



Nonepileptic seizures in the pediatric population: A qualitative study of patient and family experiences



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ABSTRACT

Objective: The objective of this study was to characterize the experience of nonepileptic seizures (NES) in young people (0–19 years) and their families, referred to a UK specialist (tertiary) pediatric hospital. The topics investigated include: accessing healthcare, how the diagnosis was first explained, impact on home life and school, coping strategies, and ideas about naming and causes.

Methods: Ten young people with NES and 29 family members took part in focus groups and telephone interviews. The data generated were analyzed qualitatively with thematic analysis.

Results: Six themes were identified from participant experiences: upset and afraid, missing out, feeling misunderstood, confusion and uncertainty, less than epilepsy, and making sense and moving on. Participants described severe disruption to multiple domains of functioning at home, educationally, and in social activities. Young people felt guilty but also overprotected, while family members felt that they were failing as parents. The journey to diagnosis and treatment was seen as unnecessarily tortuous, with access to care and treatment pathways poorly defined. Participants described feeling that a wide variety of professionals did not believe their experiences, showed pejorative attitudes, and left them feeling isolated and marginalized. The young people and family members found NES a difficult disorder to understand and sometimes could not differentiate it from epilepsy. Epilepsy was used as a benchmark for several comparisons, including highlighting the lack of support for and information about NES. Families disliked being told that it was “good news” that their child did not have epilepsy and questioned if their child should be present during initial diagnostic discussions. Participants described stressful situations as a common trigger for NES. Young people showed ambivalence towards the need to understand the condition or the choice of name used for it, whereas family members considered this crucial for achieving recovery.

Conclusions: Young people and families who live with NES experience considerable distress and impairment. Pathways to diagnosis need to be streamlined, and better integration of pediatric, mental health, and educational services is required. The use of the “good news” story to discuss the diagnosis with families should be reconsidered, as families seem to interpret this as indicating that there is no effective treatment. Educational resources and support groups for young people and families are needed. Greater understanding of experiences may allow investigation of the pathogenic mechanism and inform possible management approaches. Training of health professionals in communicating with young people and families with NES must be improved.

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1. Introduction

Nonepileptic seizures (NES) consist of changes in behavior or consciousness which to an observer resemble epileptic seizures but are not accompanied by the electrophysiological changes of epilepsy [1].

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Nonepileptic seizures have the potential to adversely affect multiple domains of child and family functioning [2]. There remains much disagreement about the ideal name for the disorder [3–5] with as many as 15 different terms existing in the adult literature [6]. The DSM5 classifies NES as a conversion disorder (functional neurological symptom disorder), and ICD-10 uses F44.5 dissociative convulsions [7,8]. Conversion disorder, nested within the diagnostic category of somatic symptom disorders, encompasses the concept that relevant psychological factors may not be apparent or easily detected at the time of diagnosis of NES.

Research into NES in the pediatric population is still poorly developed [4,5]. Clinical pathways and evidence for effective treatment are

ill-defined. Research into healthcare provision and health education is underdeveloped, mirroring the situation for other childhood “medically unexplained symptoms” (MUS) [9]. Children present to services via multiple routes and may suffer delays in diagnosis or receive inappropriate treatment, leading to poor outcomes [5,10,11]. There are no agreed diagnostic guidelines or published treatment protocols for NES in the pediatric age group [12]. The importance of communication skills training for clinicians has been previously recognized [13,14]. The manner in which the diagnosis of NES is first discussed with patients is seen as important for initiating the journey to recovery. This discussion has been identified as challenging for clinicians to undertake effectively, but a strategy which presents the absence of epilepsy as a “good news story” is generally recommended [15,16].

Very little is known about child and family experiences of NES. Qualitative research has been used with young people with epilepsy and their families to explore complex health psychosocial issues such as access to services, adherence to treatment, disruption to family and social life, coping mechanisms, and desire for support networks [17–19]. Needs and values of caregivers have also been explored [20,21], and findings have been used to improve services [18]. Qualitative research has also been used in a small number of studies of MUS in children and their families but has focused more on family than child viewpoints [9]. Key themes identified include difficulty in accessing services and negative attitudes of clinicians [9,22]. Only one qualitative study has been undertaken with eleven young adults with NES (aged 14 to 24 years), and this focused on experiences of receiving the diagnosis [23].

The aim of the current study was to explore lived experiences of young people and families with NES, including of contact with health services, receiving their diagnosis, family life, schooling, and coping mechanisms.

2. Material and methods

2.1. Setting and overview

Great Ormond Street Hospital (GOSH), London is a tertiary pediatric hospital taking referrals from across the UK. The Psychological Medicine Team (PMT) reviews routinely all children who are admitted for telemetry for characterization of seizures or as part of the GOSH epilepsy surgery program, some of whom have NES. Referrals to the PMT also come from GOSH out-patient epilepsy services and externally from throughout the UK.

2.2. Sample

In a 24-month period (November 2012–October 2014), the PMT assessed 24 children or adolescents with NES under 18 years of age. Medical causes of seizures had been ruled out by pediatricians in referring centers or at GOSH. The investigations undertaken depended on the clinical assessment of the pediatrician, but telemetry or extended EEG was performed in each case. Some children had also been extensively investigated by other medical specialties, such as cardiology. Psychiatric assessments were carried out by experienced psychiatrists and psychologists, including screening for psychiatric comorbidity, intellectual disability, and psychosocial risk. All children included in this study received a diagnosis of conversion disorder.

Subjects were excluded if the treating clinician judged that participation carried a significant risk of jeopardizing recovery (2 cases). At the time of the study, some patients had been newly diagnosed with NES. Others were awaiting, were partway through, or had completed a course of cognitive behavior therapy-informed treatment.

2.3. Data collection

Invitations to attend the focus groups were made by telephone to primary caregivers and the young people themselves if permission was

given by the parents. Separate patient and family groups were held, each on a choice of 2 dates. Each participant attended once. The two facilitators were a junior doctor (AMcW) and a clinical psychologist (FMcF).

Group sessions took a semistructured format, following a topic guide containing 4 main open questions with further prompts for use if issues were not sufficiently explored (Appendices 1 and 2). Question topics were derived from themes in the literature and clinical experiences of the research team, focusing on the lived experience of being a family with NES. Topics of particular interest included contact with health services, receiving the diagnosis, effects on education, and coping mechanisms for events. Participants were also encouraged to speak “off-topic” about any issues they felt important. The groups were recorded and transcribed by a third researcher (EB).

Families who did not want to attend were offered a telephone interview which used the same prompt questions as were used in the focus groups. AMcW conducted, recorded, and transcribed these interviews.

2.4. Analysis

Thematic analysis is a method for identifying and analyzing patterns in qualitative data which has been applied extensively to focus group and interview data in health research. Braun and Clarke [24,25] crystallized the method into 6 steps which the current authors used within a bottom-up, inductive, and experiential viewpoint [25]. The two young person focus group transcriptions were collated and analyzed as one data set. The two family groups and the parent telephone interviews were collated into a second data set as they used the same question topics and were considered by the researchers to have generated similar data.

The three researchers (AMcW, FMcF, EB) independently assigned codes until the data were judged saturated by codes. Next, the researchers collaboratively identified relationships between codes, grouping them into candidate themes, revising these through an iterative cycle until best fit was achieved. Themes were named and divided into subthemes, which were themselves defined and named. Quotations were selected to illustrate typical and interesting features.

2.5. Project approval

The project was registered with the Great Ormond Street Hospital Clinical Governance and Safety Department as Clinical Audit/Service Evaluation No. 1503.

3. Results

3.1. Participants

Participant recruitment is shown in Fig. 1, and selected demographics of participants are shown in Table 1. The 20 participating families included patients of ages 6 to 19 years (mean: 14.8 years). The 10 patients (6 males; 4 females) who attended focus groups had an age range of 11 to 19 years (mean: 15.5 years; males: 14.7, females: 16.8). Twenty-nine family members participated: 22 at focus group (11 mothers; 5 fathers; 2 grandmothers; 1 aunt; 1 sister, aged 21 years; 2 cousins, aged 14 and 12 years) and 7 by telephone (6 mothers; 1 father). Of the 3 families who attended focus groups without patients, one family felt that their child was too young (6 years) to participate, whereas the other 2 families felt that the group would be too distressing for their children who had now recovered. The reasons for nonattendance given by the 7 families who took part in telephone interviews are shown in Fig. 1.

Data on patient demographics and medical histories were gathered from detailed analysis of GOSH medical records. The clinical team judged the 2 young people with intellectual disability who attended focus groups to possess cognitive and communicative abilities necessary for participation.

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