Received: 5 February 2021 | Revised: 19 July 2021 | Accepted: 19 July 2021

DOI: 10.1111/epi.17031

Epilepsia®

FULL-LENGTH ORIGINAL RESEARCH

Outcomes of children and adolescents 1 year after being seen in a multidisciplinary psychogenic nonepileptic seizures clinic

Megan Fredwall[1] | **Debbie Terry**[1] | **Laurie Enciso**[1] | **Maggie (Mary) Burch**[1] | **Kristen Trott**[2] | **Dara V. F. Albert**[1]

[1]Department of Pediatrics, Division of Neurology, Nationwide Children's Hospital, Ohio State University, Columbus, Ohio, USA

[2]Department of Pediatrics, Division of Psychology, Nationwide Children's Hospital, Ohio State University, Columbus, Ohio, USA

Correspondence
Megan Fredwall, Department of Pediatrics, Division of Neurology, Nationwide Children's Hospital, Ohio State University, 700 Children's Drive, Columbus, OH 43205, USA.
Email: megan.fredwall@nationwidechildrens.org

Funding information
This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Abstract

Objective: Psychogenic nonepileptic seizures (PNES) are paroxysmal events that may involve altered subjective experience and change in motor activity with a psychological cause. The aim of this work is to describe a population of pediatric patients with PNES and identify factors predictive of 12-month outcomes.

Methods: We conducted a prospective observational study of children and adolescents referred to the multidisciplinary Nationwide Children's Hospital PNES clinic between November 2017 and July 2019. Information was collected from patients during clinic visits and semistructured follow-up phone calls. Descriptive statistics and Fisher exact test were used for analysis.

Results: Of the 139 consecutive patients referred to the PNES clinic, 104 were seen in clinic and 63 answered 12-month follow-up calls. Patients with comorbid epilepsy had increased rates of participation at 12-month follow-up ($p = .04$). Complete remission was achieved by 32% (20/63) of patients at 12 months. Combined PNES remission and improvement was 89% (56/63) at 12 months. Patients and families who were linked with counseling at 1 month were more likely to achieve remission at 12 months ($p = .005$). Less than half (44%, 28/63) of patients reached at 12 months had their events documented on video-electroencephalogram (EEG) at diagnosis; however, those who did were not more likely to be accepting of the diagnosis at 12 months ($p = 1.0$), be linked with counseling at 12 months ($p = .59$), or be event-free at 12 months ($p = .79$).

Significance: Remission occurred in one third of patients by 12 months; however, improvement in events was seen in 89%. Connection to counseling by 1 month was associated with increased remission rates at 12 months. Capturing events on video-EEG was not associated with increased acceptance or event freedom at 12 months. Diagnosis should be followed by strong encouragement to connect with counseling quickly to achieve a goal of increasing 12-month PNES remission rates.

KEYWORDS

care coordination, functional neurologic disorders, multidisciplinary clinic, pediatric social work, psychogenic nonepileptic events

1 | INTRODUCTION

Psychogenic nonepileptic seizures (PNES), also known as psychogenic nonepileptic events, a subtype of functional neurological symptom disorder (FNSD), are paroxysmal events that may involve altered subjective experience and change in motor activity with psychological origins. PNES affect a diverse population, and have known association with depression, anxiety, posttraumatic stress disorder, stressors at home and school, and past abuse.[1,2] History of epilepsy is another risk factor for PNES.[3] Despite all the known associations, there is a minority of patients presenting with PNES who have no known risk factors,[4,5] and a history of trauma, stressors, or psychiatric comorbidities is not required for diagnosis of PNES.[6] The population developing PNES includes patients of a wide range of ages and genders.[5] Asadi-Pooya et al. found that patients suffering from PNES are seen around the world, not only in Western countries.[7]

PNES have a significant negative impact on patients' lives. The events cause distress, interrupt school, work, and leisure activities, and can exacerbate pre-existing depression and anxiety.[8] PNES also carry an economic cost, both from increased health care utilization and from lost income due to missed work in adult patients and parents of pediatric patients.[9,10]

Once patients have been identified as having paroxysmal events, they are typically referred to neurologists, as the initial concern often includes seizures. If captured on electroencephalogram (EEG), PNES are not correlated with electrical epileptic activity. Neurologists most commonly diagnose PNES using a combination of clinical history, EEG, and videos of the patient's events. The International League Against Epilepsy Nonepileptic Seizures Task Force published minimum requirements for the diagnosis of PNES and proposed levels of diagnostic certainty, with events documented on EEG being the highest degree of certainty attainable.[6]

Treatment is challenging, with the first step being proper delivery of the diagnosis to patients and their families to facilitate acceptance. Duncan et al. have shown that diagnosis communication is pivotal, with potential to achieve complete remission if it is delivered skillfully and the patient is receptive.[11,12] Use of a script has been shown to increase rates of acceptance of diagnosis and decreased PNES frequency.[13,14]

The next step in treatment is psychological therapy, with the therapeutic approach of cognitive behavioral therapy shown to have some benefit.[15–17] Complete treatment includes multiple sessions over a period of time.[18] Access to behavioral health is often limited by resources, insurance coverage, and availability of mental health counselors, especially in rural communities, and patients may struggle to schedule and attend treatment sessions.[19] Resources for children and adolescents may be even more limited.[20] Restrictive health insurance and other financial considerations may present additional barriers to complete treatment. Much is still unknown about long-term outcomes, but a subset of patients with PNES achieve remission quickly after delivery of diagnosis.[11] A second subset can take a longer time and require therapy to gain freedom from PNES.[12] Many studies focused on long-term outcomes lose a large subset of their population at follow-up, complicating interpretation of results.[8,12,17]

Key Points

1. Connection to behavioral health within 1 month of PNES diagnosis is associated with increased remission rates at 12 months
2. In children and adolescents with PNES, acceptance of the diagnosis and improvement of event frequency both improve over 12 months
3. Capturing events on video-EEG was not correlated with increased acceptance or with event freedom at 12 months
4. A diagnosis of comorbid epilepsy was associated with increased participation in follow-up at 12 months

A prior paper describes the multidisciplinary pediatric PNES clinic at Nationwide Children's Hospital.[21] Collaboration by neurology and psychology clinicians, social workers, and nurses supported patients in accessing needed health care and facilitated follow-up. This model resulted in a majority of patients accepting the diagnosis of PNES, linking with counseling services, and reporting a reduction in PNES frequency at 3-month follow-up.[21]

The aim of this work is to describe the long-term follow-up from a population of children and adolescents with PNES who were seen in a PNES-focused clinic[21] and to identify factors predictive of 12-month outcomes in a prospective observational study.

2 | MATERIALS AND METHODS

The institutional review board at Nationwide Children's Hospital reviewed and approved this project.

2.1 | Clinic procedure

Nationwide Children's Hospital has a multidisciplinary PNES clinic focused on transitioning patients with PNES from evaluation to treatment. Referrals are typically placed by neurologists, emergency care providers, primary care clinics, or general pediatric hospitalists after a patient is first diagnosed with or suspected of having PNES. Other patients are seen for second opinion after the PNES diagnosis is given by a different center, and a few patients are seen for repeat visits if they continue to question the diagnosis. The clinic team is composed of epilepsy and psychology clinicians, a nurse, a social worker, and administrative support staff. In this clinic, appointments are joint visits connecting a patient with both neurology and psychology. The goal of the epilepsy practitioner is to confirm and explain the diagnosis of PNES; then, the psychology provider evaluates psychological risk factors, directs the patient to counseling, and provides an action plan to address ongoing events. During the visit, psychology conducts a broad psychosocial screen of emotional and behavioral functioning and school performance to identify potential underlying factors that may contribute to the development of PNES; however, a comprehensive assessment falls outside the scope of this office visit. Known psychiatric diagnoses are reported by patients and families as part of the broad screen performed by the clinic psychologist. Patients and families are then encouraged to link with empirically supported behavioral health treatment, such as cognitive–behavioral therapy, with licensed psychologists or social workers. Pharmacological interventions are not typically recommended in the clinic, but may be prescribed by other providers when appropriate for psychiatric comorbidities. Families are encouraged to follow up with their primary care physicians to discuss available options. Alternatively, they may receive a referral to our psychiatry department. The team social worker provides support to families facing barriers to care, including insurance issues, work or school concerns, transportation difficulties, or other needs. The social worker would also call families with previously identified barriers to care to support the family's ability to access the appropriate treatment services. This would be identified by previous social work involvement, or by the nurse during the follow-up call. The team nurse conducts follow-up calls using a semistructured phone interview (Appendix 1) to gather information on acceptance of diagnosis, connection to counseling, status of events, and utilization of emergency departments.

2.2 | Data collection

Data were compiled from patients who were referred to the PNES clinic between November 2017 and June 2019. Patients who delayed scheduling a clinic visit, falling outside the time window, did not have 1-year follow-up data available for analysis. All patients were contacted by phone for follow-up, even if they declined a clinic visit, with the exception of three patients who were never seen in our clinic and refused all future contact from the clinic staff. Calls were scheduled at 1, 3, and 12 months, although there were variable participation rates at each follow-up. At every follow-up time, three attempts were made to call the patient or caregiver, leaving a voicemail if possible. Even if patients did not respond to initial follow-up calls, they were contacted at subsequent follow-up dates.

2.3 | Inclusion and exclusion criteria

We included all consecutive patients referred to the PNES clinic between November 2017 and June 2019. The diagnosis of PNES may have been made by a physician prior to clinic appointment, or only suspected at the time of referral, with the diagnosis confirmed in clinic. Patients found to have a diagnosis other than PNES were excluded from follow-up calls and data analysis. Data for the descriptive population characteristics were collected from all patients who presented to clinic and answered at least one phone call (at 1, 3, or 12 months), but data analyzing trends were collected exclusively from patients who were contacted at 12 months.

2.4 | Metrics

Event occurrence frequency was reported by families at follow-up as remission (complete cessation of events), improved (any decrease in event occurrence with continued events), no change in event frequency, or worse (increase in event frequency). Families were allowed to choose the category that best fit the patient's clinical status at home, without a set time period for classification or calculations of percent change in event frequency. In an effort to focus on treatment rather than PNES, event logs were not encouraged or requested. Status of behavioral health treatment was classified as "linked" if families reported that patients were currently attending therapy sessions or had completed psychological treatment with a licensed therapist or psychologist. Patients were classified as "not linked" if they attempted to schedule but had not yet attended a first therapy session, had completed some sessions and then stopped prior to completion of treatment, or did not seek to schedule therapy.

2.5 | Data analysis

The group that achieved PNES remission was compared to the group with continued events (improved, no change, and worsening). Likewise, the group with improvement (including patients reporting remission) was compared to the group with no change and worsening event frequency. Descriptive statistics were used to describe demographics and outcomes. Event outcomes were compared using Fisher exact test, and effect sizes on outcomes are described with Phi and Cramer *V*. Relative risk ratios were calculated with 95% confidence intervals. All statistical analysis was performed using SPSS version 26.0.

3 | RESULTS

3.1 | Participation

Of the 139 patients referred to the PNES clinic between November 2017 and June 2019, 80% ($n = 111$) were seen in clinic. Of the patients referred to the clinic, six were not found to have PNES, including two diagnosed with epilepsy, two with likely other FNSD (including functional movement disorder), one uncertain whether PNES or epileptic seizures, and one likely behavioral, so were excluded from follow-up calls and data analysis. An additional subset of eight patients delayed scheduling clinic visits and subsequent follow-up calls until after the time of this study, leaving a population of 125 patients with PNES referred to the clinic within the set time. At the 1-month follow-up phone interview, 86 patients participated. Participation decreased to 74 at 3-month follow-up phone interview, and finally 63 patients participated at 12 months, including six patients who were not seen in clinic. Barriers to follow-up included no answer to phone calls, refusal to participate, and changing phone numbers. From within the final set of 63 patients, 51 patients had responded at 1-month follow-up and 47 patients had responded at 3-month follow-up. A flow diagram is shown in Figure 1.

3.2 | Population characteristics

This study examines a population of 125 patients, including 75% females and 24% males. The most common diagnostic certainty level was EEG-documented events, at 48%. Generalized convulsive movements were the most frequent type of clinical event, identified in 62% of patients. Epilepsy was present in 18% of patients. Comorbid mental health conditions were reported in 67% of patients, including 22% reporting anxiety and 16% reporting depression. Stressors were reported in 79% of patients, including 24% with school performance concerns and 14% with family conflicts. At time of initial clinic visit, 30% were already in counseling and 30% were taking psychiatric medication. Social work provided assistance to 37% of patients.

A comparison of patient characteristics between those reached at 12 months and those who were not is shown in Table 1. Similar percentages of events documented on EEG, mental health comorbidities, identified stressors, mental health treatments, and social work involvement were seen between the two groups. There was a significantly higher percentage of patients reached at 12 months who had comorbid epilepsy (25%, $p = .035$) and a lower percentage who had a normal EEG (57%) compared to those who were not reached (10% and 68%, respectively).

3.3 | Social work involvement

The social worker was an integral part of the multidisciplinary clinic. She aided 37% ($n = 46$) of patients with PNES referred to the clinic. Within that population, 9% ($n = 4$) were supported in transportation, 17% ($n = 8$) in coordination with Child Protective Services, and 74% ($n = 34$) in navigating other barriers to care. Social work provided assistance to 35% ($n = 22$) of the patients who participated in 12-month follow-up, and to 39% ($n = 24$) of the patients who did not participate. At 12-month follow-up, the group that achieved remission had a lower social work assistance rate (20%, $n = 4$) compared to the group with continued events (42%, $n = 18$); however, this was not statistically significant ($p = .16$).

3.4 | One-year trends

Acceptance of the diagnosis increased over time, with 53% ($n = 27/51$) at 1 month and 74% ($n = 35/47$) at 3 months, and remained similar with 73% ($n = 46/63$) at 12 months. At the initial clinic visit, 29% ($n = 18/63$) of patients were already linked with counseling, but this increased to 71% ($n = 36/51$) by 1 month, then to 66% ($n = 31/47$) at 3 months. Follow-up at 12 months identified 70% ($n = 44/63$) linked with counseling. Complete remission was achieved by 24% ($n = 12/51$) at 1 month, then increased to 43% ($n = 20/47$) at 3 months but decreased to 32% ($n = 20/63$) at 12 months. Combined PNES remission and improvement, describing patients who fall into the broad category of decreased event frequency including cessation of events, was 73% ($n = 37/51$) at 1 month, increased to 85% ($n = 40/47$) at 3 months, and reached 89% ($n = 56/63$) at 12 months. Figure 2 displays these trends over 12 months.

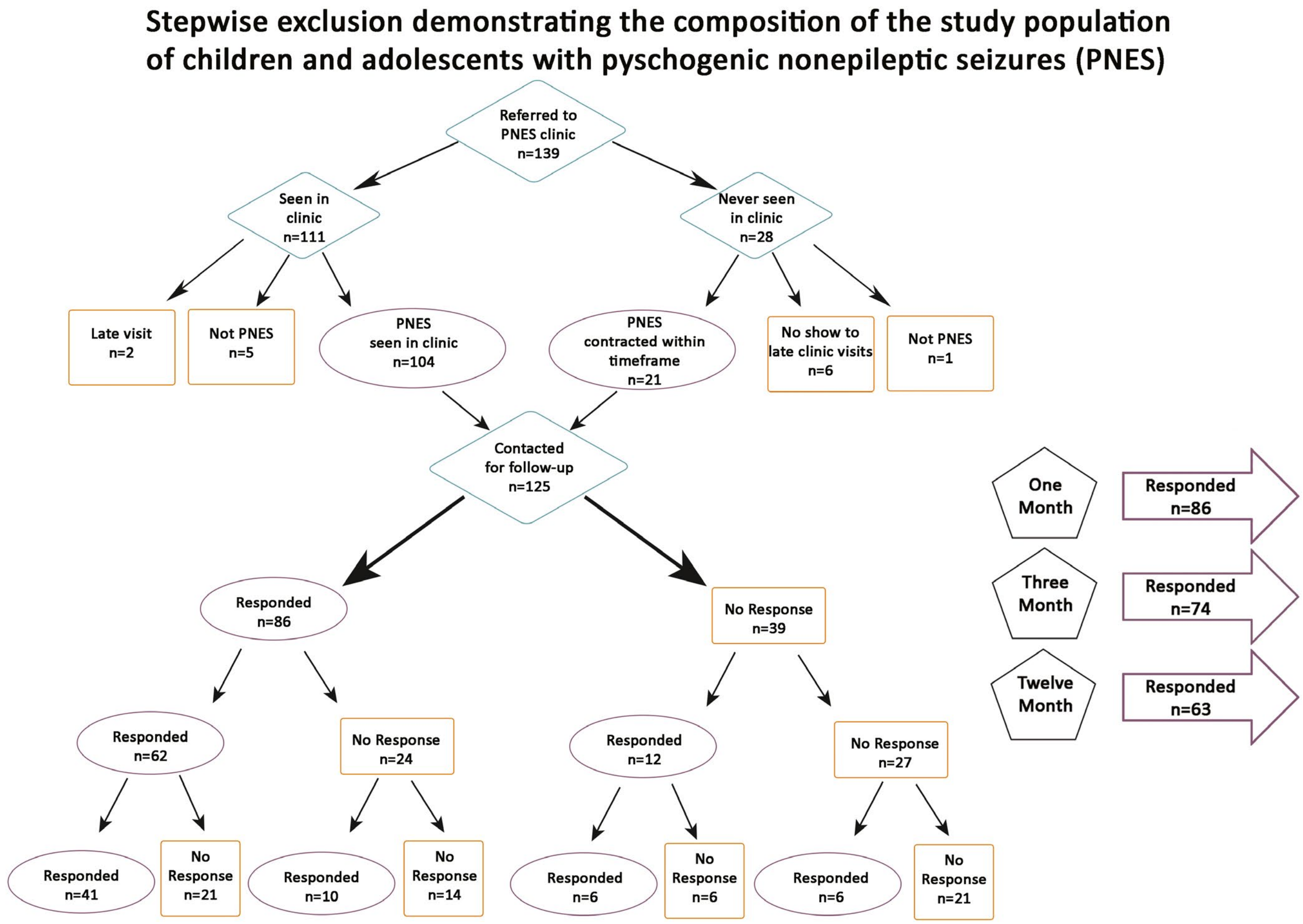


FIGURE 1 Stepwise exclusion demonstrating the composition of the study population of children and adolescents with psychogenic nonepileptic seizures (PNES)

3.5 | Outcome associations

Patient characteristics, including comorbid epilepsy, event semiology, and comorbid mental health disorders, were similar between those who achieved remission and those who did not. Patients and families who accepted the diagnosis at 1 month were more likely to achieve remission at 12 months, although this was not statistically significant ($p = .24$, Phi and Cramer $V = .20$). Early acceptance was not related to event improvement either ($p = .09$) but was found to be associated with connection to counseling at 12-month follow-up ($p = .007$, Phi and Cramer $V = .40$). Those who were linked with counseling at 1 month were more likely to achieve remission at 12 months ($p = .005$, Phi and Cramer $V = .39$). Less than half (44%) of patients reached at 12 months had their events documented on video-EEG at the time of diagnosis; however, those who did were not more likely at 12 months to be accepting of the diagnosis ($p = 1.0$), to be linked with counseling ($p = .58$), or to be event-free ($p = .79$). Table 2 displays findings of remission compared to continued events, as well as improved event frequency compared to no change and worsened frequency.

4 | DISCUSSION

Children and adolescents diagnosed with PNES within our population have increasing rates of acceptance and connection to counseling over the year following their visit to our PNES clinic, but the greatest increase is within the first month following clinic visit. Of our population, 89% reported reaching improvement in PNES frequency or remission at 12-month follow-up. It is an encouraging finding that pediatric and adolescent patients reported such a high percentage of improvement after the visit to our multidisciplinary clinic with social work support and nursing care coordination. A direct comparison of rates of improvement with a similar population from a different location is challenging, as much of the available literature tracks only remission rates in long-term studies, and our data relied on family report of remission status to describe improvement in PNES. Our previous publication, describing short-term outcomes after patients were seen in a PNES multidisciplinary clinic, reported that 75% of the studied population achieved improvement in event frequency at 3 months.[21] Sawchuk et al. described a PNES clinical care pathway, resulting in

TABLE 1 Comparison between the group of 63 children and adolescents with psychogenic nonepileptic seizures who participated in 12-month follow-up and the group of 62 who did not respond to follow-up calls

	Follow-up at 12 months, *n* = 63		No follow-up at 12 months, *n* = 62		Total, *n* = 125	
Table population, *n* = 125	***n***	**%**	***n***	**%**	***n***	**%**
Gender						
Male	13	21	17	27	30	24
Female	50	79	44	71	94	75
Other	0		1	2	1	1
Diagnostic certainty						
EEG documented	28	44	32	52	60	48
Clinically established	13	21	7	11	20	16
Probable	3	5	7	11	10	8
Possible	19	30	15	24	34	27
NA	0		1	2	1	1
Type of clinical event						
Catatonia	1	2	0		1	1
Focal movements	8	13	8	13	16	13
Generalized convulsive movements	39	62	39	63	78	62
Pseudosyncope	0		1	2	1	1
Staring/unresponsiveness	15	24	13	21	28	22
NA	0		1	2	1	1
Comorbid mental health						
Total diagnoses	43	68	41	66	84	67
ADHD	3	5	6	10	9	7
Anxiety	12	19	16	26	28	22
Autism	2	3	1	2	3	2
Bipolar	0		1	2	1	1
Depression	9	14	11	18	20	16
Intellectual disability	5	8	0		5	4
Learning concerns	1	2	0		1	1
PTSD	7	11	3	5	10	8
Sexual abuse	1	2	0		1	1
Suicidal ideation/self-harm	3	5	3	5	6	5
Comorbid conditions						
Epilepsy[a]	16	25	6	10	22	18
Epilepsy medication	21	33	8	13	29	23
Other conversion disorder	12	19	11	18	23	18
Interictal EEG						
Normal	36	57	42	68	78	62
Background abnormalities	4	6	1	2	5	4
Epileptiform abnormalities	10	16	6	10	16	13
Not performed	12	19	9	15	21	17
NA	4	6	1	2	5	4
Stressors						
Total stressors	48	76	51	82	99	79
Abuse	6	10	1	2	7	6

(Continues)

TABLE 1 (Continued)

Table population, *n* = 125	Follow-up at 12 months, *n* = 63		No follow-up at 12 months, *n* = 62		Total, *n* = 125	
	n	**%**	***n***	**%**	***n***	**%**
Family conflict	8	13	10	16	18	14
Family stressors	0		1	2	1	1
Grief	5	8	1	2	6	5
Other problem	5	8	3	5	8	6
Overscheduled	1	2	1	2	2	2
Peer problems/bullying	4	6	8	13	12	10
Perfectionist tendencies	1	2	0		1	1
Physical trauma	5	8	5	8	10	8
School performance	12	19	18	29	30	24
Substance use	1	2	3	5	4	3
Mental health treatments						
Counseling	18	29	19	31	37	30
Psychiatric medication	22	35	16	26	38	30
Psychiatry	7	11	5	8	12	10
Social work involvement						
Total involvement	22	35	24	39	46	37
Coordinate with CPS	3	5	5	8	8	6
Transportation	2	3	2	3	4	3
Other barriers	17	27	17	27	34	27

Note: Patients with epilepsy were statistically more likely to answer follow-up questions at 12 months.

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; CPS, Child Protective Services; EEG, electroencephalogram; NA, available; PTSD, posttraumatic stress disorder.

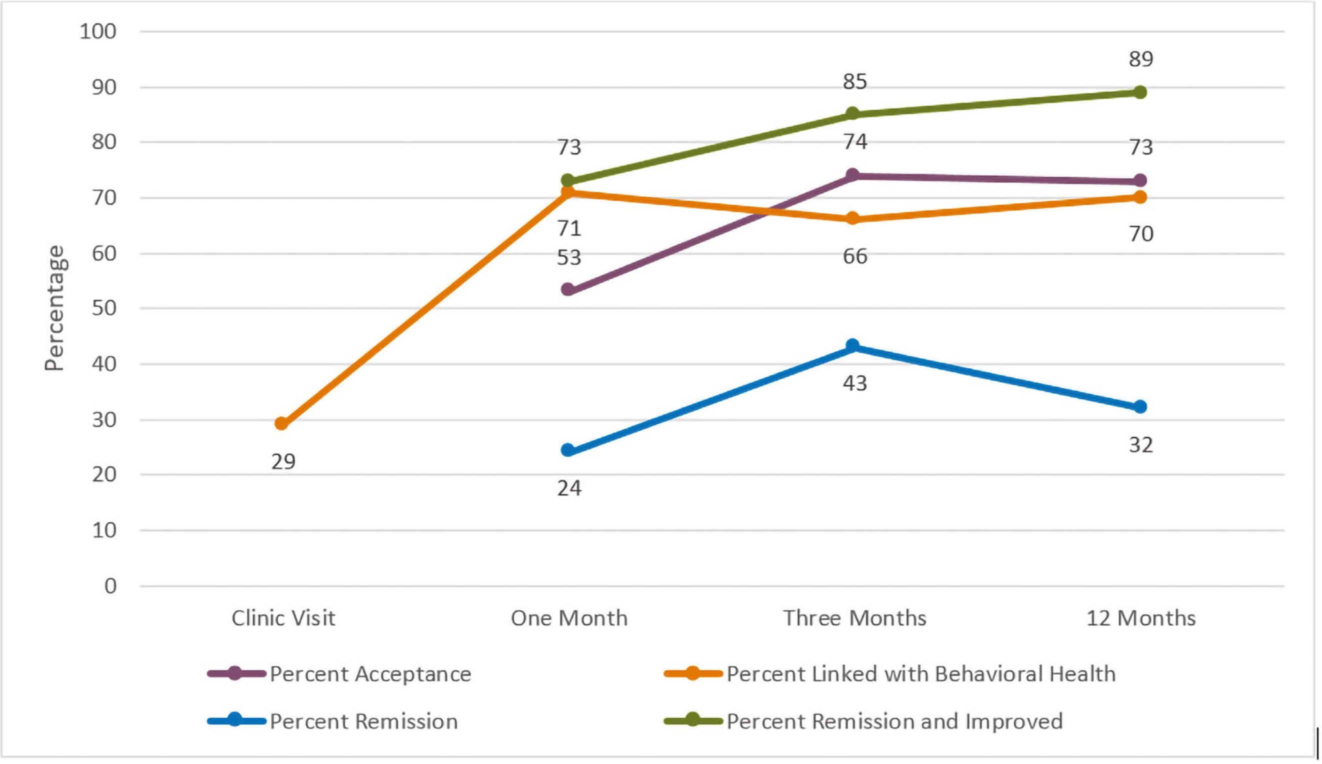
aStatistically significant differences between those who followed up and those who did not, with $p \leq .05$.

59% remission and 21% partial remission (similar to our category of improved), with an overall group of 80% who had a decrease in event frequency.[22] Looking further back to 1991, Wyllie and colleagues published a 73% remission rate in a cohort of 18 pediatric patients with PNES.[23] Deleuran et al. found that 83% of a population treated with psychotherapy had remission or >50% reduction in event frequency at 12-month follow-up,[17] comparable to our 89% improvement and remission at 12-month follow-up.

Remission rates rise within the first 3 months and fall by 12 months; however, family-reported improvement in event frequency is better sustained over time. Walther et al. shared a similar trend of initially higher remission (68%) that then decreased at later follow-up (37%).[8] More investigation is needed to elucidate potential causes for relapse in PNES over time. One possible explanation is that patients are initially diligent in establishing and following up with psychology, actively working on coping strategies, but then become complacent as they see PNES cease. As they celebrate the success in freedom from events, patients may also neglect to follow up with psychology or slip in self-care and coping strategies, leading to newly mismanaged stress, which begins the cycle of PNES again. This suggests an ongoing susceptibility to experiencing PNES with the natural ebb and flow of life stressors. Additionally, PNES bear a resemblance to outcomes for patients with depression, as they both have a psychological origin. In adolescents, Emslie et al. found a theme of increasing relapse when following patients long term, as 19% relapse at 24 weeks, then 36%–62% relapse when followed for 78 weeks.[24,25]

Furthermore, we found 21% of our cohort did not identify underlying stressors at the time of the visit. It is possible there were underlying factors that either the patient was not comfortable discussing or were not recognized by the patient due to lack of insight. These stressors may later become apparent during counseling. However, it is unclear how a lack of recognition or an absence of identified stressors may impact long-term outcomes.

Sustained remission at 12-month follow-up was associated with early connection to counseling, by 1 month. Meeting with psychology as part of the PNES visit and support from a team social worker, as in our multidisciplinary clinic, may expedite connection with mental health services following a diagnosis. As discussed earlier, the initial delivery of PNES diagnosis is vital to outcomes,



	Clinic Visit	*One Month*	*Three Months*	*Twelve Months*
Acceptance		53% (27/51)	74% (35/47)	73% (46/63)
Linked with Behavioral Health	29% (18/63)	71% (36/51)	66% (31/47)	70% (44/63)
Remission		24% (12/51)	43% (20/47)	32% (20/63)
Remission and Improved		73% (37/51)	85% (40/47)	89% (56/63)

FIGURE 2 Patient outcome trends for percentage of patients reporting acceptance of the diagnosis, linkage with behavioral health, remission (event freedom), and improvement (all patients with decreased event frequency, including those achieving remission) over time in the 12 months following the psychogenic nonepileptic seizures clinic visit

as the experience of receiving PNES diagnosis may influence a patient's motivation to connect with counseling. In contrast to our analysis of factors associated with remission, Sawchuk et al. started with the population of patients who did not achieve remission, and found that continued PNES are associated with a delay in diagnosis of PNES or events that continued for >12 months.[22]

Most clinical characteristics, including documentation of events on EEG, were similar between those reached and not reached at 12 months, with the exception of comorbid epilepsy and interictal abnormalities on EEG. Patients reached at 12 months had higher rates of comorbid epilepsy and EEG abnormalities, perhaps suggesting patients with comorbid epilepsy would be more engaged with the neurology clinic, so would be more willing to participate with follow-up phone calls from neurology staff. It is also not surprising in a group with higher rates of epilepsy that there would be higher percentages of interictal EEG abnormalities.

5 | Limitations

Our study was limited by a 50% patient attrition at 12-month follow-up, as only 63 of the 125 patients responded to calls. It would be valuable to learn the status of PNES within the population of patients not reached. It is difficult to know the outcomes of patients who did not follow up; however, the direction in which this biases results cannot be known. For example, it may be postulated that patients who did not follow up had complete remission, so did not consider it a valuable use of time to speak with the PNES clinic. On the other hand, if events have continued, parents may

TABLE 2 Data from the group of patients contacted at 12 months, comparing patients who were event-free (remission) to those with continued events as well as patients who had improvement compared to no improvement at 12 months following the PNES clinic visit

Event remission compared to continuation	PNES remission, $n =$ 18 at 1 month, $n = 20$ at 12 months		Continued events, $n =$ 33 at 1 month, $n = 43$ at 12 months		Total seen at 12 months, $n = 51$ at 1 month, $n = 63$ at 12 months	
	n	%	*n*	%	*n*	%
EEG documented	8	40	20	47	28	44
Comorbid epilepsy	6	30	10	23	16	25
Generalized convulsive movement events	10	50	29	67	39	62
Staring events	7	35	8	19	15	24
Social work involvement	4	20	18	42	22	35
No mental health diagnoses at clinic visit	7	35	12	28	19	30
Acceptance of diagnosis at 1 month	12	67	15	45	27	53
Acceptance of diagnosis at 12 months	16	80	30	70	46	73
Linked with counseling at clinic visit	8	40	10	23	18	29
Linked with counseling at 1 month[a]	16	89	20	61	36	71
Linked with counseling at 12 months	16	80	29	67	44	70

Event improvement compared to no improvement	PNES improvement, $n =$ 45 at 1 month, $n = 56$ at 12 months		No improvement, $n =$ 6 at 1 months, $n = 7$ at 12 months		Total seen at 12 months, $n = 51$ at 1 month, $n = 63$ at 12 months	
	n	%	*n*	%	*n*	%
EEG documented	24	43	4	57	28	44
Comorbid epilepsy	15	27	1	14	16	25
Generalized convulsive movement events	33	59	6	86	39	62
Staring events	14	25	1	14	15	24
Social work involvement	12	21	3	44	22	35
No mental health diagnoses at clinic visit	17	30	2	29	19	30
Acceptance of diagnosis at 1 month	26	58	1	17	27	53
Acceptance of diagnosis at 12 months	43	77	3	44	46	73
Linked with counseling at clinic visit	18	32	0	0	18	29
Linked with counseling at 1 month	33	73	3	50	36	71
Linked with counseling at 12 months	41	73	3	44	44	70

Note:: There was a statistically significant increase in event freedom at 12 months associated with linkage with counseling at 1 month following the clinic visit.

Abbreviation: EEG, electroencephalogram; PNES, psychogenic nonepileptic seizures.

[a] Statistically significant differences between those with remission and those without, with $p \leq .05$.

become disgruntled with the PNES clinic, so might choose to ignore calls. Likewise, families may have sought other opinions and wished to no longer engage with our clinic. Furthermore, lack of follow-up may be related to families moving or changing phone numbers, which would have no bearing on clinical status. Many of the patients reached at 12 months were also reached at previous time points, suggesting there may be a subset of patients more amenable to follow-up (which includes those with comorbid epilepsy) who may also have better outcomes. On the other hand, following the same population at multiple time points does allow us to better track outcomes over time.

6 | Conclusions

Early (by 1 month) connection to counseling was associated with increased remission rates at 12 months. Capturing events on video-EEG was not correlated with increased acceptance, linkage with counseling, or event freedom at 12 months. Although event documentation on EEG may be useful for diagnosis, it should not be relied on to ensure patient acceptance of the diagnosis and in our cohort was not a predictor of remission. Focus should be placed on presenting the diagnosis in a manner that increases early acceptance and is followed by strong encouragement to connect with counseling quickly to achieve a goal of increasing 12-month PNES remission rates. A multidisciplinary team that includes social work and nursing support may help families successfully connect with counseling, thus leading to better outcomes.

ACKNOWLEDGMENT

We thank the other members of our PNES clinic team, namely the administrative assistants Leigh Parsons, Danielle Denney, and Christy Tschirner, who schedule patients to be seen in the clinic.

CONFLICT OF INTEREST

None of the authors has any conflict of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

PATIENT CONSENT DECLARATION

The institutional review board (IRB) at Nationwide Children's Hospital reviewed and approved this project. The patient database was approved by the IRB and determined to be exempt from patient consent.

ORCID

Megan Fredwall https://orcid.org/0000-0003-0824-2429
Dara V. F. Albert https://orcid.org/0000-0002-3867-2297

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How to cite this article: Fredwall M, Terry D, Enciso L, Burch M(, Trott K, Albert DVF. Outcomes of children and adolescents 1 year after being seen in a multidisciplinary psychogenic nonepileptic seizures clinic. Epilepsia. 2021;00:1–11. https://doi.org/10.1111/epi.17031

APPENDIX 1

PNES follow-up question script, to be used by nurse when calling patients on the phone at 1-, 3-, and 12-month follow-up

1. Is your child still having events?
    - Remission, improved, no change, or worse?
        a. If yes, have the events changed?
    - Has your child been seen in an emergency room (ER) for events? Yes/No
        a. If yes, who made the decision to bring the child to the ER (school, parent, other caregivers, etc.)?
        b. If school, OK to discuss management with school?
    - Hospitalizations after diagnosis? Yes/No
    - Has your child been able to stop the progression of any events by using relaxation strategies?
2. Is your child currently linked with counseling/psychology services? Yes/No (Seeing a counselor, appointment scheduled, never scheduled, wait list, refused counseling, completed counseling, psychiatrist only, intermittent counseling)
    - If yes, with whom?
    - Have there been any new diagnoses (such as anxiety or depression) or medication started?
    - If no, why not? What barriers exist preventing you from receiving care?
3. Has your child been back to school?
4. How are you and your child feeling about the diagnosis of PNES? (Accepted, questioning, not accepted)
5. What questions do you still have regarding the diagnosis or treatment for your child?

Abbreviation: PNES, psychogenic nonepileptic seizures.