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Research paper

Arranged marriages in people with epilepsy: A pilot knowledge, attitudes and practices survey from India

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ABSTRACT

Introduction: Marriage is a socially challenging barrier in the personal lives of people with epilepsy worldwide. However, it is during arranges marriages, which are common in South Asian communities, that epilepsy is most profoundly stigmatizing. We hypothesized that the felt stigma associated with epilepsy during arranged marriages affects women more frequently and intensely.
Materials and methods: A pilot study in married (n = 38) and unmarried PWE (n = 58) and general public (n = 150) to explore gender-based differences in the stigma associated with epilepsy during arranged marriages.
Results: Majority unmarried PWE (87%) considered arranged marriage as the best way to realize their matrimonial plans. More unmarried women (72%) apprehended problems in adhering to their epilepsy medications regime after marriage (p 0.009) and 50% apprehended victimization in marriage on account of epilepsy (p 0.001). Moreover, 41% of the married women with epilepsy felt that the disclosure had a negative impact on their married life (p 0.047).
Conclusions: South Asian WWE experienced more felt stigma than men before and after arranged marriages and this might impact a number of health related psychosocial outcomes. The lack of past experience with epilepsy was associated with a number of misplaced beliefs about and attitudes towards epilepsy.

1. Introduction

Epilepsy, one of the commonest neurological disorders, is notable for the stigma associated with it.[1–4] Stigma denotes an attitude of the society, which discredits an individual because of a specific trait (herein, epilepsy).[5,6] It impacts a multitude of social spheres including education, employment and marriage in people with epilepsy (PWE).[7–9] Epilepsy hits hardest during matrimony, often remaining under shadows throughout its course.

Worldwide, matrimonial practices, customs and rituals vary considerably and hence the impact of epilepsy on matrimony must take into account these cross-cultural variations.[10] A peculiar matrimonial practice, known as "arranged marriage", is particularly common in parts of Asia, Africa and Middle-East[11] (more so in South Asia and South-east Asia). For instance, 89% of the marriages in India are arranged.[12] The main feature of arranged marriages is the search for and selection of a prospective spouse by parents and/or extended family through their social contacts or media using considerations of physical characteristics, socio-economic status, caste and education. The search is often followed by one or more meetings between the families of the prospective partners in which the "marriage is negotiated". Moreover, because the choice of marital partners is with the elders/family, there is limited or often no contact between the partners before marriage. In these

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matrimonial negotiations, physical or mental illnesses are considered discrediting in comparison to high income and education, social status and good looks, which might be plus-points. Hence, discrediting conditions such as epilepsy are often not disclosed (or willfully concealed) at the time of matrimonial negotiations. On the other hand, disclosure of epilepsy during marital negotiations may result in breakdown of negotiations. A recent consensus meeting of experts identified reduced marital satisfaction, increased chances of divorce, incomplete adherence to epilepsy medications leading to poor seizure control, reduced physician visits and health implications therein as potential consequences of concealing epilepsy during matrimonial negotiations.[13] The expert group identified a number of gaps in the understanding of interaction between epilepsy and arranged matrimony largely due to the lack of systematically collected population-based data on marital outcome and knowledge, attitudes and practices. Filling up these information gaps was considered crucial to elucidating measures to tackle the problem of arranged marriages in PWE. Finally, the expert group observed that the predicament of arranged marriages in PWE occurs in the backdrop of a deep-rooted gender discrimination (with bias against women) that permeates a number of pursuits including child-rearing, feeding, education, employment, property-rights and matrimony in the prevailing socio-cultural climate in these communities. Because of the gender bias, women might be subject to higher levels of felt and enacted stigma related to epilepsy and perhaps adverse marital outcomes.

We undertook an exploratory pilot survey of knowledge about, attitudes towards, and practices regarding (KAP) matrimony in unmarried and married people with epilepsy (PWE) and the general public. Post hoc, we hypothesized that women experience greater degree of felt stigma associated with epilepsy in arranged marriages and hence, undertook a comparison of the KAP responses by gender.

2. Material and methods

We surveyed three groups of people attending hospital: never-married PWE ($n = 58$), married PWE ($n = 38$), and lay people without epilepsy or a neurological disorder ($n = 150$). Unmarried and married PWE were above legal minimum marriageable age in India (>18 years for women and >21 years for men) and attended the Epilepsy Clinic at a busy secondary–tertiary care pay-for-care hospital in Northwest India. Active epilepsy, identified through a history of seizures in the past five years and ongoing treatment with epilepsy medications with the need of treatment, was confirmed by a neurologist in the study team. Those with concomitant neurologic handicap, intellectual impairment, psychiatric disturbances, or functional non-epileptic events were excluded. Lay people were recruited from those seated in the hospital reception either awaiting consultation in the clinics or those visiting hospitalized patients.

The study design and methods were approved by the institutional ethics committee. Written informed consent was obtained from all subjects. They were then handed questionnaires by volunteers. Questionnaires were carefully designed in English language by neurologists after discussion and consensus and then translated into two regional vernacular languages (Hindi and Punjabi). These forms were purpose-designed for the three groups of subjects with minor differences between the three groups. The questionnaires were similar for all three groups with minor differences. The first five questions assessed knowledge about epilepsy in relation to matrimony, e.g., could epilepsy be a legal ground for divorce? The subsequent four questions gauged attitudes towards epilepsy, for example should people with epilepsy get married? Could they bear children? Were they likely to have sexual problems? The questionnaires were filled up by the subjects themselves, though, volunteers were allowed to offer guidance if required.

The responses obtained from the three groups of subjects were double-entered in to a computerized database and then analyzed using STATA (version 13; StataCorp LP). Descriptive analysis of the responses in the three groups of subjects was performed. In addition, responses were compared between men and women among unmarried and married PWE and between people with and without exposure to epilepsy in the lay subgroup. People who answered in affirmative to any of the three questions: Do you suffer from epilepsy? Do you know someone with epilepsy? Do you have a family member with epilepsy? were categorized as exposed to epilepsy.

Statistical comparisons were performed using the Chi Square test for categorical variables (responses) and the Student's t test for continuous variables (e.g., age). p value <0.05 was considered significant.

3. Results

Demographic and clinical characteristics of unmarried and married respondents with epilepsy according to gender are presented in Table 1. There were 37 (63.8%) women among unmarried PWE and 20 (52.6%) women among married PWE. There were no significant differences between the two genders subgroups in terms of age, religion, seizure frequency and epilepsy type.

Table 1
Demographic characteristics of the sample.

Variable	Unmarried PWE ($n = 58$)	Married PWE ($n = 38$)
Gender (females)	37 (63.79%)	20 (52.63%)
Education		
Under matriculate	10 (17.2%)	11 (28.9%)
Matriculate and above	48 (82.7%)	27 (71%)
Religion		
Hindu	25 (43.9%)	14 (36.8%)
Sikh	31 (54.4%)	22 (57.9%)
Muslim	1 (1.75%)	1 (2.6%)
Current seizure frequency		
Frequent	29 (50%)	21 (55.3%)
Infrequent	17 (29.3%)	17 (44.7%)
Epilepsy syndrome		
Focal epilepsy	9 (15.5%)	17 (44.7%)
Idiopathic generalized epilepsy	30 (51.7%)	12 (31.5%)
Others	2 (3.4%)	1 (2.6%)
Unestablished	17 (29.3%)	8 (21.05%)

Table 2
Demographic characteristics of general public ($n = 150$).

Variable	Number (%)
Gender	
Males	96 (64%)
Females	54 (36%)
Age (years)	
18–39	127 (84.6%)
>40	22 (14.6%)
Education	
Under matriculate	21 (14%)
Matriculate and above	129 (86%)
Religion	
Hindu	74 (49.3%)
Sikh	66 (44%)
Muslim	5 (3.3%)

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