

An evaluation of the psychosocial impact of epilepsy on marriage in the United Kingdom

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Abstract

Objectives

The primary objective of this study was to measure the psychosocial burden for persons with epilepsy (PWE) and for their spouses and to compare and correlate this with the clinical burden of seizures. A secondary objective was to examine the presence of gender-specific differences in the perception of psychosocial burdens by both PWE and their spouses, as well as in the factors that may influence this perception. We also sought to delineate differences in perceived stigmatization if the onset of epilepsy was within matrimony or if seizure onset was prior to marriage.

Methods

A questionnaire was constructed from previously validated instruments to measure stigma and was administered to 50 PWE-spouse pairs. A copy was applied to the PWE and another was administered separately to the spouse. The medical notes were scrutinised by a Consultant Neurologist to enable an assessment of seizure severity for each type of seizure that the PWE experienced. Pearson correlation significance was examined at 95% level of significance.

Results

Higher seizure severity over the month prior to data collection correlated with smaller reporting differences in psychosocial outcome between spouses and the PWE ($p= 0.005$), an effect that maintained significance when **the period over which seizure severity was evaluated was extended to one year** ($p= 0.021$). Regarding gender-specific differences, low mood over the month prior to administration of the questionnaire was associated with worse psychosocial scores in females only ($p= 0.001$). Significant impairment in driving was correlated with worse outcomes in males only ($p=$

0.008). Male spouses' judgement on the 'overall health' of their wife correlated to seizure severity ($p=0.003$). However, the psychosocial scores reported by male spouses were inversely correlated to those of the PWE ($p= 0.042$). Finally, in PWE with seizure onset within marriage, a high degree of perceived **stigmatization** ($p= 0.025$) and low mood ($p= 0.004$) were correlated to worse psychosocial functioning. This group also tended to be more anxious when the PWE was experiencing severe seizures ($p= 0.013$).

Conclusion

Although severe seizures in this sample of couples were correlated with a smaller discrepancy in perceived seizure burden, gender-specific differences in perception of epilepsy-related psychosocial burden exist. This is true for both PWE and their spouses. Irrespective of gender, onset of epilepsy within matrimony was correlated with higher levels of anxiety and stigma. These factors need to be considered during efforts to reduce epilepsy related stigmatization, as well as in tailoring therapies that aim to support the spouse as well as the PWE.

Abbreviations

HADS, Hospital Anxiety and Depression Scale; PWE, person(s) with epilepsy; QOLIE-31, Quality of life in epilepsy inventory

Keywords

Epilepsy; gender-specific differences; marriage; psychosocial outcomes; stigma

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1. Introduction

Epilepsy is a chronic disorder of the brain, affecting roughly 65 million individuals worldwide [1]. Each year in Europe, there are 13,000 deaths due to epilepsy; 40% of which may be prevented by ensuring proper access to correct diagnosis and treatment. A possible contribution to this phenomenon may be the stigmatization of people with epilepsy, which discourages them, and their families, from seeking medical attention and the care they require.

Although it is known that seizures result from sudden, excessive abnormal neuronal discharges, across time and place epilepsy has been a discrediting disease. In ancient Mesopotamia, epilepsy was attributed to 'the hand of Sin' [2]. The Hammurabi code, dating back to 1780 BC, dictated that a person with epilepsy could not testify in court, purchase a slave or marry. In the late 19th century, Samt and others reported that people with epilepsy were prone to violence and religious ecstasy due to anxiety and hallucinations [3]. Even today epilepsy remains a hidden disease in most of the world. It was, for example, as recently as 1971 that a law prohibiting people with epilepsy (PWE) from marrying was repealed in the United Kingdom while in the United States, up until the 1970s, it was entirely legal to prohibit PWE from accessing public buildings and recreational facilities [1].

Spouses often serve as the primary caregivers of married PWE due to their central role identity and fundamental position for social support. A study conducted by Gopinath et al., in 2011 analysed the gender-specific psychosocial outcome for women with epilepsy. Comorbidities, lower employment and higher anxiety states were more frequent for women with epilepsy

than for men with epilepsy. Men with epilepsy may be more prone to accidents, accidental deaths or injuries, but women are more likely to be abandoned by their spouse [4].

The maximum gender-specific disparity observed was for marital status. Women with epilepsy experienced much more difficulty in marriage than men with comparable epilepsy syndromes and females had more difficulty finding life partners compared with males. In addition to this, women with epilepsy were at increased risk for divorce. Fertility rates in women with epilepsy are also reduced to 33% - 67% when compared with their non-epileptic counterparts [4].

Attitudes towards PWE are influenced by the extent of knowledge about the condition as well as sociological factors from cultural background. Cure and prevention are still eventual goals, but many people are unnecessarily struggling with poor health, prejudice and death due to epilepsy [5]. Research into psychosocial aspects of PWE, including the impact of epilepsy on marriage, is therefore vital to improving our understanding of epilepsy and patient care. Although disparities related to marriage were measured in Gopinaths's article, specific analysis of the effect that epilepsy may have on marriage and how epilepsy is perceived within a marriage has not been performed. Using a tailored questionnaire, this study aimed to bring to light the psychosocial aspects of epilepsy in married PWE in the United Kingdom. More specifically, the psychosocial burden for PWE and the psychosocial burden for their spouses was measured, compared and correlated with the clinical burden of the seizures.

2. Methods

This study was approved by the UK National Health Service Research Ethics Committee (REC Number: 14/LO/1529). Fully informed, written consent was obtained for all participants. Consent forms clearly stated that the participant was free to withdraw from the study at any time for any reason without prejudice to future care, and with no obligation to give the reason for withdrawal.

2.1 Procedures

Consecutive married patients and their spouses attending Specialist Epilepsy Clinics at the John Radcliffe Hospital, Oxford, United Kingdom, were invited to participate. Inclusion criteria stated that the participant was willing and able to give informed consent to enrol in the study, was married and was aged 18 years or above. The PWE was required to have a primary diagnosis of epilepsy. Patients with non-epileptic attacks were excluded as were participants who had **comorbidities (for example: focal neurological deficits, heart disease,** a learning disability, alcohol or other substance abuse as each of these could independently impact on the psychosocial impact in marriage. **The decision as to whether a co-morbidity would necessitate exclusion from the study was made by the Consultant in charge of care.** We also excluded PWE who had undergone previous epilepsy surgery, as epilepsy surgery has been shown to alter the psychiatric outcomes of epilepsy [6].

Recruitment continued until 50 PWE-spouse pairs had been enrolled in the study. Demographic information including age, ethnicity and date of marriage were recorded for both the PWE and

their spouse. A questionnaire was applied to the PWE and a questionnaire was administered separately to the spouse of the PWE. Items on the questionnaire came from previously validated instruments to measure stigma (Epilepsy Stigma Scale Emory University, Hospital Anxiety and Depression Scale (HADS), QOLIE-31) [7-9]. The questionnaire was administered face to face by a member of the study team to ensure that any queries that arose as the participant completed the questionnaire could be clarified. The spouse's questionnaire was modified such that the statements were referred to the patient: i.e., rather than reading as "people who know that I have a seizure condition treat me differently", the prompt stated that "people who know my spouse has a seizure condition treat him/her differently". On completion of the questionnaires, these were link-anonymised. The questionnaires are provided in supplementary materials.

In PWE, clinical characteristics were assessed including seizure onset, date of diagnosis, type of seizure(s), frequency of seizures, number of medications taken and epilepsy associated disorders. The medical notes were then scrutinised to enable an assessment of seizure severity (NHS Seizure Severity Scale [10]) for each type of seizure that the PWE experienced. Scores from the questionnaires were correlated with the estimated clinical severity of seizures. PWE and spouse scores were compared in aggregate and across multiple domains.

3. Results:

3.1 Demographics

Fifty spouse-PWE pairs were recruited, but four couples were subsequently withdrawn from the analyses (3 incomplete data; 1 couple were long term partners but were subsequently identified as not being married). Our population was ethnically homogeneous, with 93.62% being Caucasian (89.36% white British). It consisted mainly of middle-aged and older couples, with 68.09% of patients and 70.21% of spouses being over 45 years of age. Our patients were almost evenly split between two genders, with males being 53.2% of our patient population. Basic demographic data are illustrated in Figure 1.

3.2 Analyses

We first investigated correlations between scores on the questionnaires with seizure severity. Higher seizure severity correlates with smaller reporting differences in psychosocial outcome between spouse and the PWE at both one month ($p = 0.005$) and one year ($p = 0.021$).

We subsequently looked for specific differences in reporting within the psychosocial score. Higher overall adversity scores were correlated with poor driving performance, as reported by the patients themselves ($p = 0.009$). This correlation was slightly more significant when the spouse reported that their partner not being able to drive had a psychosocial impact ($p = 0.004$). We did not find any significant correlation between overall psychosocial score and questions related to leisure time.

Gender-specific differences

We then investigated differences arising by gender of patient and spouse. Through this analysis we identified that the aforementioned correlation between poor driving performance and adverse psychosocial outcome was driven by male PWE only. In addition, males appeared to be significantly affected if their spouse also believed that their inability to drive was a limitation ($p= 0.008$ and $p= 0.008$ respectively).

The mood of female PWE over the previous month was strongly correlated to their overall social outcome over the previous year ($p= 0.001$). There was no such effect in males. In female patients only, lower self-rating scores in questions related to cognition and a higher level of anxiety were associated with evidence of more severe seizures in the four weeks prior to completing the questionnaire (trend; $p= 0.075$). In males, these two factors and seizure severity in the preceding four weeks were not correlated.

We next wished to determine if there were gender specific differences in how spouses perceived the severity of epilepsy in their partner. There seemed to be a very significant correlation between low scores on the 'overall health' scale of a PWE as reported by male spouses and seizure severity score over the course of one year ($p= 0.003$). This was not the case when the spouse was female. However, the overall psychosocial score as reported by a male spouse was inversely correlated to their wife's assessment of her health ($p= 0.042$). The scores of female spouses on the other hand had a positive correlation with scores of male PWE – although this did not reach statistical significance ($p= 0.231$; Table 1).

Differences in epilepsy onset

As a final step, we were keen to uncover if there were differences in the impact of epilepsy on marriage should the condition pre-date matrimony or if its onset was after the couple married. In PWE with seizure onset within marriage, a high degree of perceived **stigmatization** correlated to worse psychosocial functioning ($p= 0.025$) and these PWE tended to be more anxious when experiencing severe seizures ($p= 0.013$). These correlations did not reach significance for PWE who were diagnosed with epilepsy prior to marriage. In addition, there was a significant correlation between mood and low psychosocial functioning in PWE where the diagnosis of epilepsy was made after the couple were married ($p= 0.004$), while low mood was also affected by seizure severity in this group ($p= 0.032$).

4. Discussion:

The institution of marriage, in the sense that it is the formal recognition of a close (physical and psychological) long-term bond, might be expected to act as a protective factor against perceived stigma. However, prior studies have shown that family relations can also have a destabilising effect, for instance when there is a high level of expressed emotion from the person in a caring role [11], [12]. Moreover, gender-specific differences in experiencing life as a PWE are poorly studied. Overall our results show that seizure severity (which can correlate with stigma [13]) seems to ‘galvanise’ understanding in the couple – in the sense that discrepancies in the perceived burden between spouses and the PWE are minimised when seizures are more severe. This seems to be in contrast to results from a prior study we had conducted evaluating the parent-child relationship in another chronic disease (Cooley’s anaemia) – where clinical

severity and carers' perception of the psychosocial burden did not correlate [14]. **While parent-child psychosocial interactions and dynamics are clearly different to those between spouses, it is also likely that the interactions between close family members will be different for different chronic diseases.**

Male vs female perspectives

The rationale behind exploring gender-specific differences in the perceptions of the spouse arose because differences in caregiving between males and females are well-documented, cross-cultural and even cross-species [15]. The impact of dissimilarity in empathetic style between the two sexes was examined, in terms of support for the PWE. A more deliberative approach seems to be adopted by male spouses –whose focus seems to be on medical severity, as opposed to psychosocial impact, of the condition. However it is possible that a discrepancy between perceived disease burden could result in conflict and further psychosocial deterioration of the mental health of the PWE, should they feel that their support needs are not being met. Our results seem to indicate that assisting in and/or initiating dialogue between the partners on the effect that epilepsy can have may be beneficial especially in women with epilepsy, where more severe seizures have a greater adverse impact on mood and anxiety than is seen in men. Therefore women who have had severe seizures might particularly benefit from counselling or other supportive interventions.

Onset of epilepsy

Higher levels of perceived **stigmatization** and anxiety about seizure severity in patients with seizure onset within marriage could be interpreted in the light of illness intrusiveness. Acute

lifestyle disruptions have been shown to correlate with poor quality of life for both PWE and their carers [16]. It could be argued that PWE with an early onset of epilepsy have had time to achieve a better understanding of their condition – and their ability to enter marriage could be interpreted as a sign of resilience. Moreover, although not specifically enquired about, in most cases where the epilepsy had begun before marriage, the spouses were aware of their partner's diagnosis of epilepsy prior to marriage meaning that these spouses would likely be more prepared for the consequences of epilepsy before they agreed to wed. PWE whose seizures began after they were married potentially face a more acute strain on their relationship. One way to further assess if marriage itself is a protective factor would be to analyse psychosocial scores at acute presentations in married PWE and compare these to those of unmarried PWE with the same disease duration.

Limitations of the study

One obvious limitation of this study is that it did not examine co-habiting, same-sex couples, or non-binary PWE. Particularly given the increasing prevalence of such relationships we plan to extend our research into these unions. **Similarly it would be important to replicate this work in younger participants and those from different ethnicities (as the majority of people we studied were Caucasian and over the age of 50).** It would be interesting to see whether and how such relationships may act as protective factors – perhaps with added measures relating to quantification of the intimacy of the couple's bond and how this affects stigma perception. **We also hope to perform similar studies in low to middle income countries and to examine, in a culturally specific way, what the effect of epilepsy in marriage and of marriage on epilepsy may be in other ethnic populations around the world.**

An additional weakness is inherent in analysing the total psychosocial score as the same total score can be obtained by a combination of different severity scores in the scales that it consists of, thus making the sub-analyses which we conducted, essential.

Conclusions

Our study has demonstrated important gender-specific differences in the perception of epilepsy-related psychosocial burden for both PWE and their spouses. Although severe seizures in this sample of couples were correlated with a smaller discrepancy in perceived seizure burden, when the gender of the spouse was taken into account, there were additional differences. Worse psychosocial outcomes were linked to impaired driving ability in male PWE, and low mood in female PWE – **which in turn tended to correlate with seizure severity in our female PWE group.** **In our cohort of subjects,** irrespective of gender, onset of epilepsy within matrimony correlated with higher levels of anxiety and stigma. These factors need to be considered during efforts to reduce stigmatization related to epilepsy and in the development of tailored therapies with an aim to support PWE and their spouses. **It is also evident that much more work needs to be done to better understand the complex impact that epilepsy may have on close relationships so as to be able to better offer targeted support to PWE and their partners.**

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