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Social participation in young people with nonepileptic seizures (NES): A qualitative study of managing legitimacy in everyday life

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ABSTRACT

This qualitative study explored social participation in young people with nonepileptic seizures (NES), particularly how legitimacy of illness is managed in everyday life.
Young people with NES, all female and aged between 14 and 24 years (N = 11), were interviewed and followed up over a 14-month period. The transcripts were analyzed using thematic analysis.
Four main themes were elaborated: 1) Delegitimizing experiences from families, schoolteachers, colleagues, and employers were part of everyday life. 2) Fear of being exposed to delegitimizing events resulted in the young people trying to conceal the diagnosis; for some, this resulted in isolation from all social arenas, apart from their closest relationships. 3) Support from close relationships was protective against delegitimization and contributed towards greater social participation. 4) Perceiving NES as a legitimate disorder contributed to increased social participation.
We found a relationship between legitimacy of illness experienced by the participants and the extent to which they either participated or retreated socially. Those who had an illness perception that was personally meaningful experienced their condition as being more legitimate and participated more socially.

1. Introduction

Nonepileptic seizures (NES), also referred to as psychogenic nonepileptic seizures (PNES), is among the most common conditions with medically unexplained symptoms (MUS) within neurology [1]. However, qualitative research on NES is generally lacking [2,3]. While some studies have investigated the experiences of individuals with NES in relation to their interactions with health-care services [4–7] and how they understand their condition [3,8–13], we have found only one study that focused particularly on experiences in everyday life [14]. We have not found any studies that have used qualitative methods to explore everyday life and the impact of social interactions in children and adolescents with NES. This is a key area because social interactions are likely to contribute towards the configuration of illness perception among patients with MUS [15]. Furthermore, greater knowledge and research on MUS in young people is required [16], especially studies that investigate relational aspects [17].

Nonepileptic seizures in children and adolescents often begin following difficult life experiences. A recent study demonstrated that 27/29 experienced psychosocial stressors [18]. Of these, the most frequent was peer insecurity and social anxiety (12/29), family conflicts (11/29), and bullying (6/29). Seven of these twenty-nine also had learning difficulties. These findings are in agreement with other studies [19,20]. The prognosis in children is significantly better than in adults. It can be estimated that approximately 70% of children and adolescents become seizure-free following appropriate treatment [18,21–23].

Young people with NES face several challenges associated with having a condition that is not considered "legitimate" [4]. Several studies have described how young people with NES and other types of MUS feel that their identity is under threat when their credibility is questioned [4,24]. They describe a lack of trust from the health-care services, and difficult feelings due to the contentious and uncertain condition [4,24–27].

A study of young people with Myalgic Encephalomyelitis (ME) also describes a variety of adverse conditions arising because of dropping out of the school and losing their social network. Sick leave from school and college and not being able to be with friends result in them being excluded from society [24]. This is unfortunate because social participation is a source of self-belief and confirmation of self [28,29]. Winger et al. [24] describe the young people experiencing alienation, meaninglessness, and loneliness.

The study described here is part of a larger project. The participants' experiences with receiving the diagnosis and their encounters with medical professionals have already been published [4]. In the current

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study, our aim was to explore how young people with NES experience social participation in everyday life settings, with particular emphasis on how they manage the legitimacy of their condition.

2. Methods

2.1. Study design and interviews

Eleven young people (all female), aged between 14 and 24 years and previously diagnosed with NES, participated. The participants attended a follow-up stay, of between 2 and 4 weeks duration, at an epilepsy center in Norway. The purpose of this stay was to increase their understanding of the disorder. The NES diagnosis was explained with the help of a biopsychosocial model, in which predisposing, precipitating, and maintaining factors all can play a role. The patients were then helped to recognize associations between adverse experiences and the development of seizures in their own lives. Although participants should have received a clear NES diagnosis before they were hospitalized for the follow-up stay, for 2 patients, the seizures had not been captured on video-EEG (see Table 1). In both cases, the diagnoses had been made by a neurologist at the specialist health services, and the patients were referred for treatment in mental healthcare.

The participants were included consecutively on admission, as they met the inclusion and exclusion criteria [4]. Qualitative interviews were conducted towards the end of their stays using a semistructured interview technique. The interviews lasted, on average, 65 min per interview. The interview guide was constructed following a timeline that stretched from the first time the patients had received the diagnosis up until the day that they were interviewed. The interview statements may, thus, refer to both experiences from before admission and during the admission. Details of the inclusion process and of the follow-up stay are provided in our previous publication [4].

In addition to the semistructured interviews conducted at the end of the 2- to 4-week inpatient stay, we conducted two minor follow-up studies. The first follow-up study was completed over a 14-month period after the semistructured interviews. This follow-up included: 3 home visits (totalling about 15 h), 6 telephone conversations (average of 25 min each), and 4 follow-up discussions (average of 65 min each), the latter conducted during readmissions to the epilepsy center after the main 2- to 4-week admission.

In the second follow-up study, we obtained follow-up data on seizure development through telephone interviews done by epilepsy nurses, on an average of 15.6 months after the first interview (see Table 1). All participants signed an agreement of informed consent, and the study was approved by the Regional Ethics Committee.

Table 1
Seizures recorded by video-EEG and seizure frequency reported at telephone interview 15.6 months after the semistructured interview.

Name, age (years)	Seizures captured by video-EEG, without correlation	Seizures at the time of telephone interview
Alice, 17	Yes	Improvement[a]
Kelly, 22	Yes	Seizure-free[b]
Kathleen, 19	Yes	Unchanged
Rosemary, 14	Yes	Improvement
Julia, 20	No	Seizure-free
Jennifer, 19	Yes	Seizure-free
Melissa, 23	Yes	Improvement
Angelina, 19	Yes	Unchanged
Mary, 22	No	Improvement
Kathie, 14	Yes	Improvement
Emily, 15	Yes	Improvement

[a] Improvement means approximately 50% reduction in number of seizures, except for Alice who reported a smaller reduction.
[b] Seizure-free means that the patient has not experienced any seizures for at least a year.

2.2. Data analyses

Guidelines for the qualitative method [30] were followed to ensure reliability and validity. We conducted new analyses for this current study. The analysis was performed according to thematic analyses [31].

The analyses were mainly conducted based on the semistructured interviews, but supplemented with the notes from the first follow-up study. In the first step of the analysis, all the text that referred to situations where the participants interacted with others were coded, including which people they related with, reactions from different people, what was difficult, and how difficulties were resolved. These coded themes comprise the article dataset. In the second step, coding was done in several rounds. We looked for patterns or themes and categorized them into several types of behavioral patterns. In the third step of the analysis, we used "mind maps" and tables to look for patterns, with the codes categorized under main themes.

The text was then categorized to answer the following three questions: "Which behavioral patterns are chosen?", "What are the reasons for the choice of behavioral patterns?", and "What are the consequences of these behavioral patterns?" The behavioral patterns were then divided into two main categories: open and closed. Behavioral patterns were coded as being open when the participants were open about their condition and participated socially, whereas text that indicated social withdrawal and different strategies for hiding their condition was coded as closed. The main themes of the transcribed material were then compared with the notes from the follow-up study. The final results were elaborated as an interpretation of the "open and closed" patterns of behavior, with the interpretation enriched by including the meaning and experience of the participants' illness perception and legitimacy of illness. Each analytical phase was performed in collaboration with the coauthors.

3. Results

3.1. Overview

At the time of admittance to follow-up stay, all the young people involved in this study experienced prolonged seizures with convulsions that often came without warning. Several stated that they had gained control over their seizures during the course of the hospitalization (3/11 total control and one almost control) and, therefore, did not have seizures when we interviewed them towards the end of their hospital stay. The majority (8/11) reported that prior to the onset of the condition, they had experienced stress, such as bullying, exclusion, or family difficulties. Some of the participants (3/11), nevertheless, reported that they had had no such negative life experiences.

Approximately half of the participants reported that they originally had performed well at school and in sporting activities, but their seizure condition resulted in a drop in school performance and influenced the amount of time they spent at social gatherings and with friends. One participant was in regular employment, and another was a trainee. The others were students, some of whom had, or had had, part-time jobs.

In this study, we have mainly focused on elucidating associations between the participants' experiences regarding the legitimacy of their condition and their social participation. However, it should briefly be mentioned that we also found that the symptom burden in itself contributed to social withdrawal. Reduced capacity, tiredness, and unexpected seizures all contributed to some degree of social isolation.

The findings relate to three social arenas: *close relationships*, defined as immediate family and close friends; *school and working life*, meaning relationships with those at school or work, during leisure activities, and other acquaintances or friends; and finally, *the general public*, meaning the rest of the public sphere (e.g., people encountered on public transport, at the shopping center, cinema).

According to the analyses, some participants spoke openly about their condition (e.g., open behavioral patterns) and participated socially, while