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Publication Date

2014-08-01

DOI

10.1016/j.yebeh.2014.06.019

Peer reviewed

Published in final edited form as:

Epilepsy Behav. 2014 August ; 0: 145–150. doi:10.1016/j.yebeh.2014.06.019.

Ethical Dilemmas in Pediatric and Adolescent Psychogenic Non-Epileptic Seizures

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Abstract

To date only a very narrow window of ethical dilemmas in psychogenic non-epileptic seizures (PNES) have been explored. Numerous distinct ethical dilemmas arise in diagnosing and treating pediatric and adolescent patients with PNES. Important ethical values at stake include trust, transparency, confidentiality, professionalism, autonomy of all stakeholders and justice. In order to further elucidate the ethical challenges in caring for this population, an ethical analysis of the special challenges faced in four specific domains is undertaken: (1) conducting and communicating a diagnosis of PNES; (2) advising patients about full transparency and disclosure to community including patients' peers; (3) responding to requests to continue anti-epileptic

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Disclosures: 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.

drugs; and (4) managing challenges arising from school policy and procedure. An analysis of these ethical issues is essential for the advancement of best care practices that promote the overall well-being of patients and their families.

Keywords

Diagnosis; Communication; Doctor Shopping; Disclosure; School; Anti-epileptic drugs

1. INTRODUCTION

Psychogenic non-epileptic seizures (PNES) is a remarkably challenging and complex medical condition that gives rise to a number of ethical issues with which even the most skilled clinician struggles [1–3]. Even the terminology used to refer to the diagnosis has sparked substantial debate and can negatively impact the patient’s treatment course [4, 16 – 19].¹ While the literature to date has discussed a small sampling of these issues across patient populations [4–22], it has not examined the unique moral dilemmas involved in the diagnosis and treatment of pediatric and adolescent patients with PNES [3, 22]. Awareness of these ethical challenges can help clinicians address some of the obstacles in the care of young patients with PNES. Potential stigmatization of PNES as well as the uncertainty and sensitive nature of diagnosis and management exacerbate these ethical dilemmas [3, 17, 23–29].

Ethical dilemmas are characterized by conflicting values (beliefs) that are recalcitrant to a resolution that satisfies all stakeholders. Stakeholders often include primary care providers, neurologists, psychiatrists, psychologists, epileptologists, mental health practitioners, nurses, social workers and other members of the treatment team (collectively referred to herein as “clinician(s)”), as well as the young patient, parents, other family members, peers, and school personnel [3]. In an ethical dilemma, a decision must be made by the individual(s) struggling with the dilemma regarding the relative importance of personal and professional values, one value against another. This should be undertaken knowing that concessions are necessary to preserve some values at the cost of other values which are judged to be of lesser importance. The balancing of conflicting values must be informed by the facts, including the patient’s medical condition, corresponding treatment options, and societal conditions. Elements often taken into account during ethical dilemmas include the patient and family’s treatment preferences, developmental stage, psychosocial background, quality of life, applicable laws, institutional policies, professional duties, and other practical stakeholder obligations and responsibilities. Balancing of the values in these dilemmas must be undertaken carefully and accompanied by an argument that provides reasons why one path is more justifiable than another. Although several ethically permissible sets of actions often exist, there are always wrong or poor ways of proceeding. However, with careful reflection and attention, we can avoid the wrong ways of doing things and evaluate how to best balance our values within the set of ethically permissible activities [30–31].

¹We recognize that use of the term “psychogenic non-epileptic seizures” can carry negative connotations for a parent or the young patient, thereby impeding acceptance of the diagnosis. However, using the term “PNES” for this paper allows us to highlight the psychological/psychiatric component and is a well-recognized label for this diagnosis in the literature.

The sections below focus on four specific domains wherein ethical issues arise in the care of children with a PNES diagnosis. A review of the challenges and the specific values implicated are presented in order to provide clinicians an opportunity to appreciate fully the ethical stakes. In turn, clinicians can develop their own ethical analysis to guide their practices as they promote the overall well-being of patients and their families as advisors and caretakers.

2. CLINICAL BACKGROUND AND CHALLENGES

The term PNES refers to seizure-like events that are due to underlying psychological stressors or conflicts rather than epilepsy [32]. The flurry of research over the last decade has advanced clinical understanding of PNES, but this continues to be a field in development, particularly in pediatric and adolescent patients [3, 27–28, 32–48]. Current management recommendations highlight that acceptance of the diagnosis, which depends on the exclusion of epilepsy and other disorders, is a critical first step to successful treatment [3, 28, 48]. In order for the patient and family to accept a PNES diagnosis however, several diagnostic challenges must be overcome [17, 23–24, 45–47]. These challenges serve as the foundation from which many of the ethical issues arise when working with young patients with PNES and their families.

Clinicians need to take a detailed time-consuming history from parents and when possible from the child to identify warning signs suggestive of PNES. These include, among others, an inconsistent seizure history, gradual and slow onset, as well as long duration of seizures and lack of seizure occurrence when the child is alone. Recognizing signs suggestive of PNES is particularly difficult in the 35–44% of patients that have comorbid epilepsy. Clinicians and families must overcome the temptation to focus on “real epilepsy” and ignore the psychological stressors that may also present as seizures [49]. If the patient’s history suggests that PNES is a possibility, then a video-EEG (vEEG) with no epileptiform activity during an on-going seizure and psychiatric assessment with evidence for a conversion disorder confirm the diagnosis.

A second challenge is that the vEEG and corresponding hospital stay necessitate insurance authorization, which is often limited in time and scope. This is particularly problematic because it may take considerable time for the non-epileptic episodes to emerge when in the “peaceful and non-demanding” environment of telemetry units in which children are not faced with the daily academic, social, family, sports, and chores of daily life. Even more troubling is that insurance authorizations might not include comprehensive mental health evaluations while the vEEG is conducted, and pediatric epileptologist/neurologists usually do not have the expertise to conduct these assessments. Conducting the vEEG and mental health evaluation during the same hospitalization prevents additional delays in diagnosis. A thorough mental health evaluation is essential to identify the specific psychological profile of conversion disorder that confirms the PNES diagnosis and the underlying emotional difficulties (e.g., undiagnosed learning or social problems, parenting or family difficulties, stressful competition, and others) that the child is experiencing. Introducing a mental health professional at this point in the diagnostic process may also facilitate acceptance of the diagnosis and corresponding treatment. While mental health resource availability is variable

across the country, advocating for and connecting patients with these resources is vital to promote continuity of care and facilitate understanding and acceptance of the diagnosis [50–52]. The third challenge is that children with PNES and their parents often deny the presence of any problems other than seizures. Parents may be unaware that children’s psychological problems might present as seizures. Sometimes this lack of knowledge about the child’s difficulties stem from the child’s inability to be in touch with his/her emotions and/or subtle language and communication challenges [53]. In other cases, parents struggle to accept or understand the difficulties that their child clearly communicates to them. They might resist recognizing psychological problems related to challenges with learning, social skills, family functioning, sports, and other extracurricular pursuits. Stigma associated with psychiatric disorders may exacerbate a family’s struggle to recognize underlying psychological problems and make a neurological cause, i.e. epilepsy, a more acceptable diagnosis [54]. Penetrating the barrier of “Everything is fine” demands specific interview techniques and expertise [43].

3. ETHICS IN DIAGNOSING AND COMMUNICATING THE PNES DIAGNOSIS

My child has epilepsy and you are telling me that a psychiatrist will cure her seizures?

Establishing a PNES diagnosis and communicating this information to the child and parents creates special challenges related to the values of professionalism, justice, resource utilization, and trust for healthcare providers in relation to patients, families, and other colleagues. The preservation of a therapeutic relationship plays strongly in the values at stake. In addition, clinicians strive to remain transparent, honest, and advocate for getting patients beneficial treatment as quickly as possible.

3.1 A Timely Initial Assessment

A timely diagnosis discharges a clinician’s duty to the patient, their own practice, and the health system. While mental health professionals diagnose and treat PNES [2], neurologists are in the best position to assess patients for possible PNES [27–28, 55]. Many neurologists may not consider PNES early enough in the differential diagnosis process, which can account for the frequent delays in diagnosis. Patients diagnosed with PNES must overcome treatment obstacles arising from inadequate insurance coverage and scarcity of mental health professionals who treat children with PNES. Neurologists may feel an obligation to shield their patients from these burdens by only considering PNES if other potential causes are ruled out. All of these things may lead to a delayed diagnosis and disrupts a patient’s ability to get care, which comes with a substantial burden to the individual patient and the patient’s family [58]. Young patients are at risk for misdiagnosis and cognitive delays as a result of inappropriate medical treatment, e.g. known side effects of some antiepileptic drugs (AEDs) [39]. Diagnosis and treatment at a younger age contributes to an overall better prognosis [3]. Earlier diagnosis also reduces unnecessary doctor’s visits and missed school days [59]. As such, the benefits of considering PNES higher in the differential diagnosis outweigh the perceived burdens.

3. 2 Communicating the Diagnosis of PNES

Once the PNES diagnosis and underlying psychological problems have been ascertained by the neurologist and mental health professional, a communication process relaying the diagnosis in a manner that promotes early acceptance of PNES and the treatment plan is imperative to preserve the best outcome possible for the young patient [3, 22, 40–41, 49]. The roles of the specialists involved in the young patient's care, how the information is communicated, and subsequent follow-up need to be carefully considered in the values tradeoffs that occur. Clinicians strive for a transparent process supportive of individual patient and family values while being appropriate stewards of the system and avoiding unnecessary risk to patients. This process is time-intensive and requires involvement of both the neurology and mental health team members and multiple meetings with the parents and patient [28]. This communication should pay special attention to the connotation of the language being used [16 – 19]. Although we have selected to use PNES as the disease label for this paper, clinical judgment needs to be used in selecting the best descriptor for patients and families that highlights transparency and honesty, with avoidance of stigma and negative emotional response [19].

The psychological nature of the disorder and its treatment underscore the importance of both the pediatric epileptologist/neurologist and mental health care professionals to actively participate in feedback regarding the diagnosis. While PNES is treated by mental health professionals, continued involvement by a neurologist or epileptologist is associated with better outcomes, regardless of the limited direct care provided [22]. Moreover, parents of children with PNES expect to discuss the diagnosis with the pediatric epileptologist/neurologist, and this expectation should be respected.

3.2.1 Delivering Diagnostic Feedback to the Parents and Child: Separately or Together?—Clinicians face trade-offs around providing the diagnostic feedback with patient and parents together or separately. Although circumstances vary in each case, particularly with respect to family dynamics and the child's age, we argue for providing parents and the patient initial diagnostic feedback separately. However, we also recognize limits to this approach that must be considered and balanced. Arguments for separate feedback involve at least four important domains. First, from the developmental perspective, explanation of the diagnosis needs to be done at a level that is commensurate with the child's cognitive and linguistic levels. This is supported by basic value commitments of pediatrics as a profession [60]. Second, parents might misinterpret a PNES diagnosis as suggesting that the child is faking his/her seizures and express anger towards the treatment team and towards the child. These responses can be emotionally harmful for children with PNES, impair their rapport with the treatment team, and make it even more difficult for them to talk about their underlying emotional problems and difficulties. Third, it is essential that in their feedback to the parents and separate feedback to the child both the epileptologist and mental health professional underscore that PNES does not mean faking and that there are different mechanisms for seizures, only one of which is epilepsy. This attempts to mitigate harms to the child if parents wrongly attributing moral blame to the child. Fourth, parents often respond with a sense of guilt that they did not recognize the psychological nature of the child's problems. It is important to let them, as well as the child, know that the

diagnosis of PNES requires professional expertise that they do not have. These steps provide an opportunity for parents and the patient to be in a process of acceptance and minimize the chance of harm from unreflective emotional responses.

The arguments for disclosing with both parents and child together would be primarily based on cultivating trust with patient and parents and between patient and parents through maximal transparency. This is more important in adolescent patients given developmental levels. Including a more mature child in all the conversations is respectful of their emerging independence and autonomy [60].

3.2.2 Follow-Up—After initially relaying the diagnosis and discussing the treatment plan (not discussed in this paper), parents should be asked about their concerns regarding the diagnosis of PNES and how they would like to share this information with family members, friends, and the child’s school. Identifying and addressing underlying concerns promotes engagement by the parents regarding the treatment plan and follow through. A subsequent follow-up meeting should also be scheduled to address any additional concerns that have arisen. The stakes can be high in this phase. The patient may be harmed if parents do not accept the diagnosis. Impressing upon parents the importance of the diagnosis and providing them sufficient opportunity to discuss their concerns discharges a duty to avoid harm.

4. ANTIEPILEPTIC MEDICATIONS (AEDS) IN THE TREATMENT OF PNES

A mother objects to discontinuing AEDs and accuses you of “not providing the care that is medically necessary.”

After communicating a diagnosis of PNES, clinicians with independent prescriptive authority, which in some states may include nurse practitioners or advanced practice registered nurses in addition to physicians, and families may struggle with the choice of withdrawing AEDs for the treatment of young patients for whom the drugs were previously prescribed. The ethical dilemma that the prescribing clinician faces is discontinuing AEDs in a timely manner without losing the trust and confidence of the patient and/or the patient’s parents. In cases where PNES is confirmed as the only seizure disorder, continued treatment with AEDs is unnecessary and could be associated with adverse cognitive and behavioral effects. In a recent survey of 236 neurologists (84% of whom are pediatric neurologists in academic settings), up to 96% of respondents felt confident about discontinuation of AEDs [58]. Yet, approximately 22% of respondents reported parental requests to continue AEDs influenced their decision. This study suggests that professionals in epilepsy care that lack sufficient knowledge about PNES may be more likely to continue AEDs at a parent’s request [58]. These professionals may also be more likely to continue AEDs in order to facilitate acceptance of the diagnosis and/or to prevent a delay in psychological treatment [58]. This alternative, however, can cause a string of ethical and medical problems with lifelong consequences for the patient and family.

A clinician is not obligated to provide medical treatment deemed to be inappropriate or ineffective [61–62]. Even so, a clinician may be concerned that refusing a request to continue AED treatment will result in the family seeking out a clinician who would unquestioningly supply them with requested medicines, i.e. “doctor-shopping.” This risk

may be heightened if parents observe their child's non-epileptic episodes becoming worse. Parents may also wish to continue AEDs as a means to avoid social stigma associated with PNES, particularly at school. Additional factors that may impact a practitioner's decision-making at time of withdrawing AEDs include whether mental health treatment is available and whether the practitioner has sufficient knowledge about PNES [58]. The clinician that complies with a request for continued AEDs risks substantially more harm to the patient and the patient's family. AEDs may have a deleterious impact on the patient's cognitive function and behavioral and mood side effects such as irritability and mood instability [63]. Instead of continuing to prescribe AEDs, exploring the underlying reasons for why the parents want to continue AEDs despite the PNES diagnosis allows the physician to directly address parents' concerns regarding discontinuation.

5. COUNSELING FAMILIES ON COMMUNICATING THE DIAGNOSIS TO INVOLVED CAREGIVERS AND PEERS

School personnel unaware of a student's PNES diagnosis call 911 when the student experiences a seizure at school, resulting in repeated admissions to the emergency department and inappropriate invasive interventions. The student's seizures worsen with each admission.

Patients and their families may turn to clinicians for advice regarding disclosure of PNES diagnosis to third-parties, including school nurses, school administrators, teachers, day care providers, and peers. The clinicians' obligation is to counsel patients and their parents on the conflicting values that are at stake: preserving the patient's and family's privacy, protecting the patient from social stigma and physical harms, and promoting continuity of therapeutic care. The clinician should educate the patient and their family that these values are not easily reconcilable and deciding whether to disclose the diagnosis involves an inherent tradeoff. Ultimately the child's parents or legal guardian, and when appropriate the child, have substantial discretion regarding disclosure. Clinicians should honor their decision and work with the family to mitigate the associated tradeoff.

5.1 The Choice of Non-Disclosure

Families choosing not to disclose a PNES diagnosis may do so to preserve the family's privacy and protect the child from the harms of social stigma. Concerns with disclosing the diagnosis may include under-reaction or even over-reaction to the condition by other adult caregivers, as well as ridicule and bullying by peers. Many children with a PNES diagnosis already have symptoms of other psychiatric comorbidities such as conversion disorder, depression and anxiety [33]. Negative reactions by others could increase the child's symptoms and decrease their self-worth and confidence, ultimately exacerbating the non-epileptic events.

Families need to be aware of the tradeoffs associated with non-disclosure. While respecting a family's decisions, clinicians should ensure that families are aware that continuity of care may be disturbed and the child may be at risk for inappropriate and invasive medical treatment from emergency care if third parties take the patient to an Emergency room [1, 64].² This challenge is particularly important given the potential dissemination of false

medical information that could be entered into the chart through collateral informants. Once this information enters a patient's chart, it opens the possibility to confound health care. Further, a child may struggle reconciling previous lessons "to always tell the truth" with a new directive to not disclose or even lie about their disorder. Parents need to clarify how a strategy of non-disclosure is consistent with broader life philosophies they hope to teach their child. This feeling of deception or withholding by the child may be experienced as a psychological burden.

Some steps may be taken to mitigate these risks. The clinician may provide the family with a school action plan that they can discuss with school personnel in an effort to preserve continuity of care and avoid inappropriate medical treatment, such as AEDs. The child may also be advised to make general statements regarding his or her condition, such as a doctor is helping with his or her events. Families need to understand though that while these actions may help mitigate the tradeoffs, some loss, as described above, cannot be fully eliminated if choosing not to fully disclose the PNES diagnosis to others.

5.2 The Choice of Disclosure

In contrast, disclosing a PNES diagnosis to other caregivers integral to the child's care promotes continuity of therapeutic care and may prevent inappropriate medical interventions when seeking emergency medical care. Families may believe that disclosing the diagnosis promotes the value of truth telling, strengthens the child's self-worth, helps the child to accept the disorder without shame or embarrassment, and is an opportunity to educate others about the disorder in an effort to decrease the prevalence of associated social stigma. Again, full disclosure is not without its tradeoff. As with non-disclosure, clinicians are obligated to educate families that forgoing privacy in favor of continuity of care puts the child at risk of the harms associated with social stigmas as discussed above. Bullying by peers may be verbal or even physical and the reactions from adult caregivers can be particularly detrimental to the child's mental and emotional health. Moreover disclosing a PNES diagnosis to insurance companies may result in lack of coverage for neurological follow-up. Ultimately, disclosure, like non-disclosure, carries the risk of exacerbating the child's PNES. Clinicians should work with families to mitigate these risks.

6. SCHOOL AND FAMILY INTERFACE AND ETHICAL DILEMMAS

A school nurse says “the episodes she is having are not real, why should she get different treatment” in response to an action plan for a student being bullied because of PNES.

6.1 The Need to Override School Procedures

Even after providing the diagnosis, having a care plan in place, and counseling on disclosure, patients and their families face special dilemmas in the school context. Although medical professionals have effectively educated educators about how to respond to epileptic

²It should be noted that the very language of “seizure” in PNES may also have some of these same risks if people wrongly associate these types of seizures with the need to treat as if it were epilepsy. There is always a concern of inappropriate emergency room visits or medications be administered. Addressing the nature of the illness in the school action plan can minimize this risk.

seizures, there continues to be a gap when seizures stem from PNES. This has resulted in a pressing ethical dilemma in the school setting: how to best accommodate care for students with PNES when it requires overriding usual school procedures related to general responses to seizures that use Epilepsy as the paradigm. This needs to be done while still maintaining school safety and not asking educators to extend beyond their scope of expertise. Difficult value choices balance the needs of an individual with PNES against the importance of a uniform response that will benefit patients with epilepsy in the school environment.

While a PNES episode may not have the same etiology as an epileptic seizure, if it manifests behaviorally as a seizure in the judgment of the school observer, school administration often feel obligated to follow school procedures for addressing seizures [65]. In some schools, this includes calling 911 (68% of the twenty-seven school nurses surveyed indicated that this is their school policy); in other schools, the school nurse may be tasked with administering rectal valium [66]. Such procedures can exacerbate triggers that result in new non-epileptic episodes and make effective treatment for PNES more difficult.

Schools working closely with parents and the treatment team need to focus on what should be done for a student whose seizures should not be treated in the way that epileptic seizures are treated. Doing so, however, is not without tradeoffs; efforts to override usual procedures for one child may take substantial resources, both on the part of the school and the clinician. The treatment recommendations can be disruptive and have opportunity tradeoffs for other students, teachers, and support staff. Moreover, schools could risk exposure to liability for failing to follow standard procedures, particularly when the young patient has a co-morbidity of epilepsy. Schools are often more tolerant of a false positive response than a false negative, preferring to send a student to emergency care that does not need it than fail to send a student with epilepsy who needs emergency care. Finding a balance that addresses medical necessity of the child's treatment of PNES with school policies and resources can be a delicate and difficult proposition. However, if medical personnel are engaged with the school and the patient's parents, and recognize the limits of their own authority in the school environment, a balanced solution that optimizes the child's chances for a full recovery can be achieved.

6.2 Proposed Plan to Override School Policy and Procedures

In the United States, two pieces of legislation governing educational accommodations for students with disabilities may provide a partial resolution to this dilemma: (1) the Individuals with Disabilities Education Act of 1990 (IDEA) and (2) the Americans with Disabilities Act (ADA) Amendments Act of 1990, including its 2008 amendments. If the student meets the criteria of disability, then the IDEA requires the school to develop an Individualized Educational Plan (IEP) that provides accommodations to address the needs identified by the IEP evaluation process [67]. This IEP requirement may be the element that moves the balance of values toward best medical treatment, since it clarifies the school's obligation to provide a specific plan. Under some elements of the ADA Amendments Act of 2008, the school must consider how an identified impairment affects any major life activity of the student and, if necessary, must assess what is needed to ensure that student's equal opportunity to participate in programming.

The recommended course of action may require writing the plan into an IEP. Schools may ask for the input of the treatment team, but parents need to interact directly with the school because they have legal standing to negotiate an IEP with the school. Clinicians should advocate for their patients in helping to create a school environment that will contribute to alleviating the underlying causes of the PNES and not continue to exacerbate it. It is important for clinicians to recognize that there are other real values and tradeoffs to both families and schools in trying to implement these strategies. These tradeoffs include a variety of resources and efforts that must be accounted for as well as the further stigma that might result in having an IEP with a designation of being disabled.

7. CONCLUSION

Even the most skilled clinician struggles with ethical dilemmas that arise during diagnosis and management of pediatric and adolescent PNES patients. Children are dependent on adult authority figures to guide their physical and emotional development and are particularly vulnerable to peer influences and potential bullying. These relationships coupled with the uncertainty and stigma surrounding PNES result in complex dilemmas for treating clinicians. Significant mental health, social and community resources are frequently necessary to effectively treat this patient population, but these resources are scarce. The needs of this patient population are frequently unmet [52].

Careful consideration and weighing of conflicting ethical values by key stakeholders is essential for advancing best care practices that promote the overall well-being of patients and families. When considering the dilemmas that arise in the diagnosis, treatment and counseling of patient and their families at least the following six ethical values should be accounted for in addition to other standard considerations: (1) trust, (2) transparency, (3) confidentiality, (4) professionalism, (5) autonomy of all stakeholders and (6) justice. In particular, clinicians need to be reflective about how their decisions or guidance to parents might weaken one of these in order to safe-guard others of the list. The ethical dilemmas span the entire disease course and require collaboration across disciplines. This paper begins to elucidate some of the dilemmas unique to this patient population and the practical challenges that must be overcome to resolve them. Continued discussions are necessary to identify and assess the variety of ethical dilemmas faced while caring for young patients with PNES.

Acknowledgments

This research was supported by the National Institute of Neurological Disorders and Stroke of the National Institutes of Health under award R13NS080513. The content is solely the responsibility of the authors and does not represent the official views of the National Institutes of Health.

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Highlights

- Unique ethical dilemmas arise throughout the disease course for young with PNES.
- Contextual factors and practical obstacles can exacerbate these ethical dilemmas.
- Physicians are obligated to counsel patients and parents on conflicting values.
- Management strategies must reflect careful prioritization of underlying values.
- Further ethics-based discussions are needed to promote best care practices.