individuals closest to the young people showed signs of recognising the condition, it gave them comfort and made it easier for them to participate in social activities (Karterud et al., 2016). If a young person's interpretation of PNES was one that they could accept, socialising was also made simpler for them (Karterud et al., 2016). It has been discovered that a PNES explanation that links unconscious processes to seizures might help young individuals overcome self-doubt (Karterud et al., 2015). Their personal understanding of their condition appeared to be aided by the giving of a multifaceted, biomedical explanation from a holistic viewpoint that emphasised how stress may create physical reactions, as well as functioning as a potential safeguard against being stigmatised as mentally ill by others (Karterud et al., 2015). Young people believed that being taken seriously and understood was the key to progressing (Karterud et al., 2015).

Table 1: Showing Key Points of Studies

Authors	Publication year	Sample	Qualitative/Quantitative Methodology	Key Finding
Irwin	2000	N-35 (24 female, 11 Male)	Qualitative	10 were avoiding school because of bullying, poor performance, or falling behind in academics; 8 had traumatic histories of violence and physical and sexual abuse; 4 experienced substantial family conflict; and 3 had problematic relationships with their moms.
Karterud	2016	N=11, 11 females	Qualitative	4 main concepts: 1) Everyday life included delegitimizing events from relatives, teachers, coworkers, and employers. 2) The young people tried to hide the diagnosis out of fear of being subjected to delegitimizing events; for others, this led to seclusion from all social settings except their closest ties. 3) The protection against delegitimization and increased social engagement provided by intimate ties. 4) The perception of NES as a real disease encouraged more social interaction. They discovered a link between the individuals' level of social participation or withdrawal and the legitimacy of their disease. People who felt intimately connected to their sickness perspective viewed their condition as more authentic and engaged in more social activities.

Karterud	2015	N=11, 11 female	Qualitative	The study identified three key themes: a threatening self-image, belief in oneself, and getting an explanation that makes sense. Patients initially perceived their diagnosis as psychological, resisted it, and felt resisted. They also experienced suspicions of staging seizures, leading to doubts about the voluntariness of the attacks.
Lancman	1994	N=18	Qualitative	Seizures were characterized by unresponsiveness, generalized violent movements, and trembling. Neuropsychological testing failed to show major abnormalities, and seizures significantly affected patients' quality of life. No significant predictors of clinical outcome were found.
McWilliams	2016	N=10, (4 females, 6 Males)	Qualitative	Nonepileptic seizures (NES) affect young people and families, causing distress and impairment. To improve diagnosis and treatment, streamlined pathways, and better integration of pediatric, mental health, and educational services are needed. Reconsidering "good news" stories and providing educational resources and support groups are crucial. Improved health professionals' communication skills with NES are essential.
Morgan	2013	N=34 (23 Females, 11 Males)	Qualitative	Functional seizures, similar to epileptic seizures, are understudied and face long diagnostic delays, limited treatment options, and stigma. A case-control study found associations with PTSD, anxiety, depression, cerebrovascular disease, and sexual trauma, suggesting sexual trauma may mediate female sex-related functional seizures.
Say	2014	N=34 (23 Females, 11 Males)	Quantitative	They concluded that both diseases had a significant risk of mental problems; in addition, PNES

				teenagers experience more stresses and have poorer levels of self-esteem. The results of this study highlight the significance of mental therapies in paediatric PNES and epilepsy.
Yi	2014	N-25 (14 Females, 11 Males)	Quantitative	Predisposing factors for PNES include familial, social, and specific events. Treatments include psychotherapy, psychopharmacological therapy, and psychotherapy and psychopharmacological therapy. Children have better outcomes than adults, despite high psychological comorbidities.

Notes: N = sample size; F = female; M = male

The quality assessment findings:

As previously noted, to assess the quality of included research, a categorization system of low, moderate, and high quality was adopted alongside criteria from the CASP qualitative checklist (CASP, 2018). Overall, seven studies (Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; Morgan et al., 2013; Irwin, Edwards & Robinson, 2000) were judged to be of excellent quality according to this standard, while one research (Lancman et al., 1994) was judged to be of intermediate quality.

Giving a clear definition of their objectives, picking an acceptable methodology, and putting in place an adequate recruiting approach all received the highest grades across all studies. Seven studies received the maximum score of 3 for their data analytic rigour and the clarity of their conclusions, which were the second-best values among all research. The research by Lancman et al. (1994) was the only exception to this rule since there was insufficient disclosure of the data processing procedure and scant discussion of participant viewpoints on social consequences. Six studies received the highest marks for the usefulness of their research (Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; Morgan et al., 2013; Irwin, Edwards & Robinson, 2000) and the suitability of their data gathering methods. Due to problems including a lack of a clear description of the type of data gathered or a lack of explanation for the techniques selected, two researchers (Say et al., 2014; & Lancman et al., 1994) received a score of 2 for their data collection. Due to problems such as a lack of information about how their study added to prior knowledge, one study received a score of 2 for the value of their research (Lancman et al., 1994). One study received a score of 1 for this question due to problems including a lack of discussion on how their findings may be applied to other situations and a failure to identify future research topics that could still be required (Irwin, Edwards & Robinson, 2000).

Study scores differed more widely when it came to the appropriateness of the study design, taking into account the interaction between the researcher and participants, and taking ethical considerations into account. For the suitability of their research design, five studies received the highest ratings (Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016; Say et al., 2014; & Morgan et al., 2013), while the other three studies received a moderate score of 2 (Yi et al., 2014; Lancman et al., 1994; & Irwin, Edwards & Robinson 2000). Six research (Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; Morgan et al., 2013) only marginally emphasised ethical consideration, while two studies Lancman et al., 1994; Irwin, Edwards & Robinson 2000) appeared to almost completely ignore it in their writing. In none of these experiments was anything said about ethics committee approval. One study received the highest marks (Karterud et al., 2015), two studies received moderate marks (Karterud et al., 2016; McWilliam et al., 2016), and one study received the lowest marks (Lancman et al., 1994) for failing to clearly address this relationship in their write-up. This is in

reference to the four studies for which the question regarding the adequate consideration of the relationship between the researcher and participants was deemed relevant.

Discussion

This systematic review aimed to synthesise all available information on the views of parents, carers, and families of children and adolescents with PNES. The idea of legitimacy and the significance of understanding, a significant history of distress before the onset of seizures, the negative effects of PNES, and reporting of factors that may affect continuing with the illness were found to be common themes among the included studies. Evidence from the pediatric literature generally built on earlier conclusions from the adult research, showing a potential commonality of experiences with PNES that cuts across generations. In the study by Fairclough et al. (2014), for instance, adult participants expressed a desire for support because they had felt as though the legitimacy of their illness had been questioned. Similar experiences were also highlighted in relation to the legitimacy of pediatric PNES across three studies in this systematic review (Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016). In both the adult and pediatric literature, there was significant distress prior to PNES and a mostly unfavorable impact (Dickinson, Looper, Groleau, 2011; Fairclough et al., 2014; Karterud et al., 2016; Karterud et al., 2015; McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; Lancman et al., 1994; Irwin, Edwards & Robinson, 2000). While similarities between the experiences of adults and children with PNES were observed, the causes of these similarities varied. The loss of independence described in adult and pediatric populations (Dickinson, Looper, Groleau, 2011; McWilliam et al., 2016) is one illustration of this. A loss of independence for adults with PNES was the loss of their driver's license as a result of their seizures (Dickinson, Looper, Groleau, 2011), whereas a loss of independence for children was the inability to interact with friends or the insistence of parents to travel with them on public transportation (McWilliam et al., 2016).

Findings from the literature draw attention to the challenges posed by a pediatric PNES diagnosis and the effects they may have on the young person and their family. In the literature, young individuals with PNES frequently described unfavorable interactions with friends, instructors, physicians, coworkers, and employers who implied that their seizures were fake, that they were in control of them, and that it was up to them to get better (Karterud et al., 2016; McWilliam et al., 2016). Young individuals said that they automatically assumed they wouldn't be believed or treated seriously by medical experts (Karterud et al., 2015). It was also said (McWilliam et al., 2016) that healthcare personnel who operate in non-specialist settings have a basic lack of awareness of pediatric PNES. In fact, a study with 61 pediatricians in Denmark who practice neuropsychiatry and social psychiatry revealed differences in coding practices, variation in the use of the "gold standard" video-electroencephalograph (v-EEG) to aid in the diagnosis, and disagreement over the terminology used to describe PNES and diagnostic approach (Wichaidit et al., 2015). Such discrepancies observed among experts in pediatric PNES may exacerbate the uncertainty around this diagnosis that young people and their families already feel (Wichaidit et al., 2015).

Both young people with PNES and their families expressed concern about how this diagnosis would affect their present and future lives; young people felt remorse for the burden their illness might be putting on their families, and family members felt resentment that they were powerless to do more to help when a seizure occurred (McWilliam et al., 2016). Additionally, PNES was found to have a significant negative effect on social, behavioural, and academic functioning, which included job loss, avoiding vacations and daily outings, losing one's independence and friends, relationship issues, academic underachievement, and poor school attendance (McWilliam et al., 2016; Say et al., 2014; Yi et al., 2014; Lancman et al., 1994). The high rates of psychopathology that have been linked to this condition have an additional negative influence on the lives of young people with PNES and their families (Plioplys et al., 2014). According to research, children with PNES are substantially more likely than their siblings to have numerous psychiatric disorders, such as depression, anxiety, and post-traumatic stress disorder (PTSD) (Plioplys et al., 2014). When combined, the research's findings on the experiences of young people with PNES and their families emphasise the need for clinical guidelines to be created to make it easier to diagnose and treat this condition, allowing this population to receive better support during this trying time.

The quality assessment's findings were mostly favourable, with seven studies receiving high scores and one receiving a moderate score. It has previously been advised to utilise the CASP qualitative checklist (CASP, 2018)

when evaluating research critically (Hannes et al., 2011). However, care should be used when interpreting the outcomes of our quality assessment. First off, the CASP qualitative checklist was somewhat modified for this study in order to include all identified articles and to make it easier to create a category grading system. Second, a scoring system has not been created for use with the CASP qualitative checklist since it was originally designed to be used as a teaching tool. In the current study, this was fixed by ranking original response alternatives on a scale of 1-3. However, the CASP qualitative checklist, which was created by a group of subject-matter experts, was substantially upheld in this review. This allowed for some level of trust to be placed in the quality assessment's findings. Future evaluations may be able to get around this constraint by evaluating the quality of papers that explore the personal and family perspectives of pediatric PNES using more established rating systems.

The omission of grey literature, which was outside the purview of the current systematic review, is another drawback. Grey literature, which might include documents like government reports, conference papers, theses, dissertations, and committee reports, is evidence that has not been published by for-profit academic publishers (Haddaway et al., 2015; Paez, 2017). Through the possible increase in the number of sources investigating personal and family perspectives on pediatric PNES, the inclusion of grey literature may have given a full picture of the scientific evidence that is now accessible (Mahood, Van Eerd, Irvin, 2014). The inclusion of grey literature may also lessen the possibility of publication bias and improve the review's general thoroughness (Paez, 2017). Following the application of stringent inclusion and exclusion criteria, a select few papers were chosen for inclusion in this evaluation. However, this could be an example of the little research conducted generally in the field of pediatric PNES (Reilly et al., 2014). To get a more complete picture of the literature that is now accessible, future assessments should make an effort to examine grey literature as well.

Despite these drawbacks, several advantages must also be considered. To the best of our knowledge, this study fills a gap in the literature by making an effort to carefully examine the research on the viewpoints of children and adolescents with PNES, as well as the perspectives of their parents, carers, and relatives. The recurring themes found in the pediatric literature show methods in which parents, teachers, and other carers may help a child with PNES cope well with their disease. Clinicians need to be careful when giving diagnoses, including choosing a term for the ailment that is suitable. The use of a label emphasising its connection to epilepsy may help the general public comprehend that each illness requires a distinct therapeutic strategy (McWilliam et al., 2016; Morgan, 2012). Avoiding terminology related to fabrication may help young persons with this disease and their families feel less stigmatised and may also make it easier for the young person to accept their condition (McWilliam et al., 2016; Morgan, 2012). It is necessary to provide a satisfactory explanation of PNES, one that emphasises the contribution of stress and other unconscious processes to the induction of physical responses (Katerud et al., 2015).

Conclusion

During the care of the patients' PNES & their families showed a fundamental lack of awareness of this condition and the healthcare workers in non-specialist settings were unclear about how to examine & manage PNES. Due to a lack of awareness family members of PNES' patients exhibited a lack of understanding of the condition's nature. So, there is a need to widespread education on pediatric PNES is necessary since research has shown that young individuals with this disease feel more at ease when those closest to them show that they understand their sickness (Katerud et al., 2016). Professionals working in this sector must create clinical standards so that children with this ailment and their families can receive the proper care during diagnosis and beyond.

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