Health related quality of life of people with non-epileptic seizures: The role of socio-demographic characteristics and stigma

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ABSTRACT

Purpose: People with non-epileptic seizures (NES) consistently report poorer Health-Related Quality of Life (HRQoL) than people with epilepsy. Yet, unlike in epilepsy, knowledge of how social factors influence the HRQoL of adults with NES is limited. To add to the evidence base, this study explores the relationship between HRQoL and perceived stigma among adults with NES, and the role of socio-demographic characteristics.
Methods: Data was gathered from a survey of 115 people living with the condition, recruited from online support groups. Participants provided socio-demographic and health-related data and completed a series of questions investigating their HRQoL (QOLIE-31) and stigma perceptions (10-item Epilepsy Stigma Scale).
Results: Participants were found to experience high levels of perceived stigma (median 5.2, mean 4.9). A significant and moderate inverse correlation was observed between HRQoL and stigma ($r_s - 0.474$, p = < 0.001); suggesting higher perceptions of stigma contribute to poorer HRQoL among adults with NES. Stigma perceptions were found to be most strongly associated with the seizure worry ($r_s = -0.479$), emotional wellbeing ($r_s = -0.421$), and social functioning ($r_s = 0.407$) HRQoL domains. Participants who reported being in employment or education were found to have significantly better HRQoL than those who were not (p = < 0.001).
Conclusion: More (qualitative and quantitative) research is justified to understand how – and why – those with the condition experience stigmatisation, and the factors that impede and help facilitate the participation of people with NES in education and employment.

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1. Introduction

There has been a marked shift in thinking about what health is and how it is measured; with traditional clinical outcomes increasingly giving way to, or used in conjunction with, patient reported outcome measures (PROMs) [1]. Health related Quality of Life (HRQoL), is a multidimensional PROM construct used to assess the perceived impact of health status on quality of life; comprised of physical functioning, emotional status, and social well-being domains [2].

People with non-epileptic seizures (NES), often referred to as psychogenic non-epileptic seizures (PNES) or non-epileptic attack disorder (NEAD), consistently report poorer HRQoL than those with epilepsy [3–5]. A recent systematic review of the literature identified 14 studies arising from ten separate research projects (data collections) that have explored associations between independent factors and HRQoL in this patient group [6].

The evidence available suggests a strong adverse association between psychological factors and the HRQoL of adults with NES. Several studies show depression to be a strong predictor of poorer HRQoL in this patient group [3–5,7–15]. Other psychological factors associated with poorer HRQoL in people with NES include the number/severity of mood and emotional complaints [3,9,14,15], illness perceptions [16], dissociative experiences [8,11], somatic symptoms [9,10,15], and escape-avoidance coping strategies [8,17]. Condition-related factors, such as older age of onset [15,18] and experiencing the condition for a shorter period of time [15] have also been shown to adversely affect HRQoL. As with epilepsy patient groups [19], seizure freedom has been shown to be positively

associated with HRQoL in patients with NES [20]. However, whereas systematic reviews of the literature have found seizure frequency to a (modest) predictor of HRQoL in adults with epilepsy [19], the same was not found to be true for adults with NES [6].

Yet, as Mitchell and colleagues point out [11], studies that attempt to produce a model to explain the factors that are associated with HRQoL in adults with NES only account for 65% of the variance at best [3]. Our limited understanding of how social factors affect the HRQoL of those living with NES probably contributes to this shortfall. There are significant knowledge gaps in relation to domains such as stigma, employment status, and social and family relations [6].

HRQoL in this patient group has been negatively associated with family roles and affective family involvement subscales using the Family Assessment Device (FAD) [5], suggesting the roles and influence of significant others to be a potentially important predictor of HRQoL for people with NES. There is also some evidence that concerns about relationships with the main caregiver seem to cause more distress in those with NES than patients with epilepsy [21]. We know that the stigma associated with epilepsy is considerable and that it has negative effects on HRQoL [22] – in fact, it may account for more HRQoL variance than clinical outcomes (such as seizure frequency and side-effects of antiepileptic drugs) [23]. However, whereas there is a wealth of research to support the view that the social prognosis of epilepsy is often less good than the clinical one [22], comparatively little research has explored the social impact of NES [24], and none has explored the relationship between stigma and HRQoL in this patient group to date. The only study to have examined the role of socio-demographic variables found no significant correlation between employment status, marital status, having children, religious involvement, and proximity to family and HRQoL [15], but more research is needed to substantiate these findings.

To add to the evidence base, this study seeks to explore the relationship between HRQoL and perceived stigma among adults with NES, and the role of participants' socio-demographic characteristics. Findings ('statistical pointers') will inform an upcoming qualitative study exploring the stigma perceptions of people with the condition, which will include exploring participants written texts about their family relations and the social impact of NES. Taken together, we hope to identify social dynamics that will contribute to larger (multiple regression) studies aiming to produce a model to explain factors affecting the HRQoL of adults with NES.

2. Methods

A link to an in-depth (86-item, 233-question) survey comprised of polar, frequency, Likert scales, and open questions was advertised to members of 20 patient and practitioner-led online support groups and websites for people with NES (based in the UK and US; not disclosed for reasons of confidentiality, details available on request). The survey was piloted among 25 people living with the condition. Final survey data were organized around four key themes: 1) the diagnostic journey 2) access to and experience of treatment 3) interactions with healthcare professionals and 4) social support and social stigma. Advertising commenced May 2016 and final data collected from 1 July to 1 October 2016.

To include as many people with NES as possible, the only inclusion criteria were that participants had to be over 18 years of age and had received a diagnosis of NES by a health professional. Participants were advised that we used the term NES throughout the survey to describe diagnoses of psychogenic non-epileptic seizures (PNES), non-epileptic attack disorder (NEAD), and other diagnostic terms sometimes used to describe the condition and

symptoms; such as, dissociative, conversion, functional, and pseudo seizures. They were also informed that we used the term seizure throughout the survey, whilst recognising that some people experience non-epileptic events in which they do not exhibit movements, only briefly lose consciousness, or experience an altered state of consciousness, or a mixture of these behaviours and sensations. Participants were advised that, unless otherwise stated, to consider the term "seizure" to include such "events". Those with a dual-diagnosis of epilepsy and NES were asked to only comment on non-epileptic seizures and events wherever possible. Participants were able to save their answers and return to the survey via a secure and automated email link. Typically, open (free-text) questions were optional and all others mandatory. The smart-logic survey format helped to protect against participants giving conflicting answers, and to 're-check' and correct responses when they did so.

This study uses a subset of the full survey data to explore associations between the socio-demographic and health-related characteristics of participants, their HRQoL, and levels of perceived stigmatisation; using the measures listed below.

2.1. Measures

Participants were asked a range of socio-demographic and health-related questions, as indicated in Table 1.

The 31-item Quality of Life in Epilepsy inventory (QOLIE-31) [25] was used to measure HRQoL. The inventory, designed for adults with epilepsy aged 18 years and older, is divided into seven subscales that explore various aspects of patients' health and wellbeing: emotional well-being, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects, and overall quality of life (a single-item subscale). A weighted average of the multi-item scale scores is used to obtain a total score. Although specifically designed for people with epilepsy, there are important clinical similarities and shared concerns between NES and epilepsy patient populations. A review of health status measures did not produce any better tools to assess the construct of HRQoL in this patient population [26]; and a recent systematic review identified the QOLIE-31 as the most popular measure in studies exploring the HRQoL of this patient group [6].

Stigma was measured using the Epilepsy Stigma Scale developed by Dilorio and colleagues [27]. The ten-item scale assesses the degree to which a person believes that their seizure condition is perceived as negative and interferes with relationships with others, rated on a 7-point scale from strongly disagree (1) to strongly agree (7). Item responses are summed to yield a total score. In this study, overall median scores (1–7) were calculated. Higher scores are associated with greater perceptions of stigma. To our knowledge, the measure has not been validated in a NES patient population. We assessed the scale for internal consistency and found α coefficient for the responses of our (n = 115) participants to be 0.89.

2.2. Statistical analysis

Analysis of the data was performed using SPSS, version 24. To guard against assumptions of normality and homogeneity of variance, and because measures include ordinal data, non-parametric tests of significance and correlation were used. In some cases, mean scores are presented or discussed for comparative purposes. The primary outcome measure was QOLIE-31 (weighted) total score. The Mann-Whitney U Test was used to compare quantitative variables between two independent groups. Spearman's rank correlation coefficient (r_s) was used to compare continuous and ordinal data variables. The strength of correlations were defined as: 0–0.39 weak, 0.4–0.69 moderate, and 0.7–1