# Outcomes in Children and Adolescents With Psychogenic Nonepileptic Events Using a Multidisciplinary Clinic Approach

Journal of Child Neurology 2020, Vol. 35(13) 918-923 © The Author(s) 2020 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/0883073820939400 journals.sagepub.com/home/jcn

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#### Abstract

**Background:** Psychogenic nonepileptic events (PNEE) are paroxysmal events that resemble epileptic seizures but are caused by psychological factors. Coordination of care has been recommended as one strategy to integrate care and improve outcomes. We aim to evaluate patient outcomes in a multidisciplinary pediatric psychogenic nonepileptic events clinic that includes care coordination. **Methods:** All patients referred to the multidisciplinary psychogenic nonepileptic events clinic were entered into a prospective database. Follow-up calls were made by the clinic nurse at 1 and 3 months following the visit. **Results:** A total of 101 unique patients were reviewed. Ninety-six appointments were scheduled, and 83 appointments were completed (86%). Social work identified barriers in 38 patients, and 76% of those assisted completed their appointment. At 1 month, two-thirds of families were reached, 50% were accepting of the diagnosis, and 70% had clinical improvement in events. By 3 months, 75% had clinical improvement, 76% were receiving mental health services, and 73% were accepting of the diagnosis; however, more had also returned to the emergency department. Families needing assistance from social work tended to have worse outcomes. Increase in acceptance was nearly statistically significant (P = .058) from 1 to 3 months; however, it was not so for clinical improvement in events (P = .623). **Conclusions:** Implementation of a multidisciplinary team with care coordination allowed for follow-up for children and adolescents with psychogenic nonepileptic events and mitigation of barriers to care and can improve clinical outcomes. After being seen in our clinic, many families had accepted the diagnosis, most of the patients reached had event improvement and were successfully linked with counseling at the 1- and 3-month follow-ups.

#### **Keywords**

psychogenic nonepileptic seizures, functional neurologic disorders, pediatric social work, care coordination

Received April 8, 2020. Received revised May 24, 2020. Accepted for publication June 10, 2020.

Psychogenic nonepileptic events (PNEEs) are paroxysmal changes in behavior that resemble an epileptic seizure but are not the result of excessive electrical activity in the brain, and are instead caused by psychological factors.<sup>1</sup> Psychogenic nonepileptic events can have a significant impact on quality of life.<sup>2</sup> In children and adolescents, psychogenic nonepileptic events may be tied to school-, peer-, or family-related challenges.<sup>2</sup> Clinical management of psychogenic nonepileptic events can be challenging and requires an integrated care approach with both neurology and mental health providers to achieve optimal outcomes.<sup>3</sup> Patients with psychogenic nonepileptic events tend to have high healthcare use including emergency services.<sup>4,5</sup> Coordination of care by nurses and social workers has been recommended as one strategy to help integrate the care of these patients and improve their outcomes, but little is known about the optimal way to integrate a multidisciplinary approach.<sup>6</sup>

Furthermore, long-term outcomes, including acceptance of the diagnosis and remission from events, as well as healthcare utilization after diagnosis, in pediatric patients with psychogenic nonepileptic events are not fully understood.<sup>2</sup> Few studies have reported outcomes for children and adolescents with psychogenic nonepileptic events, and although many reports are positive, there are often high rates of attrition.<sup>2</sup> Early

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acceptance of the diagnosis has been linked to improved outcomes; however, patients and families may have difficulty accepting the diagnosis.<sup>7</sup>

We aim to evaluate the clinical outcomes of a multidisciplinary team approach that included care coordination in children and adolescents diagnosed with psychogenic nonepileptic events in a prospective, observational study. We hypothesize that adding a nurse and social work coordinators before the visit in the psychogenic nonepileptic events clinic would improve show rates to clinic. We also hypothesize that patients who benefited from care coordination and attended their clinic appointment would be more likely to accept the diagnosis, connect with mental health services, achieve remission from events, and have less frequent visits to the emergency department at 1 and 3 months following the clinic visit.

## Methods

The PNEE Clinic at Nationwide Children's Hospital is a clinic in which patients are seen by both an epilepsy provider (DT and DVFA) and a psychologist (KT). The purpose of this joint visit is to provide another opinion regarding the diagnosis and to serve as a bridge from neurology to mental health services. Patients are typically seen once in a joint appointment, then are transitioned to Behavioral Health for ongoing treatment and management. Occasionally, follow-up in the clinic is necessary. As part of ongoing quality improvement efforts for the clinic, a nurse, and social worker were added to the team to help with care coordination for patients seen in the clinic and to facilitate follow-up. There is no standardized approach to diagnosis of in our center; patients may have the diagnosis made clinically or have events confirmed on a video electroencephalographic (EEG) recording. Referrals to clinic are made by many clinical services, with the majority from inpatient and emergency department neurology evaluations. Referrals from primary care pediatricians, other specialties, and outside centers are also accepted. The clinic tries to see patients expeditiously following a diagnosis of to solidify the diagnosis, provide education, and answer questions to help the family accept the diagnosis, and quickly move patients toward treatment and recovery. The levels of diagnostic certainty proposed by the International League Against Epilepsy (ILAE) are used by our clinic to categorize the confidence in the diagnosis.<sup>8</sup>

Clinic outcomes measured included patient attendance to clinic, need for social work intervention, and the presence of nurse follow-up by phone. Patient outcomes measured at follow-up included patient and family acceptance of the diagnosis, clinical status of events, return to the emergency department and hospitalizations for events, and linkage with mental health services.

#### Patient Database

All consecutive patients referred to the PNEE Clinic from November 1, 2017, to December 31, 2018, were entered into a prospective database. Patient characteristics including gender, age at event onset, age at diagnosis, level of diagnostic certainty, characteristics of the events, if events were captured on an EEG, interictal EEG findings (if an EEG was performed), comorbid mental health diagnoses, history of trauma or abuse, identified psychosocial stressor, the presence of other functional neurologic symptom disorders, comorbid epilepsy, and if the patient was taking any anticonvulsant or behavioral medications at the time of diagnosis were recorded.

## Clinic Process

After a referral was placed, the clinic administrator scheduled the appointment and notified the team. A licensed social worker reviewed the chart for potential barriers to attending the appointment. The role of the social worker is to support the family's self-efficacy and resilience by assessing for and mitigating barriers to care. The social worker looked specifically at the patient's attendance rate to previous appointments within the Nationwide Children's Hospital system, active insurance and the insurance type, distance from the hospital, history of social work involvement, and current custody and placement of the patient. If the patient was noted to have concerns in any of these areas, the social worker contacted the family before the appointment to assist with mitigating barriers and linking the family to appropriate resources to facilitate and promote treatment adherence.

A nurse on the team called the family the day prior to remind them of the appointment and was present in clinic to room and meet the family on the day of the appointment. The nurse then made follow-up phone calls at 1 and 3 months after the appointment. All patients referred to the clinic were called for follow-up, regardless of attendance in clinic. For families who were not reached on initial call, repeat attempts were made up to 3 times, and attempts to reach were again made at the 3-month time point. Follow-up questions asked included the status of the events, have the patient and family accepted the diagnosis, has the patient returned to school, has the patient returned to the emergency department or been hospitalized for events or recurrent events since the last follow-up call, and is the patient receiving mental health services. In addition, the nurse provided further counseling or interventions if needed. For example, if the nurse identified that the patient had not been able to connect with mental health services, the nurse, psychologist, and/or social worker provided guidance on how to obtain an appointment. If a patient or family was not accepting the diagnosis and events continued, a follow-up clinic visit or further testing might be offered. There were a few families who were reached but did not provide answers to questions about acceptance or clinical status of events at the time of the follow-up calls; these patients were assumed to be not accepting and have no change in the clinical events, respectively.

#### Statistical Analysis

Descriptive statistics were used to present demographic data. Comparison of acceptance and remission rates between the 2 follow-up time points were made using a paired sample t test. Follow-up data for comparison was not available before the implementation of care coordination and establishment of the database.

# Results

During the study period, a total of 103 consecutive referrals were made to the PNEE Clinic at Nationwide Children's Hospital. Four of these patients were re-referred for follow-up appointments after an initial evaluation before 2018. One patient was referred for a follow-up appointment but was never seen in clinic, 1 additional patient was referred from an outside center and was never seen as an inpatient or outpatient at our



**Figure 1.** The percentage of patients diagnosed with psychogenic nonepileptic events (PNEE) with different levels of diagnostic certainty. The highest level of certainty being those documented on EEG and the lowest is possible when a diagnosis is made based on a witness or self-report of the event.<sup>8</sup>

center; both were excluded from the analysis, leaving a total of 101 unique patients included in the analysis. Ninety-six appointments were scheduled, and 83 appointments were completed (86%).

# Patient Demographics

Of the patients referred, 76 were female (75%). The mean age at event onset was 14.2 years, and the mean age at diagnoses was 14.8 years. Twenty-two patients (22%) had comorbid epilepsy. Thirty-nine (39%) patients had private insurance, 57 (56%) were on public insurance plans and 6(6%) were without insurance. About half of the patients (48%) had their events documented on an EEG, giving the highest degree of diagnostic certainty for psychogenic nonepileptic events; 16 (16%) of diagnoses were clinically established and 37(37%) were either possible or probable diagnostic certainty (Figure 1). The majority of patients (61%) had clinical semiology of generalized convulsive movements during their events, 13 (13%) had focal movements, 23 (23%) with staring and unresponsiveness, 1 patient had psychogenic nonsyncopal collapse, and 1 had catatonia. Nine patients (9%) were on an anticonvulsant medication at the time of diagnosis without a prior history of epilepsy. Two patients (2%) had epileptiform abnormalities on EEG without prior history of epilepsy. In 1 patient (0.9%), although an initial diagnosis of psychogenic nonepileptic events was suspected, she was ultimately diagnosed as having epileptic seizures. An additional patient had a remote history of epilepsy, presented with recurrent staring events that were suspected to be psychogenic nonepileptic events but were ultimately felt to be recurrence of her epilepsy and resolved with restarting anticonvulsant medication. A third patient with comorbid epilepsy presented with new events thought to be psychogenic nonepileptic events. Events were captured on EEG and did not have an EEG correlate; however, the semiology suggested the events could be epileptic, arising from a deep focus that was negative Table 1. Patient Demographics and Characteristics of Events.

Characteristic	n (%) or mean
Demographic	
Female gender	76 (75)
Mean age at event onset, y	I 4.2
Mean age at diagnosis, y	14.8
Comorbid epilepsy	22 (22)
Diagnostic certainty	
Documented on EEG	49 (48)
Clinically Established	16 (16)
Probable or Possible	36 (36)
Clinical Semiology	
Generalized convulsive movements	62 (61)
Staring and unresponsiveness	23 (23)
Focal movements	13 (13)
non-syncopal collapse	I (I)
Catatonia	I (I)
On an anti-convulsant at diagnosis	9 (9)
Epileptiform EEG findings without a history of epilepsy	2 (2)
Comorbid psychiatric illness	69 (68)
On psychiatric medications at diagnosis	29 (29)
Reported history of sexual abuse	6 (6)
Prior or concomitantly functional neurologic disorder symptoms	15 (15)

on scalp EEG. Further investigations were planned to determine the etiology of the events.

Sixty-nine (68%) patients had previously diagnosed mental health comorbidities at the time of psychogenic nonepileptic events diagnosis (ADHD, depression, anxiety, learning disabilities, bipolar, prior trauma, PTSD, as well as 3 patients with autism and 4 with intellectual disability). Six patients (6%) reported prior history of sexual abuse and 15 (15%) had a history of prior or concomitant other functional neurologic disorder symptoms. In 73 patients (72%), we were able to identify a potential underlying psychosocial stressor, including but not limited to peer conflict, academic struggles, internal pressures or perfectionistic tendencies, and family discord. Twenty-nine patients (29%) were on psychiatric medications, and 30 (30%) were in counseling at the time of diagnosis. (Table 1)

## Social Work Involvement

The social worker reviewed every referral during the study period. Potential barriers to care were identified in 38 cases. Of those cases, there were 8 occasions that social work assisted with coordination with Child Protective Services, 4 times social work assisted with transportation to the appointment, and 26 times social work assisted with other barriers to care, which might include lack of insurance, assessing for accommodation need due to distance from the hospital (such as gas reimbursement or overnight lodging), assessing for barriers due to history of nonadherence to appointments and other psychosocial factors. Out of the 38 instances when social work contacted a family, 2 chose not to schedule and 7 did not show, the rest (76% of those assisted) completed their appointment in the



**Figure 2.** The percentage of patients who were accepting of the diagnosis, questioning, or not accepting of the diagnosis at the 1- and 3-month follow-up time points. Differences in acceptance of the diagnosis between the 2 time points was nearly statistically significant (P = .058).

clinic. Most of the families the social worker assisted were on public health insurance (84%, including one patient listed as no coverage). Similar rates of mental health comorbidity (61%), comorbid epilepsy (24%), prior or concomitant other functional neurologic disorder symptoms (18%) were seen in this subcohort.

## Patient Outcomes at 1 Month

Of the 101 patients in whom a follow-up phone call was attempted, 64 families (63%) were reached. Three families asked not to be contacted for follow-up, including for 1 patient who was subsequently diagnosed with epilepsy and not psychogenic nonepileptic events. Of the families who completed the follow-up phone call, 32 were accepting of the diagnosis (50%), an additional 23 (36%) were questioning the diagnosis, and 9 (14%) were not accepting of the diagnosis (Figure 2). Forty-eight patients (75%) were either already receiving mental health services or were awaiting an upcoming appointment with a mental health provider. Forty-five patients (70%) were in remission from events or were improving, 14 (22%) had no change in events, and 3 (5%) were worse (Figure 3). A total of 6 patients (9%) reported a return to any emergency department (Nationwide Children's Hospital or outside institution) for recurrent events. Of the 10 patients who no-showed to their psychogenic nonepileptic events appointment, 7 could not be reached for follow-up. Of those that were reached, 2 had accepted the diagnosis and the remaining were questioning; 2 were seeing a counselor, whereas 1 refused counseling; 2 were reported as in remission and 1 having improvements in events.

### Patient Outcomes at 3 Months

Fifty-five patients (54%) were reached at 3 months. Of the patients reached, 40 (73%) were accepting of the diagnosis, 2 (4%) were not accepting, and 13 (24%) were questioning the



**Figure 3.** Percentages of change in clinical events at the 1- and 3-month follow-up time points. Differences in event remission and improvement between the 2 time points were not statistically significant (P = .623).

diagnosis (Figure 2). This was an almost statistically significant increase in acceptance from 1 to 3 months (P = .058) (Table 2). There were no patients who were unaccepting of the diagnosis at 1 month who then reported acceptance at 3 months; however, there were 6 who were questioning the diagnosis at 1 month who then moved to acceptance at 3 months. Forty-two (76%)were actively receiving mental health services or were awaiting an appointment. Forty-one patients (75%) reported that their events were improved or in remission, 10 (18%) had no change in events, 3 patients (5%) were worse (Figure 3). Differences in event remission or improvement were not statistically significant from 1- to 3-month follow-up (P = .623) (Table 2). There were 25 patients who achieved remission or improvement from events at 1 month who had sustained improvement at the 3-month follow-up, 7 patients who did not see improvement or remission in events at 1 month who then had improvement by 3 months and 3 patients in whom there was initial improvement at the 1-month time point and then subsequent worsening of events in between the 1- and 3-month time points.

A total of 11 (20%) had returned to an emergency department for recurrent events within the 3 months after the psychogenic nonepileptic events visit. This included 2 patients who had been to the emergency department in the first month after the appointment and again between the 1- and 3-month followup, another 6 patients had only been to the emergency department between the 1- and 3-month follow-up, and an additional 3 patients who were not reached at the 1-month follow-up call who reported returning to the emergency department for events at the 3-month call. Only 3 of the families who no-showed to clinic were reached for follow-up at 3-months, and all were accepting of the diagnosis with remission from events: 1 was seeing a counselor, 1 was awaiting an appointment, and the third had refused counseling.

There were a total of 45 patients (45% of the total cohort, 70% of those reached at 1-month) reached at both time points, 19 that were reached at the 1-month follow-up that were not

Paired Samples Test Paired Differences 95% Confidence Interval Standard of the Difference Standard Error Significance Mean Deviation Mean Lower Upper df (2-tailed) t Improved and Remission at one- and three-months .230 .045 .608 .092 -.139 .496 43 .623 .383 -.004 -1.948 44 .058 Diagnosis Acceptance at one- and three-months -.111 057 -.226

**Table 2.** Results of paired sample *t* test comparing acceptance and improvement rates from one to three months. Comparison of acceptance rates and clinical improvement and remission of events between the two time points did not achieve statistical significance.

reached at 3-months and 9 that were reached at 3-months that were not reached at the 1-month time point.

For the families that had involvement from our team social worker, the 3-month outcomes were different. Patients in this group had lower percentages of accepting of the diagnosis (45%), linkage with behavioral health (39%) or to have improvements in their clinical events (45%), compared with the entire group (73%, 76%, and 75%, respectively).

## Other Patient Outcomes

On follow-up calls with the nurse, several patients were questioning the diagnosis or needed further clarification on management of the events, and the nurse care coordinator was able to address these concerns. In 2 patients who were not accepting of the diagnosis at the 1-month follow-up phone call and in whom their events had not been captured on an EEG, long-term monitoring was ordered, which was able to confirm the diagnosis of psychogenic nonepileptic events. In addition, several families were having difficulty accessing local mental health services and assistance was provided.

## Discussion

We have successfully implemented a pediatric multidisciplinary psychogenic nonepileptic events clinic and incorporated care coordination. The addition of care coordination allowed for early identification of potential barriers to care and opportunities to implement resources. Care coordination also allowed for improved follow-up. Healthcare system-related barriers to care for patients with psychogenic nonepileptic events have been identified as "lack of access to neurology and mental health services" and "lack of care coordination and communication among different healthcare systems and providers."6 Implementation of care coordination in this clinic has helped to mitigate these barriers. We have improved access to neurology and mental health services by integrating mental health providers within the neurology clinic as recommended by Sawchuk, Austin, and Terry as one key component in an ideal model of care for psychogenic nonepileptic events.<sup>6</sup> In addition, care coordination has decreased some of the barriers to patients attending their appointments, therefore increasing access to the services. The follow-up calls provided by the nurse as part of care coordination has improved communication between the patient and the psychogenic nonepileptic events team and identified communication gaps with other medical and mental health providers outside of the psychogenic nonepileptic events team. For example, if a school nurse or treating therapist does not understand the response or treatment plan, the team can reach out to clarify the plan.

At 1-month, two-thirds of families were reached by phone and half were accepting of the diagnosis. Three-quarters of patients were either already receiving mental health services or were awaiting an upcoming appointment with a mental health provider. The majority were in remission from events or were improving and very few had returned to the emergency department for recurrent events. By 3-months, a greater percentage of patients had clinical improvement in events and were accepting of the diagnosis; however, more had also returned to the emergency department. Although the number of patients accepting the diagnosis did increase from 1-to 3months, there were no families who moved from unacceptance at 1-month to acceptance at 3-months, further highlighting the importance of early acceptance.<sup>7</sup> Many patients achieved improvements or remission early by 1-month and sustained at 3-months, a few patients achieved improvement or remission between the 1- and 3-month time point, and a few patients experienced regression in events between 1 and 3 months. Likewise, the percentage of patients receiving mental health services did increase from the time of diagnosis (30%) to the 1-month follow-up (75%), but there was no change from 1 to 3 months (76%), likely suggesting patients staying in counseling, without additional patients entering counseling over the follow-up period; however, this may also be limited by follow-up attrition. Rates of remission in our cohort are within range of previously reported remission rates for pediatric patients with psychogenic nonepileptic events, ranging from 18% to 72%, however; we report improved follow-up rates as previous studies have lost up to 68% of patients to follow-up.<sup>2</sup> Differences in acceptance rates between patients who attended their psychogenic nonepileptic events appointment and those who did not were difficult to evaluate given the small numbers of families reached for follow-up after not showing for the appointment. However, among those who were reached, all

were reporting remission or improvement in events, suggesting that some families may be able to accept the diagnosis without being seen in a specialized psychogenic nonepileptic events clinic.

We did find trends toward lower rates of acceptance, linkage with behavioral health, and improvements or remission of events at 3-months among the families in whom our team social worker provided assistance. This is likely a reflection of greater psychosocial stressors and family dynamics that may contribute to worse outcomes in these families. Currently our team social worker is involved with the families before their appointment to assess for barriers to care specific to attending the scheduled PNEE Clinic visit. These findings suggest the need for social work assistance following the clinic visit as well, to assess for barriers to recommended behavioral health treatment and offering resource support.

## Limitations

There are several limitations to this prospective observational study. A lack of standardized diagnostic approach led to differences in the level of diagnostic certainty among the patients seen in the clinic. There is significant patient attrition to follow-up phone calls, and we cannot know the clinical status or acceptance of the diagnosis in patients who were not reached. Furthermore, the majority of patients that were reached at 1-month were also reached at 3-months. Although this allows us to better track patients over time, this may also contribute to sample bias in the data. Lastly, we did not have sufficient historical data to make appropriate comparisons. This lack of comparable historical controls before the establishment of the database and implementation of care coordination limits interpretation of these results.

# Conclusions

Implementation of a multidisciplinary team with care coordination by a nurse and social worker allowed for more consistent follow-up for children and adolescents with psychogenic nonepileptic events, mitigation of barriers to care, and may improve clinical outcomes and attendance at psychogenic nonepileptic events clinic appointments. Although there is no historical comparison of follow-up for our cohort, with the current model, after being seen in our clinic, the majority of families had accepted the diagnosis, most patients were in remission from events and were successfully linked with counseling at 1- and 3- months following the clinic visit. Prior reports have emphasized that early acceptance of the diagnosis leads to improved outcomes. These results suggest a multidisciplinary team approach that includes collaboration between neurology and behavioral health, care coordination with nursing, and social work support should be considered in the development of a pediatric psychogenic nonepileptic events clinic.

#### Acknowledgments

We would like to acknowledge the other members of our psychogenic nonepileptic events clinic team, namely, the administrative assistants Leigh Parsons, Danielle Denney and Christy Tschirner who schedule patients to be seen in the clinic.

#### **Author Contributions**

DT contributed to the study design, drafting and editing the manuscript. LE participated in the drafting and editing of the manuscript. KT contributed to the study design, drafting and editing the manuscript. MB participated in the drafting and editing of the manuscript. DVFA contributed to the study design, data analysis and interpretation, drafting and editing the manuscript.

#### **Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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#### **Ethical Approval**

This project was reviewed by the Institutional Review Board (IRB) and deemed exempt from full review (STUDY00000880).

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