Original Article

Functional Neurological Symptom Disorders in a Pediatric Emergency Room: Diagnostic Accuracy, Features, and Outcome

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ABSTRACT

BACKGROUND: In children, functional neurological symptom disorders are frequently the basis for presentation for emergency care. Pediatric epidemiological and outcome data remain scarce. **OBJECTIVE:** Assess diagnostic accuracy of trainee's first impression in our pediatric emergency room; describe manner of presentation, demographic data, socioeconomic impact, and clinical outcomes, including parental satisfaction. **METHODS:** (1) More than 1 year, psychiatry consultations for neurology patients with a functional neurological symptom disorder were retrospectively reviewed. (2) For 3 months, all children whose emergency room presentation suggested the diagnosis were prospectively collected. (3) Three to six months after prospective collection, families completed a structured telephone interview on outcome measures. **RESULTS:** Twenty-seven patients were retrospectively assessed; 31 patients were prospectively collected. Trainees' accurately predicted the diagnosis in 93% (retrospective) and 94% (prospective) cohorts. Mixed presentations were most common (usually sensory-motor changes, e.g. weakness and/or paresthesias). Associated stressors were mundane and ubiquitous, rarely severe. Families were substantially affected, reporting mean symptom duration 7.4 (standard error of the mean ± 1.33) weeks, missing 22.4 (standard error of the mean ± 5.47) days of school, and 8.3 (standard error of the mean ± 2.88) of parental workdays (prospective cohort). At follow-up, 78% were symptom free. Parental dissatisfaction was rare, attributed to poor rapport and/or insufficient information conveyed. **CONCLUSIONS:** Trainees' clinical impression was accurate in predicting a later diagnosis of functional neurological symptom disorder. Extraordinary life stressors are not required to trigger the disorder in children. Although prognosis is favorable, families incur substantial economic burden and negative educational impact. Improving recognition and appropriately communicating the diagnosis may speed access to treatment and potentially reduce the disability and cost of this disorder.

Keywords: functional neurological disorders, somatoform disorders, conversion disorder, medical education, emergency

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Introduction

Somatic complaints without a medical explanation are encountered frequently in pediatric primary care clinics (15% to 50%),[1-3] placing considerable demands on time and resources.[4] There is considerable variation regarding nomenclature for these symptoms. Terms based on presumed etiology (psychogenic and hysteria) are problematic as they imply a purely psychiatric process and may be perceived as dismissive or insensitive.[5-7] Others have argued for the use of "dissociative states." This term

suggests a specific but unproven mechanism related to a lack of integration of actions and motivations.[5] "Medically unexplained" is accurate but implies diagnostic uncertainty, suggesting the need for continued diagnostic testing.[6] Historically, the Diagnostic and Statistical Manual of Mental Disorders (DSM) classified these symptoms as somatoform disorders. DSM-5 proposes the category of somatic symptom disorders with the synonymous terms "conversion disorder" and "functional neurological symptom disorder" to describe this condition.[5,8] We adhered to this current nomenclature because it implies a mechanism (changes in brain function) without claiming a particular etiology.[5]

This study grew from the authors' perception that children with functional neurological symptom disorder frequently present to the emergency room and use substantial health care resources, but little epidemiological or outcome data exist to guide management. The published frequency of this disorder in childhood varies widely, from 1-4:100,000 in the United Kingdom and Australia[4,9] to 1:1,000 in Germany.[10] In contrast, it makes up a sizeable fraction of consults for neurologists. Across diverse types of clinics—general neurology,[11] epilepsy,[12] neuromuscular, and movement disorders[13]—functional neurological complaints represent 5-20% of patient visits. Of adults admitted to neurology inpatient units, 9% are later found to have a functional etiology.[14] Functional neurological symptom disorder represents 15% of pediatric psychiatry visits (in urban India[15]), but no comparable data exist for other populations. It is unknown how frequently children present for subspecialty or emergency room care, making it difficult to develop management and treatment plans specifically geared toward these settings.

For any disorder, understanding the local demographics, risk factors, manner of presentation, and prognosis is fundamental to establishing effective treatment programs. Improved institutional information about children with functional neurological symptom disorder may speed diagnosis and referral for appropriate mental health treatment.

One faces methodological challenges when diagnosing functional neurological symptom disorder in childhood, e.g., the lack of developmentally appropriate diagnostic interviews; the necessity to seek out and integrate multiple sources of information[4]; the perceived need to "exclude" organic causes[16,17]; and physician and/or family discomfort with the diagnosis. By describing diagnostic accuracy, demographic characteristics, phenomenology of presentation, management practices and clinical outcomes, we hope to facilitate faster diagnoses and improved outcomes in this poorly understood childhood disorder.

Patients and Methods

Our Institutional Review Board approved this study as a quality improvement project and waived the need for patient consent. We assessed two distinct patient cohorts, one retrospectively and one prospectively collected. We set a low bar for inclusion in our prospectively collected data set (the clinical impression of a trainee) and a high bar for inclusion in our retrospective data set (the final diagnosis by supervising clinicians). To determine diagnostic accuracy of neurology trainees, we compared the initial diagnostic impression of trainees with the final diagnosis of neurology and psychiatry attending physicians. Six months after final case collection, all cases were reviewed to ensure that no other diagnosis could better explain the presenting symptoms.

The retrospective cohort was a subset of all inpatient psychiatry consultations observed at Boston Children's Hospital, a 395-bed tertiary medical center, from spring 2010 to spring 2011. Patients were included when diagnosed with functional neurological symptom disorder by both neurology and psychiatry supervising clinicians. To determine accuracy, we reviewed neurology emergency room consultations to ascertain whether trainees considered a functional neurological disorder. Stringent criteria were established before conducting this review; the trainee must have used one of the following words and/or phrases in the assessment and/or plan: somatoform, psychogenic, functional, nonorganic, conversion disorder, nonepileptic seizure, or astasia-abasia. Such statements in other parts of the note, documentation of functional examination findings, or later inclusion of functional neurological symptom disorder by attending physicians were insufficient to meet threshold.

The prospective cohort was accrued consecutively >12 weeks (October 2012-January 2013). We requested that neurology trainees log emergency room cases in which functional neurological symptom disorder was suspected in the differential diagnosis (Fig 1). To assess diagnostic accuracy in the prospective cohort, residents' initial diagnostic impressions were compared with the final diagnosis of neurology and psychiatry attending physicians (in the emergency room; following admission; at outpatient follow-up; or during inpatient psychiatric stay). For patients with extramural neurologists, we contacted those providers to determine their final diagnosis. For patients who had both neurology and psychiatry visits, the diagnostic impression of psychiatry was also assessed.

Data collected in the prospective series included demographics, nature of symptoms, preexisting medical and/or psychiatric diagnoses, reported stressors, diagnostic procedures performed (computed tomography, magnetic resonance imaging, electroencephalography [EEG], or lumbar puncture), and mental health-related interventions. Patients were assigned to functional neurological symptom disorder subgroups based on DSM-5 criteria[8] to determine manner of presentation.

Clinical outcome and parental satisfaction in the prospective series were determined by a structured telephone interview (Appendix 1) administered to families and patients in combination with chart review. Patients were contacted between 3 and 6 months after initial presentation in the emergency department (mean, 22 weeks; range, 13-37). Follow-up data included duration of residual symptoms, total number of emergency room visits, missed school days and parental days of work, alleviating factors, presence of and satisfaction with outpatient mental health providers, and additional tests done outside the initial hospital visit. Families rated their satisfaction with the neurology consultation in a Likert-scale and suggested improvements.
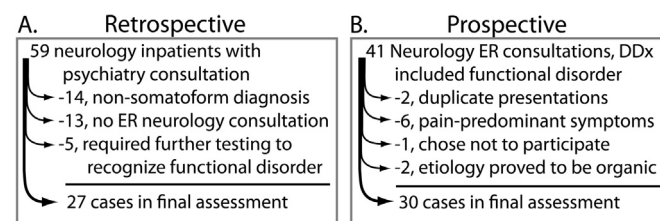
FIGURE 1.
Patient ascertainment and selection. (A) Retrospective: Exclusion criteria included presentation for nonfunctional psychiatric signs (e.g. psychosis), patients without antecedent neurology ER consultation, and patients whose functional neurological signs were identified only by subsequent (post-ER) testing. (B) Prospective: Where second presentations during the study period were present, only the first presentation was used for analysis. Exclusion criteria included patients with pain as the primary symptom (e.g., headaches) and refusal to participate. Patients with an organic diagnosis were excluded for demographic, prognostic, and treatment data, but retained in calculations for assessing diagnostic accuracy. ER = Emergency room; DDx = Differential diagnosis.

Results

Diagnostic accuracy

In the retrospective cohort, the diagnostic consideration of functional neurological symptom disorder of a trainee predicted the final diagnosis by attending neurologists and psychiatrists in 93% (25 of 27 cases). In the prospective cohort, attending neurologists and psychiatrists confirmed the initial diagnostic impression of neurology trainees in 94% (31 of 33 cases; Fig 2). Cases were reviewed at 4-43 months after presentation; no diagnoses of functional neurological symptom disorder were overturned, and no subsequent conditions arose that could better explain their symptoms.

Clinical characteristics

Patients with functional neurological symptom disorder received emergency neurology consultations 2.6 times per week during our prospective case collection. Demographic characteristics of both series can be observed in Fig 2A. Patients used health care at a high rate, with 48% (15/31) receiving brain and/or spine magnetic resonance imaging, and 39% (12/31) receiving neurophysiological studies. Eighty percent of EEGs were followed by a repeated EEG. Thirty-five percent (11/31) received mental health consultation during their visit, typically during the medical admission. Of note, for both retrospective (14/27) and prospective (15/31) series, half of these patients presented outside the 8 am-11 pm period when child psychiatry consultation is available in our emergency room. Reported stressors can be observed in Fig 3. Mixed-subtype presentations were most common (usually combined anesthesia, paresthesia, and focal paresis), followed by nonepileptic seizures (Fig 4).

Clinical outcomes

Data were available for 30 of 31 patients of the prospective cohort (Fig 2B). Symptom duration and other clinical data were capped at the time of follow-up (mean, 23 weeks; standard error of the mean ± 1.36; range, 13-37), with symptom resolution in 83% (25/30).

Parental satisfaction

At the end of our structured follow-up questionnaire, families were asked about satisfaction and any suggestions for improvement. Parents frequently offered more than one suggestion, and these were coded by study coordinators into subcategories (Fig 5). Parents reported being "very satisfied" or "satisfied" with their emergency room neurological care in 86% of cases (26/30). However, even this "satisfied" group made many suggestions for improvement, with a majority expressing the need to improve communication with health care providers. Thirty percent (9/30) reported receiving inadequate information about functional disorders and insufficient help in finding mental health resources. Seventeen percent (5/30) felt abandoned, with providers not spending enough time, and 16% (5/30) felt clinicians did not establish good rapport at the time of initial diagnosis. These feelings were reported more frequently in the families that

A	Retrospective mean (range)	Prospective mean (range)
n =	27	31
Age	14.1y (8-20y)	14.8y (8-21y)
Age >18y	1/27	3/31
Age < 13y	5/27	7/31
Gender	74% F	67% F
Admitted to Hospital	100%	38.7%
Diagnostic Accuracy	93%	94%

| B	Prospective Cohort Only	
Persistent symptoms at follow-up	17% (5/30)	
Neurologic comorbidity	50% (15/30)	
Psychiatric diagnosis	30% (9/30)	
	mean	range
Symptom duration	52 +/- 7days	1-210 days
Number of ER visits	2.1 +/- 1.5	1-6
School days missed	22.4 +/- 30	0-120*
Parental work days missed	8.3 +/- 16	0-60$^{\tau}$

FIGURE 2.
Clinical characteristics and outcomes. (A) Demographic information for retrospective and prospective patients. (B) Prognostic and descriptive information for prospective patients. Neurological comorbidities (15 cases) were varied and ranged from migraines (five cases), neurodevelopmental disabilities (four cases), demyelinating disease (three cases), epilepsy (one case), cerebrovascular malformation (one case), and neurofibromatosis (one case). Psychiatric comorbidities (nine cases) most commonly included anxiety and/or depression. *, One patient dropped out of college. τ, One parent lost his job, and two parents stopped their job search, as a result of their child's symptoms.

expressed dissatisfaction; nevertheless, they were present even in those that were satisfied with their care. This discrepancy suggests that parental responses might have been skewed by attempting to please interviewers and not reporting their actual level of (dis)satisfaction.

Discussion

This clinical study suggests that neurology trainees' diagnostic impression was accurate in predicting the later
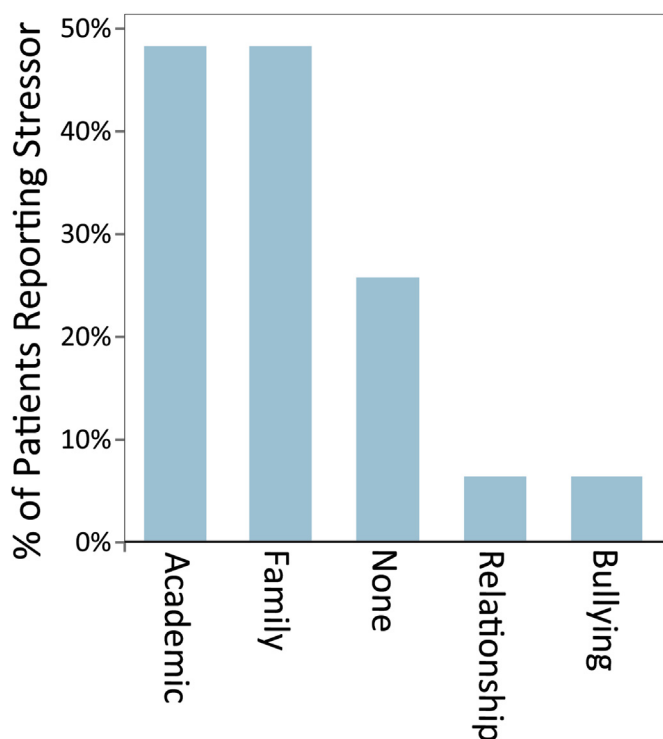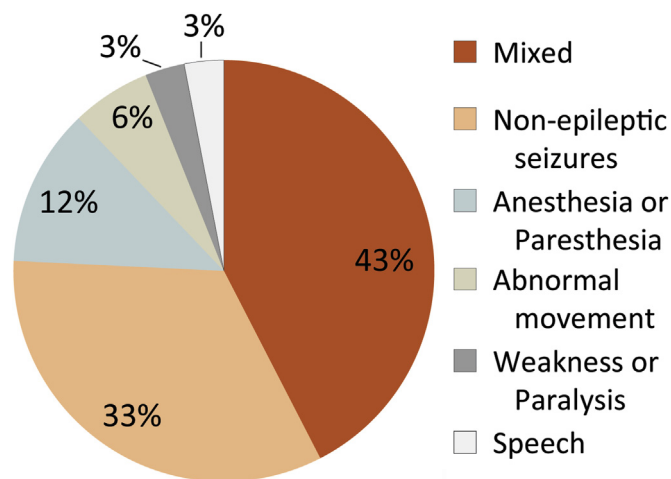
FIGURE 3.
Frequency of reported stressors. Stressors classified according to extant literature. Some patients reported multiple stressors. No instances of physical or sexual abuse were elicited. (Color version of this figure is available in the online edition.)
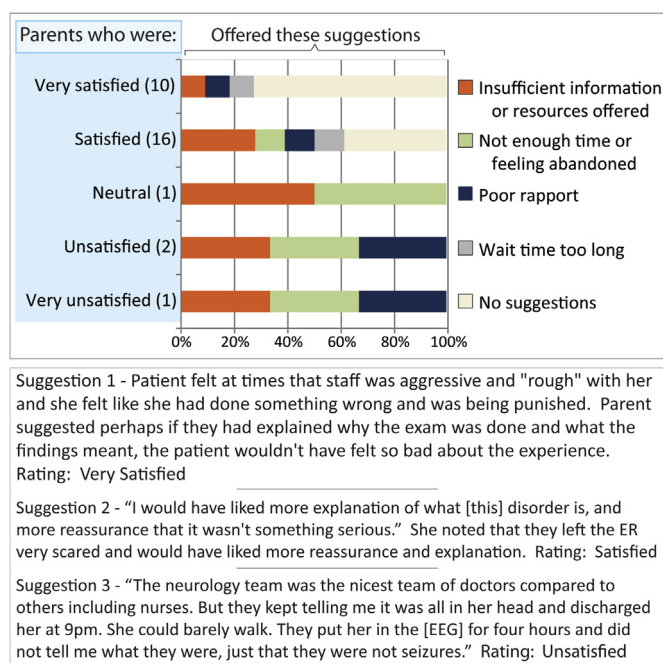

FIGURE 4.
Phenomenology of presentation. The manner of functional presentation in our prospective cohort was similar to that previously reported, with a high percentage of mixed and nonepileptic seizure semiologies. (Color version of this figure is available in the online edition.)

diagnosis of a functional neurological symptom disorder in 93-94% of patients. This was demonstrated using both prospectively and retrospectively collected cases and remained consistent when the basis of inclusion was the final diagnosis of an attending physician or the initial impression of a neurology trainee. In the two prospective cases that proved to have organic causes (complex partial seizure and epidural abscess), testing recommended during the neurology consultation led directly to these diagnoses. Care was not delayed in either case by inclusion of functional neurological symptom disorder in the differential diagnosis. No patients were later diagnosed with a disorder that could better explain their symptoms.

This level of accuracy is similar to that previously demonstrated in adults[18-20] and in one pediatric series.[21] This point is particularly relevant to outcomes in children, where delays in diagnosis predict treatment failure.[22] Early recognition and treatment of functional neurological symptom disorder leads to resolution or substantial improvement in 80-90% of childhood sufferers[23-25] in contrast with adults (refractory in two thirds of patients[26]).

This study also confirms findings that have been previously demonstrated in childhood functional neurological symptom disorder: it is highly disruptive to school and parental work and it consumes substantial health care resources. In spite of these negative features, short-term prognosis (3-6 months) appears quite good. This is consistent with previous findings that functional neurological symptom disorder in children tends to be brief and have a substantially better prognosis than in adults.[25] Although

this study was not designed to assess the absolute or relative frequency of childhood functional neurological symptom disorder, with almost three patients presenting to our emergency room per week, it appears to be a common reason for emergency neurological consultation in our hospital.

In several important ways, however, these childhood cases do not conform to the historical model of functional neurological symptom disorders. First, our patients did not report severe stressors. No instances of physical or sexual abuse were identified. It is important to note that the emergency room is a less-than-ideal setting for eliciting such histories of trauma, and a thorough evaluation with standardized questionnaires was not feasible. It is possible, therefore, that some stressors may have gone undetected. Nevertheless, 25% (8/31) of these patients denied even common and mundane stressors, concordant with similar findings in adults, emphasizing the role of other genetic and biologic susceptibilities.[27] Second, prior psychiatric diagnoses (29%) were less common than neurological comorbidities (48%). All patients who denied the presence of stressors also lacked a prior psychiatric comorbidity. Clinicians holding to the historical model that one must uncover a preexisting psychopathology or psychological stressor to validate the diagnosis of functional neurological symptom disorder would therefore have missed at least a quarter of patients in our study. There was not a clear pattern of symptom automimicry—functional neurological symptoms were generally distinct from any preexisting neurological diagnoses. Finally, the most common presentation was mixed sensory motor, similar to prior reports from the United Kingdom, Ireland, and Australia[9,28] and contrasting with epidemiologic data from other nationalities: paralysis (Singapore),[29] nonepileptic seizures (Turkey),[30] or syncope (India).[31]

In our experience, clinicians often treat functional neurological symptom disorder as a "diagnosis of exclusion," not to be accepted until all other potential diagnoses have been exhaustively evaluated. In contrast, the present

FIGURE 5.
Parental satisfaction and suggestions for improvement. At 3-6 month follow-up, parents were asked to suggest ways to improve the ER care provided by neurology residents. Upper panel: suggestions for improvement organized by level of parental satisfaction with the neurology ER consultation. The number of families giving each rating is indicated in parentheses. Parents frequently offered more than one type of suggestion. Lower panel: three representative suggestions are provided, edited for length and to preserve patient privacy. It is notable that none of these suggestions cite disagreement with the diagnosis; rather, all wished for better communication about the methods of diagnosis and the prognosis of functional neurological disorder. EEG = Electroencephalography; ER = Emergency room. (Color version of this figure is available in the online edition.)

study suggests that clinical assessment is accurate in assessing this disorder in childhood. The diagnosis should be considered when suggestive physical examination findings are noted (e.g., Hoover's sign,[32] entrainment of tremors,[33] forced eye closure during nonepileptic seizures,[34] tunnel vision,[35] and astasia-abasia[36]) and/or historical elements not consistent with neurological disease are elicited (e.g., preserved consciousness during a generalized seizure). It should not be made simply because results of investigations are normal, the symptoms are unusual, or the patient has a prior psychiatric history. We believe that such a careful clinical examination is well within the capacity of pediatric and emergency medicine physicians, if recognition of functional neurological symptom disorder has been a part of their training.

Such educational efforts are especially important in areas without access to child neurology and psychiatry consultation in the emergency room. Since early diagnosis of functional disorders is associated with substantially improved prognosis,[23-25] involvement of emergency room providers will be critical in improving the systems of care for these children.

One limitation of our study lies in the possibility that the retrospective and prospective phases are not comparable. Retrospective data were assembled from psychiatry consultations after hospital admission. In contrast, case ascertainment in our prospective cohort occurred in the emergency room, with less than half being admitted to the hospital. Similarly, patients in our retrospective cohort presented 1 year before our prospective collection, with each group evaluated by overlapping but distinct groups of trainees. Therefore, it is conceivable that the two groups were embedded in different clinical contexts or were subject to differing clinical decision-making schemas. In light of these potential confounding factors, we limited our comparison of both cohorts to a single feature: diagnostic accuracy. In spite of these differences, the demographic data for our two groups were very similar (Fig 2), suggesting that our data sets are indeed comparable.

Finally, the strength of our conclusions is limited by our small sample size. However, our primary finding—the diagnostic accuracy of neurology trainees—is bolstered by the combination of independent prospective and retrospective groups of patients. Replication of these results in a larger sample is necessary to generalize our findings.

Our study identified two practice deficiencies that, if corrected, will allow us to advance the care of patients with functional neurological symptom disorder. First, on follow-up interview, one third of parents (10/30) reported receiving too little information about their diagnosis and/or inadequate resources. The importance of adequately communicating the diagnosis cannot be overemphasized and may in itself have therapeutic value.[37,38] Second, specific treatment was offered to a small percentage of patients. Only 53% (16/30) of our prospectively collected patients with a formal diagnosis went on to utilize mental health services, and 6% (2/30) had physical therapy. Pharmacologic[39] and cognitive behavioral therapies[40,41] have been suggested to be effective, and physical therapy has demonstrated efficacy with motor symptoms,[42] but no data exists to predict which children might require such interventions.

One reason these care deficiencies exist is a lack of training in the recognition and management of functional neurological symptom disorder. In our training program, we developed curricula specifically to address this knowledge gap. In addition to lectures, every resident takes part in workshops to improve physician-patient-parent communication regarding functional disorders. These sessions use live interaction with professional actors, followed by structured feedback. A second reason for these care deficiencies is the absence of standardized management plans. We have implemented a stepwise approach to care that guides clinicians in evaluation and referral to mental health services. These guidelines are especially important when patients are unable to see psychiatry in the emergency room, including half of the patients in our series.

A final and more complex reason for these deficiencies is the scarcity of mental health resources in our communities, both the lack of professionals who treat children and of structures that link primary physicians, neurologists, and mental health providers. A neurologist's recommendation to seek out mental health services is ineffectual if families cannot find providers in their area. As a corollary, it is important to note that not all patients with functional neurological symptom disorder require intervention by mental health, and premature referral without adequate

communication may further stigmatize their condition. Some patients may feel psychological treatment to be unacceptable and benefit from guidance and self-help.[40] Patients with predominant motor symptoms may improve with a physical therapy program within a cognitive-behavioral framework.[42] The neurologist's role is important in making the diagnosis, coordinating care, and appropriately referring patients depending on individual needs.

As this series demonstrates, patients with functional neurological symptom disorder frequently return for additional emergency room visits, undergo repeated diagnostic testing, and may cause significant parental workday losses. It is our opinion that a more comprehensive, multidisciplinary approach to these patients, with emphasis on rapid diagnosis and increased availability of pediatric providers with expertise or interest in treating functional disorders would deliver both improved clinical care and considerable cost savings.

Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.pediatrneurol.2014.04.009.

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