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Post-Diagnosis Neurological Care for Patients with Psychogenic Nonepileptic Spells (PNES)

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Abstract

Objective—This study investigated continuity of neurological care for patients discharged from the epilepsy monitoring unit (EMU) with a diagnosis of psychogenic nonepileptic spells (PNES). PNES, seizure-like episodes that cannot be explained by abnormal electrical brain activity, are challenging for patients to understand and accept. Consequently, after diagnosis patients commonly fail to start recommended psychotherapy and instead pursue redundant medical care. As consistent relationships with healthcare providers may help, we instituted standard follow-up for patients diagnosed with PNES.

Methods—We performed a retrospective observational cohort study of adults diagnosed with PNES in our EMU. In November 2013, we began routine scheduling of post-discharge follow-up neurology appointments. We compared pre-intervention (November 2010–October 2013) and post-intervention (November 2013–May 2016) cohorts with regard to clinic attendance, understanding the diagnosis, compliance with recommendations, and event frequency.

Results—We identified 55 patients in the pre-intervention cohort and 123 patients in the post-intervention cohort. We successfully implemented the intended practice changes; more patients had follow-up scheduled by discharge (pre-intervention 2% vs. post-intervention 36%, $p<0.001$), time to follow-up decreased (46 days vs. 29, $p=0.001$), and providers more consistently queried understanding of diagnosis (38% vs. 67%, $p=0.03$). Explicit planning for continued care did not produce the anticipated patient-provider relationships, as follow-up in clinic was low (38% vs. 37%). For patients who attended clinic, the intervention did not improve establishment of psychiatric care, compliance with medication recommendations, understanding of diagnosis, or event frequency. The odds of reduced event frequency were non-significantly increased with understanding the diagnosis (OR 3.75, $p=0.14$). Recommending antiepileptic drug (AED) discontinuation was associated with increased odds of event freedom (OR 6.91, $p<0.01$).

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Conflicts of Interest:

None of the authors has any conflict of interest to disclose.

Significance—Scheduling follow-up for patients diagnosed with PNES did not facilitate ongoing patient- provider relationships due to poor clinic attendance. As follow-up is unreliable, the inpatient visit is a critical window of opportunity for intervention.

Keywords

psychogenic non-epileptic spells; transitions of care; epilepsy monitoring unit

1. Introduction

Psychogenic non-epileptic spells (PNES) are seizure-like episodes of altered behavior or movement that cannot be explained by abnormal electrical brain activity or by another physiological cause[1]. PNES can be very difficult to diagnose as it mimics epilepsy; on average, there is a seven-year delay to correct diagnosis during which time many patients are treated, typically ineffectively, with antiepileptic medications[2–4]. It is often not until comprehensive evaluation in the Epilepsy Monitoring Unit (EMU) with video electroencephalography (EEG) that a diagnosis of PNES is determined[5,6].

Given this prologue, a new diagnosis of PNES can be surprising to patients, challenging to understand, and difficult to accept[7–9]. With the delivery of a PNES diagnosis, often a deep- rooted conviction is abruptly overturned and consequently the initial communication between physician and patient is both challenging and important[7,10,11]. Furthermore, a critical transition of care must be facilitated at this time; PNES is a psychiatric disorder and is treated with psychological interventions which have traditionally been delivered by mental health providers[1,12,13]. Even for patients who are interested in psychotherapy, scheduling an appointment with a psychologist or psychiatrist for the recommended treatment can be onerous due to inadequate insurance acceptance[14] and a shortage of providers[15]. For all of these reasons, patients with PNES commonly fail to engage with a mental health provider and instead pursue redundant, unhelpful neurological and medical care[16,17].

It has been hypothesized that ongoing support and consistent relationships with healthcare providers can improve outcomes for patients with PNES[1,18,19]. More broadly, the literature on transitions of care supports the utility of a follow-up appointment after discharge to ensure that the care plan is executed properly[20,21] and suggests that proactive scheduling of appointments improves follow-up[22,23]. Therefore, we instituted standardized follow-up neurology appointments for patients diagnosed with PNES after discharge from the EMU. This study investigates the impact of our intervention through comparison of pre-intervention and post-intervention patient cohorts.

2. Methods

2.1 Study Design

We performed a retrospective observational cohort study of patients diagnosed with PNES in our EMU from November 2010 to May 2016. During this time period, the general approach to diagnosis involved capturing a patient's typical event(s) on video EEG. The attending neurologist would then confirm the absence of correlating epileptiform activity, the absence

of clinical characteristics supportive of seizure (e.g. stereotyped nature, occurring from sleep, suggestive of frontal epilepsy or simple partial seizure), and the absence of a physiological etiology (e.g. syncope, hypoglycemia). Once confident in the diagnosis, the attending neurologist would discuss the diagnosis of PNES with the patient and briefly explore precipitating factors. While there was no formal script, all attending neurologists employed a common approach of presenting the diagnosis in a positive light by explaining it was good news that the patient had PNES rather than epilepsy. Inpatient psychiatric consultation was not standard, but would be completed if indicated by psychiatric symptoms or patient interest. An individualized care plan would then be developed regarding discontinuation of antiepileptic medications and establishment or continuation of outpatient psychiatric care; follow-up with the primary outpatient neurologist was not routinely recommended or scheduled. Beginning in November 2013, a standardized program of outpatient follow-up with the Penn Epilepsy Center was implemented as a quality improvement initiative to augment the previously described process. In this program, a post-discharge appointment with the patient's primary neurologist or nurse practitioner was scheduled prior to patient discharge from the EMU and the patient was reminded of the follow-up appointment at the time of discharge. Furthermore, the patient was advised that this follow-up appointment would be an opportunity to discuss his or her PNES diagnosis, review the treatment plan, and ask any further questions. Likewise, providers were educated that the goals of this visit were to explain the PNES diagnosis, to explore the patient's understanding of the diagnosis through conversation, and to review compliance with the treatment plan. This appointment was scheduled to occur 2–4 weeks after discharge from the EMU. Lastly, patients were given written materials that answered frequently asked questions, suggested additional resources, and reinforced the importance of follow-up.

In this study, we compared a pre-intervention and a post-intervention patient cohort. Approval was obtained from the University of Pennsylvania Internal Review Board and informed consent was waived.

2.2 Study Population

Patients were identified from the EMU logbook. Inclusion criteria were (1) discharge from the EMU between November 2010 and May 2016, (2) a new or confirmed diagnosis of PNES, and (3) age >17 years. Patients were excluded if they had a coexistent diagnosis of epileptic seizures or if their primary neurologist was outside of the Penn Epilepsy Center. Patients discharged from November 2010 to October 2013 were assigned to the pre-intervention cohort and patients discharged from the EMU from November 2013 to May 2016 were assigned to the post-intervention cohort.

2.3 Data Collection and Measures

The EMU report, which provides a formal summary of the history of present illness, daily clinical and electrophysiological data, and diagnosis made during the EMU hospitalization, was reviewed for each patient. Additionally, the electronic medical record was reviewed for subsequent neurology appointments and data was collected from the first neurology clinic encounter following the date of EMU discharge. For each patient, demographic and clinical information at admission was collected including age, gender, history of a mood disorder

(anxiety, depression, and/or bipolar disorder), history of a psychotic disorder (schizophrenia, schizoaffective disorder, and/or hallucinations), history of abuse (physical, sexual, and/or emotional), current relationship with a psychiatrist, duration of disease, use of antiepileptic medications, and employment outside of the home.

Process measures of secured appointment at time of discharge, time to follow-up appointment, attendance to initial appointment, inquiry regarding patients' understanding of diagnosis, and attendance to additional appointments were abstracted. Outcome measures of event frequency, understanding of diagnosis, engagement with a mental health provider, adherence to treatment plan, employment status, driving status, and health care utilization were assessed. Understanding of diagnosis was defined as the patient being able to articulate his or her insight that the events were not due to epilepsy or seizure. Reduced event frequency was defined as a >50% decrease in events; event freedom was also noted. Improved employment status was defined as transitioning from unemployed outside the home to employed outside the home. All data were gathered from the electronic medical record and abstracted through a RedCap standardized template to create a RedCap database[24].

2.4 Statistical Analysis

Statistical analysis was performed with Stata version 14.0. The chi-square test, Fisher exact test and Wilcoxon rank sum test were used as appropriate, based on variable attributes and distribution, to compare clinical characteristics and outcomes of the two cohorts. Univariate logistic regression was applied to the full study sample to investigate predictors of improved event frequency as well as predictors of attendance to the follow-up appointment. Multiple logistic regressions were not performed due to the absence of significant associations with univariate analysis. In the instances of missing data, we performed complete case analysis. Significance was defined as $p < 0.05$

3. Results

We identified 178 patients who met the inclusion criteria for the study period. The median age of the population was 40 years (interquartile range 29–48) and 80% percent of the population was female. While 73% of patients had a history of psychiatric disease, only 40% of patients were under the care of a psychiatrist at baseline. A history of physical, sexual, or emotional abuse was reported by 17% of patients. At time of diagnosis, 30% of patients had psychogenic events for more than 5 years and 78% of patients were being treated with antiepileptic medication. Twenty- six percent of patients reported employment outside of the home.

There were 55 patients in the pre-intervention cohort and 123 patients in the post-intervention cohort. No differences were observed in demographic characteristics between the two cohorts except for a difference in duration of disease, which was found to be greater in the post- intervention cohort (see Table 1).

Elements of care during the EMU hospitalization that were potentially related to the outcomes of interest were similar between cohorts, namely completion of inpatient

psychiatry consultation (33% vs. 41%, $p=0.31$) and recommendation of antiepileptic medication discontinuation (69% vs. 59%, $p=0.26$).

Our intervention was successful in improving the process measures of securing follow-up appointments by the time of patient discharge and decreasing the wait to follow-up appointments (see Table 2). Furthermore, more patients in the post-intervention group were explicitly asked about their understanding of the diagnosis. However, our intervention did not increase follow-up appointment attendance.

Clinical outcomes were similar for the pre-intervention and post-intervention cohorts at the time of follow-up with no difference in expressed understanding of PNES diagnosis, establishment of care with a psychiatrist or psychologist, adherence to antiepileptic medication recommendations, or improved event frequency (see Table 3). The only statistically significant difference was fewer patients were driving at the time of the follow-up appointment in the post-intervention cohort, which most likely relates to a change in reporting practices over this time period.

Our intervention did not significantly impact follow-up attendance or clinical outcomes, thus we performed an exploratory analysis to consider which factors might improve clinical outcomes and could be targeted in future programs. As the two cohorts were similar in baseline characteristics and outcome measures, these cohorts were combined to investigate determinants associated with improved event frequency. Understanding the diagnosis of PNES increased the odds of reduced event frequency by 3.75 but did not reach statistical significance ($p=0.14$, 95% CI 0.60–23.25). Recommendation of antiepileptic medication discontinuation while in the EMU was significantly associated with event freedom (OR 6.91, 95% CI 1.34–35.52, $p<0.01$). None of the other potentially modifiable factors were associated with improved event frequency (Table 4).

Further analysis of predictors showed attendance to follow-up appointment was not associated with age, gender, psychiatric comorbidity, engagement with psychiatry at baseline, treatment with antiepileptic medication at baseline, inpatient psychiatric consultation, or recommendation to discontinue antiepileptic medication. A history of abuse was significantly associated with decreased odds of attending follow-up (OR 0.37, 95% CI 0.14–0.95, $p=0.03$). There was a trend towards decreased odds of follow-up attendance with increased duration of illness (OR 0.54, 95% CI 0.27–1.11, $p=0.09$).

4. Discussion

This study evaluated an initiative to sustain the patient-provider relationship after diagnosing PNES in the EMU. Despite deliberate provision for ongoing involvement through explicit recommendation and scheduling of follow-up appointments, this relationship was infrequently established as only about a third of patients ultimately attended clinic.

Outpatient follow-up after discharge from hospitalization can be challenging in general[23]. While patients with PNES are commonly lost to follow-up in research studies[17], follow-up in neurology clinic after diagnosis has not been well-characterized. One study found only 47% of those who reported a willingness to follow-up actually did follow-up with their

neurologist[7]. Though we anticipated low clinic attendance, it was unexpected that purposeful planning and discussion of continuity of care with patients would have no measurable impact on attendance. Two subgroups in particular were even less likely to follow-up with neurology, those with a history of abuse and those with a longer duration of PNES; these patients may warrant special attention in development of their treatment plans. Fifty-eight percent of patients who followed up in our study had successfully engaged a mental health provider at the time of follow-up, consistent with previously observed engagement by patients referred for functional disorders[25]. Failure to engage with a mental health provider was due to absence of a formal recommendation at the time of EMU discharge, patient refusal, or scheduling challenges; at least 20% of these patients reported difficulty with mental health provider availability or insurance coverage.

Implementation of our follow-up program did not significantly increase the number of patients with improved event frequency. For the combined cohort, event freedom was achieved for 27% and reduced event frequency was achieved for 59% at an average follow-up of 43 days. These rates are similar to previously published data; event-freedom has been reported as 35–50% at three months from PNES diagnosis[26,27] and event reduction has been observed in 36–74% of patient with PNES at three months to nine months of follow-up[10,27,28]. Although our period of follow-up was brief, prior studies have shown that communication of the PNES diagnosis alone can have a profound and immediate impact. In one study, close to 90% of patients who achieved event freedom reached this mark right after receiving their diagnosis, although several patients then relapsed[27]. In fact, event freedom may actually decrease with time out from diagnosis[29]. Therefore a short follow-up period can capture the largest effect of an intervention though obviously cannot measure sustainability.

Several predictors of positive outcome for patients with PNES have been identified and include higher educational status, being accompanied to clinic visits, younger age of onset, less dramatic symptomatology, and shorter diagnostic latency[17,26,29]. We were interested in identifying potentially modifiable factors and found 1) a non-significant association between understanding of diagnosis and event reduction, and 2) a significant association between recommendation of antiepileptic medication discontinuation and event freedom. A study of 84 patients with PNES interviewed about their understanding and reaction to their diagnosis after psycho-educational intervention found that while understanding was not correlated with event freedom, patients' reaction to the diagnosis was correlated. In this study, patients with angry and/or confused reactions were more likely to have ongoing events[30]. This discrepancy in findings between our study and the interview-based study could be due to a difference in the timing or the language of inquiry. Regardless, both studies clearly support the critical role of patient perception of diagnosis and this finding has been further substantiated in qualitative investigations[8,9]. The positive impact of recommending antiepileptic medication discontinuation on event frequency is more complex to interpret. The most common reason to continue antiepileptic medication for a patient diagnosed with PNES is that each unique event type has not been captured on video EEG and therefore epilepsy has not been ruled out. However the recommendation to discontinue antiepileptic medication may have therapeutic benefit, in giving the patient a concrete action toward recovery or in simply affirming the diagnosis. Therefore if the clinical suspicion of

PNES alone is high, we may be doing a disservice by allowing antiepileptic medication continuation.

While patients with PNES can benefit from longitudinal therapy and support[8,9,31], our data demonstrates that due to unreliable follow-up the inpatient visit is a critical window of opportunity. Furthermore, the priority during hospitalization likely should be facilitation of patients' understanding of their diagnosis. How to best accomplish understanding and acceptance warrants further study and innovation. Inpatient psychiatric consultation is not routinely performed for patients diagnosed with PNES and the benefit is unclear with regard to mood disorder diagnosis and treatment. However, there may be unmeasured benefit of psychiatric consultation in supporting the PNES diagnosis and assisting with transition of care[32]. While additional inpatient attention is costly, the profound utilization of resources by patients with PNES after diagnosis suggests that a potentially preventative investment in the inpatient setting may be worthwhile[16].

The most notable limitation to this study is that clinical outcomes were only obtained for patients who attended follow-up. It is not known whether failure to attend follow-up means patients are doing well or poorly, and therefore our findings cannot be generalized to the entire population of patients diagnosed with PNES. However this bias should apply equally to the pre-intervention and post-intervention cohorts. As any follow-up appointment, no matter how remote from EMU discharge, was reviewed, there is length time bias that favors follow-up attendance in the pre-intervention cohort. Scheduling follow-up with either the patient's outpatient neurologist or nurse practitioner may have weakened our intervention, however this is the standard scheduling practice for all patients discharged from the EMU at our epilepsy center. The information captured during follow-up appointments focused on mental health care services and event frequency. In future evaluations, it would be beneficial to collect additional measures of clinical outcome such as a measure of health related quality of life[33].

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Highlights

- We initiated standard neurology follow-up for patients diagnosed with PNES in the EMU
- Despite provision for continuity of care, only 37% of patients attended follow-up
- Just over half of patients who followed-up had engaged a mental health provider
- Due to poor follow-up, the inpatient visit is a key opportunity to impact prognosis

Table 1

Demographic and clinical characteristics at hospitalization

	All patients N=178	Pre-intervention N=55	Post-intervention N=123	p value
Age, median (IQR)	40 (29–48)	38 (29–46)	41 (28–50)	0.28 ^a
Female gender (%)	142 (80%)	46 (84%)	96 (78%)	0.39 ^b
Psychiatric comorbidities present ⁺ (%)	130 (73%)	36 (65%)	94 (76%)	0.13 ^b
		<i>Mood d/o 33</i>	<i>Mood d/o 81</i>	
		<i>PTSD 2</i>	<i>PTSD 12</i>	
		<i>Psychotic d/o 1</i>	<i>Psychotic d/o 11</i>	
		<i>Other 17</i>	<i>Other 45</i>	
History of physical, sexual, or emotional abuse (%)	30 (17%)	6 (11%)	24 (20%)	0.16 ^b
Engaged with psychiatry [*] (%)	60/149 (40%)	16/46 (35%)	44/103 (43%)	0.36 ^b
Duration of disease >5 years [*] (%)	51/168 (30%)	9/49 (18%)	42/119 (35%)	0.04 ^a
On AED(s) (%)	139 (78%)	43 (78%)	96 (78%)	0.98 ^b
		<i>>1 AED 20</i>	<i>>1 AED 56</i>	
Employed outside the home [*] (%)	30/116 (26%)	7/33 (21%)	23/83 (28%)	0.47 ^b

Abbreviations: IQR = interquartile range, d/o = disorder, PTSD = post-traumatic stress disorder, AED = antiepileptic drug

^aWilcoxin Rank Sum,^bchi-square,^cFisher exact⁺not mutually exclusive^{*}data not available for all patients (denominator specified)

Table 2

Intervention process measures

	Pre-Intervention N=55	Post-Intervention N=123	p value
Follow-up appointment scheduled (%)	43 (78%)	105 (85%)	0.24 ^b
Follow-up appointment secured by time of EMU discharge (%)	1 (2%)	44 (36%)	<0.001 ^c
Time from EMU discharge to follow-up appointment in days, median (IQR)	46 (23, 77)	29 (19, 39)	0.001 ^a
Did not attend follow-up appointment (%)	34 (62%)	78 (63%)	0.84 ^b
	<i>No show 8</i>	<i>No show 32</i>	
	<i>Cancellation 14</i>	<i>Cancellation 28</i>	
	<i>Not scheduled 12</i>	<i>Not scheduled 18</i>	
Attended follow-up appointment (%)	21 (38%)	45 (37%)	0.84 ^b
During follow-up appointment, explicitly asked if diagnosis was understood (%)	8/21 (38%)	30/45 (67%)	0.03 ^b
Attended second neurology appointment (%)	11 (20%)	22 (18%)	0.74 ^b

Abbreviations: EMU = epilepsy monitoring unit, IQR = interquartile range

^aWilcoxin Rank Sum,

^bchi-square,

^cFisher exact

Table 3

Outcome measures at follow-up neurology appointment

	Pre-Intervention N=21	Post-Intervention N=45	p value
Reported an understanding of diagnosis when asked (%)	6/8 (75%)	25/30 (83%)	0.62 ^c
Engaged with psychiatrist or therapist at time of follow-up appointment (%)	12 (57%)	26 (58%)	0.96 ^b
Not engaged with psychiatrist or therapist at time of follow-up appointment (%)	9 (43%)	19 (42%)	0.96 ^b
	<i>Not recommended 4</i>	<i>Not recommended 4</i>	
	<i>Scheduling issues 1</i>	<i>Scheduling issues 5</i>	
	<i>Unknown 4</i>	<i>Not interested 3</i>	
		<i>Unknown 7</i>	
Adhered to recommendation to come off AED(s) (%)	10/19 (53%)	27/37 (73%)	0.13 ^b
Reduction (>50%) in event frequency at follow-up appointment [*] (%)	8/17 (47%)	25/39 (64%)	0.23 ^b
Event freedom at follow-up appointment [*] (%)	2/17 (12%)	13/39 (33%)	0.11 ^c
Driving at time of follow-up appointment [*] (%)	7/16 (44%)	4/36 (11%)	0.02 ^c
Employment status improved from EMU to time of follow-up appointment [*] (%)	0/15 (0%)	2/32 (6%)	1.00 ^c
Utilization of health care from EMU to time of follow-up appointment (%)	1/21 (5%)	5/45 (11%)	0.66 ^c

Abbreviations: AED = antiepileptic drug, EMU = epilepsy monitoring unit

^b chi-square,

^c Fisher exact

^{*} data not available for all patients (denominator specified)

Table 4

Univariate odds of improved event frequency

	Event Reduction (>50%)		Event Freedom	
	OR (95% CI)	p value	OR (95% CI)	p value
Inpatient psychiatry consult	1.44 (0.46–4.54)	0.53	1.97 (0.58–6.68)	0.28
Recommended change to AED(s)	1.19 (0.37–3.87)	0.77	6.91 (1.34–35.52)	<0.01
Understanding the diagnosis of PNES	3.75 (0.60–23.25)	0.14	3.38 (0.35–32.64)	0.25
Engaged with psychiatrist or therapist at time of follow-up appointment	0.60 (0.20–1.83)	0.37	0.58 (0.18–1.93)	0.38
Adhered to recommendation to come off AED(s)	0.64 (0.18–2.31)	0.49	0.91 (0.25–3.36)	0.89

Abbreviations: OR = odds ratio, CI = confidence interval, AED = antiepileptic drug