

Social participation in young people with non-epileptic seizures (NES): a qualitative study of managing legitimacy in everyday life

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Abstract

This qualitative study explores social participation in young people with non-epileptic seizures (NES), particularly how legitimacy of illness is managed in everyday life.

Young people with NES, all females 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 with 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.

Key words: Delegitimization; Medically unexplained symptoms; Non-epileptic seizures; Participation; Illness perception; Social isolation

1. Introduction

Non-epileptic seizures (NES), also referred to as psychogenic non-epileptic 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 healthcare 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].

NES in children and adolescents often begins 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 healthcare services, and difficult feelings due to the contentious and uncertain condition [4, 24-27].

A study of young people with ME also describes a variety of adverse conditions arising as a consequence of dropping out of the school and losing their social network. Sick leave from school, college and not being able to be with friends results 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 and colleagues [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 study our aim is 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 bio-psychosocial 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 semi-structured interview technique. The interviews lasted, on average, 65 minutes 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 detail in our previous publication [4].

In addition to the semi-structured interviews conducted at the end of the 2-4 weeks inpatient stay, we made two minor follow-up studies. The first follow-up study was completed over a 14-month period after the semi-structured interviews. This follow-up included: 3 home visits

(totalling about 15 hours), 6 telephone conversations (average of 25 minutes each) and 4 follow-up discussions (average of 65 minutes each), the latter conducted during re-admissions to the epilepsy centre after the main 2-4 week admission.

In the second follow up study, we obtained follow-up data on seizure development through telephone interviews done by epilepsy nurses, on average 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.

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 on the basis of the semi-structured interviews, but supplemented with the notes from the follow-up section. In the first step of the analysis, all the text that referred to situations where the participants interacted with others was 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 section. 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 co-authors.

Table 1.

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 totally 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, 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 etc.)

According to the analyses, some participants spoke openly about their condition (e.g. open behavioral patterns), and participated socially, while others tried to conceal their condition (e.g. closed behavioral patterns). Although the participants were on a continuum between being open or closed behavioral pattern, one or other tended to dominate (open 7/11 participants, closed 4/11 participants). The following main findings were identified:

3.2 Closed behavior pattern and social withdrawal

The most common reason that the participants gave for attempting to hide their condition, was fear that others might consider NES as an illegitimate illness.

3.2.1 Delegitimizing experiences

The participants had many everyday experiences in which they felt that others considered their condition illegitimate or intimidating. Although most felt that their close friends and family provided support, there were also examples in which those who were nearest to them did not believe them, or were embarrassed when their children experienced seizures in public. This type of reaction from those closest was reported to result in a negative self-image for the patient.

Mary 22 years: "My father would be going to buy food and I wanted to go with him .. "Yes .. but can you? You mustn't lie down and have some seizure, we don't have time for you making a fuss".. And when he said that .. (..) ..I imagine if that were to happen at a shopping center when I'm out with friends .. what would they do? How would that be seen? Yes .. You become afraid of what people will think of you .. (..) .. I retreated a lot, because I did not want to have a seizure in public."

At school and in working life, the participants said that they felt more respected and better understood by peers and friends than by teachers and employers. Teachers' reactions and indirect attitudes would usually be illustrated by snide comments that indicated that they believed that the participants could control the seizures. Advice and simplistic solutions, such

as that they should be less stressed, gave a feeling of not being understood. In the workplace, participants felt delegitimized by employers and colleagues stating that it was up to themselves to recover. Among the general public, the participants expected to be considered in a delegitimizing way. They had learned that if they told strangers about NES, they could be labeled as mentally ill.

Julia: "... You are a bit afraid to say it to people that you do not know very well, because they tend to say: "oh .. you are that type .." ..."

Feeling exposed and not legitimate in public spaces affected the participant's self-image and perception of their condition.

3.2.2 Concealing the diagnosis: a protection against stigmatization

Concealing their condition and avoiding the opinions of others was the most reported strategy used for tackling delegitimization. Closed behavioral patterns occurred to different extents, with the most extreme being isolation from all social arenas, apart from with the closest family. This included not attending school, not socializing with friends, taking sick leave, and avoiding being in any public places.

*Kathleen, 19 years: "When someone new from school sees me when I have a seizure and they say: "you did this and you didn't stop," .. (..) .. then I worry that they will think lots of negative things. They'll think I'm a complete lunatic.....
I'm rarely out among other people. I'm mostly with those who know how I am and what really goes on when I have seizures."*

An alternative option was to participate socially, but try to keep the diagnosis concealed. At school such a strategy required that the participants controlled all the information that was exchanged between different parties about their condition. In the quote below it can be seen that Alice is afraid that the teachers have told her classmates that her seizures are NES while she was hospitalized. She is afraid of losing her position in the social hierarchy as a result of it

being known that she has a controversial diagnosis, of being labeled as a person with mental health problems who gets treatment at the psychiatric department.

*Alice, 17 years: "I was furious if they (the teachers) said something while I was away .. (..) .. I'll sue them for breach of confidentiality.
I do not want to tell the teachers this .. (..) Really, I want to say that they diagnosed epilepsy."*

In the workplace, some pretended for as long as possible that the condition was undiagnosed. When forced to provide their employer with an acceptable reason for increased sick leave, an uncomfortable position arose. Even if they wanted to let the employer and colleagues know about the condition, providing a satisfactory explanation could still be difficult. Sharing the diagnosis with others was challenging when the participants themselves did not really understand the diagnosis, and hence consider it as not really being acceptable.

Mary 22 years: "It is alright (that the employer) not knowing what it is for a while, but when it starts to be an even longer period .. (..) .. Then pressure is applied again ... (..) .. You're not so ill that you can't be at work .. and then trying to explain something that you do not even understand yourself is very difficult and worrying."

Mary: a bit later on: ".....but I got the feeling that it was my mental health that gave me seizures. .. (..) .. But how was I going to be regarded if that was the case? ... So it was quite nice to say "no, I do not know what it is .." It meant that no one could put me into a box "Ah - you are mentally ill .. but can't you just fix it?""

A constant theme was that the amount of information the participants provided about their diagnosis, depended on what they thought the receivers of the information were able to accept. Participants who linked their condition with mental illness, but without any more nuanced understanding, immediately categorized themselves negatively as a result of identification with a psychiatric diagnosis.

3.3 Open behavior pattern and social participation

The participants described how support and understanding from close relations and a perception of NES as a legitimate disease contributed towards greater social participation.

3.3.1 Support and understanding from close relationships

On an everyday basis, the participants were most open with those to whom they were closest. For some the openness was only with their parents, but other participants were also open with friends. One reason for being open towards someone close was a desire to be believed and understood; this wish was mostly met. As close friends and family became more knowledgeable, they developed a shared understanding of the condition. The participants themselves mostly took responsibility in explaining the condition.

Mary, 22 years: "When I am discharged (from the Epilepsy Centre), I'll go to mum and bring this booklet with me (..) .. and sit down and talk to her about it, so that she can understand what this is. What she can do for me is to try to understand as much as possible .. (..) .. and see how I really am, instead of seeing it from the viewpoint of a completely healthy person."

A common understanding of the distress and challenges caused by seizures in those closest provides assurance. Having close friends and family close by at various social arenas was helpful, as they could answer questions following a seizure. This was experienced as being protective against getting into socially vulnerable situations.

Rosemary, 14 years: "Friends want me to come out with them, but I say: "What if I have a seizure?" They say: "It will be fine, we'll get you into the bathroom or something ..". (....) I won't have to say very much, because my friends know that I am very tired after a seizure and they'll answer for me if anyone wants to know anything."

Social participation in school and leisure time was greater if there was openness with close friends and family. Although we found that support from close relationships contributed

towards increased social participation, we did not find any association between seizure frequency and support from close relationships. We also did not find any association between a participant's seizure frequency and their extent of socially activity.

3.3.2 Perceiving NES as a legitimate disorder.

Several participants said that whilst they first tried to conceal the diagnosis, as time went by they developed greater openness and increased social participation.

Kelly, 22 years: "I know I have seizures, and I know that I have problems. It has taken me a long time ... But I'm happy that I have reached where I am today. When I get seizures in public I care ... not. What happens, happens."

Jennifer related at a follow-up discussion that she resented others seeing her seizures, but that had not hindered her social participation:

Jennifer, 19 years: "I drool and spit; it is horrible. I do not want anyone else to see me like this, but the coaches are good and remove the others. It is only a condition and I'm not really like that ... I've never experienced that people associate me only with seizures. I think you have to be open, it provides peace of mind for me and the others. My experiences have only been positive."

Jennifer does not experience NES as a condition that "affects all of her" or labels her negatively. It seems that she is secure in her own identity despite her NES-diagnosis. We found that participants, who themselves perceived their condition as acceptable and understandable, participated more socially. It was also easier to participate socially if the participants themselves felt that the explanation for their seizures was acceptable.

Jennifer: "When people ask, I say that they are epilepsy-like seizures and come from my body reacting to stress...I had a rather large seizure and was paralyzed, so I had to sit in a wheelchair ... (..) I thought it better to sit in a wheelchair and get out, than to sit at home."

Understanding the condition as being a result of stress affecting the body seemed to make sense to many. As the participants recognized correlations between their own life stresses and seizures, it was also easier for them to talk about the condition to others. Overall, a meaningful understanding of why they had developed seizures and previous positive experiences with being open about their condition increased social participation.

4. Discussion and conclusion

4.1. Discussion

The analysis showed that our participants' social response patterns depended on the young people themselves, and their perceptions, as well as their social circle (their family, schoolteachers, colleagues and employers), who tended to perceive NES as illegitimate. This resulted in carefully considering to whom they were able to disclose their condition, how they should act in everyday situations, and the extent to which they participated socially or isolated themselves.

4.1.1 Delegitimization and impact on sense of identity

We found that our participants tried to hide the condition because they feared that others would categorize them negatively. They were afraid of being defined as "not credible" or as "mentally ill". Both these possibilities incorporate some doubt regarding whether they really were sick. The experience of having their credibility questioned arose when others hinted that their seizures were willfully produced, or that it was expected that they could cure themselves. One strategy for coping was isolating themselves. Another strategy was to conceal the diagnosis for as long as possible.

Several studies have, like ours, found that both the patient and their circle tend to perceive bodily ailments that are unexplained by disease, as being "not real" or "all in the mind" [32-34]. Feeling that their condition is illegitimate complicates the individual's status as being sick and their role as a patient [24,34].

What we found, could be described as delegitimization; that is perceptions and definitions of disease are systematically refuted [35]. Delegitimization further addresses existential issues,

affecting behavior, self-esteem, and identity. Our analyses demonstrated that our participants' experiences verged on being stigmatization, as defined by Goffman [36]. These concepts of stigma according to Goffman [36] may clarify further how delegitimization may frame identity. According to Goffman [36], a stigma is a highly discrediting, negative characteristic. Conditions or characteristics of individuals that are perceived as discrediting within the community could lead to threatening those individuals' social identity [36]. According to the concept of Goffman, stigmatization can occur when there is discrepancy between a person's *actual* and *apparent* identities [36]. The *apparent* social identity is the first impressions that an individual obtains of another person. This first impression incorporates normative expectations of the other person's character and qualities [36]. A "NES diagnosis" may thus trigger a cascade of stereotypical impressions in others, including, for example, that individuals with NES are feigning their seizures, and thus that they are "dishonest" people [4].

However, according to Goffman [36], a person's *actual* social identity is how the person actually is, and their essential personality. The attempts of our participants to isolate themselves socially and conceal their condition can be understood as a reflection of their need to preserve their *actual* identity. However, this is probably a detrimental strategy because social isolation may have negative consequences for their sense of connectedness with others [33, 37]. Furthermore, social isolation limits the possibilities for positive self-validation [28-29, 37] and may cause a loss of self-esteem [28].

4.1.2 Social participation and experienced legitimacy of illness

Our results provide clues that some specific factors contribute towards the participants becoming skilled at increased social participation. We identified two main aspects regarding why some participants chose open behavioral patterns and increased social participation. The first aspect is related to relational experiences and the second aspect is related to how the participants themselves perceive their own condition.

Regarding the first aspect, we found that previous experiences in which there had not been a feeling of delegitimization provided reassurance and a foundation that contributed towards increased social participation. This particularly applied in close relationships. Openness, in terms of explanations and information provided beyond close friends and family, were seen as

deliberate attempts to avoid delegitimization. The importance of support from parents and friends has also been described in adults with NES [14], and in young people with other types of MUS [24,27]. Pretorius and colleagues [14] have also described social support from family, friends, and colleagues as being extremely important because it may counteract social isolation.

Regarding the second aspect, it seems that the participants' own perceptions of their own condition was important regarding the extent to which they felt delegitimized or not. It appeared as though those who participated more socially did not fear their *actual* identity being threatened as a result of the diagnosis. This was expressed as: *this is a condition; I'm not like this*. This could appear to be associated with those that experienced the diagnosis as legitimate, meaningful, and understandable, and that they themselves believed that their seizures were real. Overall, it appears that an understanding of the condition that includes a higher level of credibility, and increased meaning, can be used as a defensive resource against delegitimizing events, and thereby have a positive effect on the adolescents' social participation.

Our study has some limitations according to the small sample size, which may inhibit a solid analytic transferability. The follow-up period was also relatively short. If the follow-up period had been longer and repeated, it could have provided more support to the association between a meaningful diagnosis explained via the biopsychosocial model and social participation. Further, we were unsuccessful at recruiting male participants and the average age of our participants was also rather high due to changes in recruitment criteria [4]. More research into our participants' home environments would have improved our study, but this was not easy. Many had tried to conceal their diagnosis, and several had isolated themselves from the outside world. It could have been considered an invasion of privacy to intrude further into their social arenas.

Nevertheless, our findings provide useful pointers on the mechanisms and interplay between how young people with NES manage the legitimacy of their condition and social participation. Thus, the results of this study could be considered as a relevant supplement to the existing published research.

4.2. Conclusions

- Fear of delegitimization because of a controversial diagnosis, may result in young people with NES isolating themselves socially.
- Young people with NES experienced that their families, schoolteachers, colleagues and employees at their workplaces hinted that they had more control over their seizures than they themselves expressed and were convinced about.
- Support from close friends and family was protective against delegitimization events and thus crucial for the participants' social participation.
- Our analyses show that there is a close association between illness perception and social participation. Among our study participants, those who had a personally meaningful understanding of their condition, considered it as legitimate to a greater extent, and participated more socially.

Our results highlight the need for further research regarding the interplay between the way diagnosis is communicated to the patient, the configuration of illness perception, and social participation in people with NES.

An important goal in communicating the NES diagnosis should be that it is recognized as a legitimate condition by both the patient and their families. Health care personnel have an important role in developing an understanding and a language that allows acknowledgement of NES as a legitimate condition. Education and openness with relatives, friends, school, and workplaces are especially important for children and adolescents diagnosed with NES.

We confirm that we have read the Journal's position on issues involving ethical publication and affirm that this report is consistent with its guidelines. We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details provided.

Conflict of interest

The authors declare that there is no conflict of interest in this work.

Authors' contribution

HK, corresponding author, has contributed substantially to the conception and design of the study, and analysis and interpretation of data. Further she has been responsible for the acquisition of data, drafted the article, and approved the final version.

ORH has contributed substantially to the conception and design of the study, and analysis and interpretation of data. Further, he has contributed to revising the article critically for important intellectual content, and approved the final version before submitting.

MBR has contributed substantially to the conception and design of the study, and analysis and interpretation of data. Further, she has contributed to revising the article critically for important intellectual content, and approved the final version before submitting.

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