



Family and sexual life in people with epilepsy



Rūta Mameniškienė^{a,*}, Jevgenija Guk^b, Dalius Jatužis^a

^a Vilnius University, Department of Neurology and Neurosurgery, Center for Neurology, Vilnius, Lithuania

^b Department of Neurology, Vilnius University Hospital "Santariskių klinikos", Vilnius, Lithuania

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ABSTRACT

Having epilepsy is much more than having seizures. Epilepsy can have a severe negative effect on quality of life, affecting social relationships, academic achievement, housing, employment, and the ability to live and function independently. We undertook a cross-sectional study in a tertiary epilepsy center in Lithuania, aiming to assess the influence of epilepsy and aspects relating to epilepsy (employment, stigma, anxiety) on patients and their families, and to estimate their quality of family life and sexual functioning. We asked patients to complete a questionnaire about their socio-demographic situation, their seizure types and antiepileptic medications, and their quality of family and sexual life. Our results confirmed that epilepsy seriously influences family life. One third of our patients are lonely and half are childless. Epilepsy leads to difficulty in finding a job, especially for men, and unemployment affects their status in the family. People with epilepsy are uncomfortable interacting with those of the opposite sex and tend to conceal their medical condition from their partner. One third have sexual dysfunction, yet only a quarter of them seek professional help. There is a clear need to improve self-confidence and to reduce social stigma in people with epilepsy, and to encourage them to discuss their problems with specialists.

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1. Introduction

Epilepsy is one of the most common serious chronic neurological diseases, with over 50 million people worldwide having epilepsy [1]. Having epilepsy is much more than having seizures. More than any other condition, epilepsy is accompanied by depression, anxiety and attention disorders, headache, infertility and low sexual libido. Some 30–50% of people with epilepsy have behavioral, emotional, and mood disorders [2].

People with epilepsy experience challenges in school, uncertainties about social and employment situations, and limitations on their driving and independent living. The negative effects of epilepsy on their quality of life can be severe, and may involve family and social relationships, and academic and life achievement. Those most debilitated by epilepsy are not necessarily those with the most frequent seizures, but rather those who lack social support [3,4]. Furthermore, people with low social support are more likely to have psychological and physical ailments [5].

Previous epidemiological surveys have consistently found that people with epilepsy more often report having never being married, compared to those without epilepsy [6,7]. Married people are known to report better psychological and physical health than unmarried people

[8]; those in a relationship have a higher quality of life, and considerably better mental wellbeing than people who are lonely [9].

Several published studies have reported on the psychosocial aspects of epilepsy and its impact on quality of life and social functioning, and its associated psychological problems [10–13]. Nevertheless, there is little information about its impact on family life. People with epilepsy appear to have greater likelihood of sexual dysfunction than those with other chronic neurological illnesses. Reduced sexual desire and/or sexual arousal may affect 25–33% of people with epilepsy [14]. Sexual dysfunction is common in this population and adversely affects quality of life and family relationships. This may be caused by the epilepsy itself, by antiepileptic medications or by psychological problems [15,16]. Our study aimed to evaluate and estimate the influence of epilepsy on the lives of people with epilepsy in Lithuania: specifically on employment, stigma, anxiety within the family, quality of family life, and sexual functioning.

2. Participants and methods

This cross-sectional study was performed in the Epilepsy Centre of Vilnius University Hospital Santariskiu klinikos. We obtained ethical consent for the study from the Ethics Committee of Lithuania. We included patients with a diagnosis of definite epilepsy who were older than 18 years, taking antiepileptic drugs, able to speak and understand the Lithuanian language, and willing to participate in the study. We excluded patients with significant mental retardation, evident cognitive

* Corresponding author at: Epilepsy Centre, Department of Neurology, Vilnius University Hospital "Santariskiu klinikos", Santariskiu str. 2, LT-08661 Vilnius, Lithuania.
E-mail address: ruta.mameniskiene@santa.lt (R. Mameniškienė).

decline and dementia, major depression, psychiatric and other severe medical illnesses, psychogenic non-epileptic seizures, a single epileptic seizure only, and those with epilepsy duration for less than one year.

We gave participating patients a detailed description of the study, and obtained their written consent. We excluded patients who reported seizures on the day of study inclusion, those taking medications other than antiepileptic drugs, and those who did not fully complete the questionnaires. We gave questionnaires to patients before they entered the consultation room and later compared the information gathered to that recorded in their outpatient cards.

2.1. Data collection tools

The questionnaire comprised five themes: 1) socio-demographic; 2) disease and treatment; 3) familial status and quality of familial life; 4) sexual life; and 5) Hospital Anxiety and Depression scale (HAD) [17]. The socio-demographic questionnaire included information on age, sex, education, and employment. The epilepsy-related questions included disease duration, seizure type(s) and frequency, and the names of antiepileptic drugs and other medications. The questions on family life concerned marital status, timing of marriage compared to epilepsy diagnosis, number and age of children, and other aspects that could affect family life. We asked patients to evaluate their family life on a numeric rating scale, asking the question: "Please rate the quality of your family life on the scale below", where 0 means "poor, could not be worse" and 10 means "excellent, could not be better".

The questions on people's sex life included those about sexual dysfunction, the possible reasons for this, and possible solutions. If patients reported problems in their sex life, we asked them to tick options from those listed (reduced sexual desire, pain during intercourse, vaginal dryness, erectile disorder, ejaculation problems, anorgasmia, or others). We also sought their possible explanations for this, with possible answers being: a) fear of rejection, b) fear of a seizure during intercourse, c) partner's fear of a seizure during intercourse, d) physical disability, e) antiepileptic drugs, and f) other. We also asked "Have you ever had a seizure during sexual intercourse?"

We categorized those scoring 0–7 points on the HAD scale as having no anxiety or depression, and those scoring 8 or more as having anxiety or depression. After patients completed the questionnaire, the researcher offered to clarify and help them to answer any questions that they had found unclear.

Before distributing the questionnaire, the study team members reviewed it for its simplicity, readability and content; an epilepsy expert checked its scientific and clinical content. We pilot tested 20 patients to modify or exclude questions that were difficult to comprehend.

2.2. Statistical analyses

We calculated descriptive statistics using Microsoft Office Excel 2007 and SPSS Statistics 20.0. We presented socio-demographic data as proportions (%) and expressed quantified data as means with standard deviations. Since our data showed a non-normal distribution, we used non-parametric tests. We used descriptive statistics, Spearman correlation analysis, Mann–Whitney *U* test and Kruskal–Wallis test for data analysis. We used Chi-square and Fisher's exact test to assess differences between groups and regarded *p* values of <0.05 as significant.

3. Results

Five hundred and six out of 583 responders met the inclusion criteria. There were more females than males ($p = 0.001$). Half of responders ($N = 253$) reported that their epilepsy started before the age of 18 years. Over half (266 (52.6%) of the respondents (113 males and 153 females) were married or lived with a partner, 143 (28.3%) lived with other family members (parents or children), and 97 (19.2%) lived alone. Men and women were equally likely to be living alone (46

(21.4%) males and 51 (17.5%) female, respectively) or to be living with parents/children (58 (26.0%) and 87 (29.9%), respectively). Only 118 (23.3% of all; 43.4% of 272 ever married) responders were married while already having epilepsy, 85 (29.2%; 52.8% of ever married) females vs. 33 (15.3%; 29.7% of ever married) males ($\chi^2 = 14.205$, $p < 0.001$). Of those whose epilepsy started before the age of 18 years, 73 males (28.8%) and 55 females (33.9%) were married, whereas among those whose epilepsy began after the age of 18 years, 120 males (47.4%) and 56 females (43.5%) were married. Interestingly, only 45 (17.8%; 37.5% of 120 married individuals) were married after being diagnosed with epilepsy ($\chi^2 = 2.406$; $p < 0.001$): 14 (11.3%; 21.9% of 64 married) men and 31 (24.0%; 55.5% of 56 married) women.

Table 1 gives the patients' socio-demographic and disease-related characteristics.

Over half of the responders (64.5%) identified problems finding a job because of their epilepsy, especially men (62% of males and 49% of females; $\chi^2 = 7.85$, $p = 0.05$). Ninety-three of 471 (19.7%) responders had concealed their epilepsy from their partner at the start of their relationship (17.8% of males and 21.6% of females) and 48 (10.2%) still kept their illness a secret (11.9% of men and 8.9% of women). Thirteen (5 men and 8 women) of them lived with a partner during the study. Two hundred and nine (41.3%) responders (46% of single people living alone, 48.6% of single people living with other family members, and 34.7% of married or those who live with a partner, ($\chi^2 = 33.899$, $p < 0.001$)) reported that their epilepsy made them feel uncomfortable when dealing with opposite sex. Over half (51.2%) were sure that public attitudes towards epilepsy influenced their family life. This was the case for 56% of single responders (56.2% of those living in another family and 55.8% those who live alone), compared to 47.3% of respondents who were married or living with a partner; this difference did not reach statistical significance ($\chi^2 = 5.74$, $p = 0.057$) and there was no difference between the sexes. Fifty-two (19.5%) respondents who lived with a partner stated that they had avoided having children because of epilepsy.

Over half ($N = 137$; 57.1%) of single people (62.9% of those who were living alone) considered that epilepsy negatively impacted upon their family life and 117 (48.6%) preferred to be alone because of their epilepsy: this compares to 42.7% of those who lived with their parents (37.9% of females and 50.0% of males) and 58.3% of responders who lived alone (54.9% of females and 60.9% of males). Over half (54.5%) of responders (103 (39.3%) living with a partner thought that their family life would be better without epilepsy, compared with 83 (56.6%) of those who lived with others and with 62 (63.4%) of those living alone) ($\chi^2 = 27.580$, $p < 0.001$), but there was no significant difference between males and females. From those who could make the comparison, 76 (51.4%; 60.5% of males and 41.7% of females) noted that their family life had changed after being diagnosed with epilepsy; 34.5% (38.2% of males and 30.6% of females) reported that their partners took more care of them after the diagnosis. However, 10.8% (14.5% of men and 6.9% of women) reported that they now relied less upon their partner. Table 2 shows patients' answers to the question, "Does epilepsy influence your familial life?"

Over half (34 (55.7%) of divorced responders noted that epilepsy was the main reason for their divorce. Eighty nine (55.3%) single patients reported that epilepsy was the main reason for their ending a long-term relationship. Table 3 shows the reasons for this.

Quality of family life was rated only by those who were married or living with a partner, or those who were single but living with other family members (their parents or children) ($N = 412$). Patients' scores for the quality of their family life were lower in those with a longer duration of epilepsy, younger age of onset of epilepsy, more frequent seizures, fewer years of education, single, older, male, unemployed, using more antiepileptic drugs, and having more anxiety and depression. However, we found no significant difference between quality of family life scores by the type of the seizures or by the number of children ($p > 0.05$). Table 4 shows how the mean quality of family life scores relates to socio-demographic and disease characteristics.

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