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Review

Ethical dilemmas in pediatric and adolescent psychogenic nonepileptic seizures

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ABSTRACT

To date, only a very narrow window of ethical dilemmas in psychogenic nonepileptic seizures (PNES) has been explored. Numerous distinct ethical dilemmas arise in diagnosing and treating pediatric and adolescent patients with PNESs. 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 PNESs, (2) advising patients about full transparency and disclosure to community including patients' peers, (3) responding to requests to continue antiepileptic 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.

1. Introduction

Psychogenic nonepileptic 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,

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

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corresponding treatment options, and societal conditions. Elements often taken into account during ethical dilemmas include the patient and family 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].

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 is 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]. However in order for the patient and family to accept a PNES diagnosis, several diagnostic challenges must be overcome [17,23,24,45–47,56–57]. 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 who 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 ongoing 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 nonepileptic episodes to emerge when in the "peaceful and nondemanding" 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 epileptologists/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 are 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 stems 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 create 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 and 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 disrupt 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 of 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 contribute to an overall better prognosis [3]. Earlier diagnosis also reduces unnecessary doctor 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 [3,22,40,41,49,56–57]. The roles of the specialists involved in the young patient's care, how the information is communicated, and subsequent follow-