



Impact of Epilepsy on Marriages in People with Epilepsy: An Ethnographic Evaluation

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The sole author designed, analysed, interpreted and prepared the manuscript.

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Short Communication

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ABSTRACT

Epilepsy is considered as a stigma in our society. This becomes more prominent among those who are in marriageable age. In this paper 21 PWE who attended an outpatient epilepsy clinic at a secondary-level hospital in Northwest India between 01.01.2015 and 31.03.2015 formed the case material for this study. Four cases were deeply interrogated and it was found that all of them denied the revealing of epilepsy to their prospect marriage partners. Two of them also denied of revealing them about taking ADE'S. It was found that PWE's face many social and psychological problems while marriage negotiations and even after marriage.

Keywords: Epilepsy; marriage partners; psychological problems; chronic illness.

1. INTRODUCTION

Epilepsy is a common illness in the world. Epilepsy affects 50 million people worldwide. Epilepsy is a chronic illness. The disease results

1% of days lost to ill health globally [1,2]. Epilepsy is associated with substantial stigma and discrimination in the Indian subcontinent as in many other low-and middle-income countries (LMICs) where culture has a strong influence on

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life of people. Epilepsy, one of the most common neurological disorders is also perhaps the most stigmatizing of all although epilepsy is a medical condition, the person with epilepsy also has to cope with its psychological and social consequences [3-5]. Epilepsy has many non-medical effects on the people with epilepsy, their family and community. It also affects the marriage institution of people with epilepsy. Marriage is one of the important social institutions prevalent in all societies of the world with varying degree of sacramental values. In contrast to the western societies, marriage in Indian society is considered as an indispensable and durable social binding [6] Menski 2010). Sociologically, the marriage whether is arranged by others or chosen for love by the individuals to be wedded, marriage is a structured and has patterned set of social relations and practices. It is embedded in norms and values regarding what marriage should be and is. There are explicit social prescriptions and sanctions by public bodies, the state, religion and community [7].

2. MATERIALS AND METHODS

21 PWE who attended an outpatient epilepsy clinic at a secondary-level hospital in Northwest India between 01.01.2015 and 31.03.2015 formed the case material for this study. Their conversation were recorded with their consent. Tape-recorded conversations in native language (Hindi or Punjabi) were transcribed and subsequently translated to English language for discussion among, and analysis by experts. The written transcripts as well as tape-recorded conversations were presented at a one day, round-table meeting of epilepsy experts, neuropsychologists, a sociologist and a legal expert. The opinion of the experts and discussions thereof were also recorded and reviewed in preparation of this manuscript. The consensus opinion of the experts is rendered in this manuscript. Four conversations touching upon marital design or experiences in PWE are presented here for their representativeness.

Conclusions of this study is based upon issues which were highlighted during the conversation with PWE.

Case Study 1: ABC, female, 21 years came in with her mother for the first consultation. She had generalized tonic clonic seizures from 7 years. She was initiated on valproate but later switched to levetiracetam 4 years ago and thereafter had no further seizures.

Mother: She is getting married in 4 weeks time.

Doctor: Oh, she is taking her epilepsy medications? Mother: Yes and she had not any seizures.

Doctor: Good. But have you told the prospective groom or his family that she has epilepsy and is taking epilepsy medications.

Mother: No, we do not intend to tell them.

Doctor: So, how will she be able to take medications surreptitiously?

ABC: Yes, it will be difficult but we will manage somehow.

Case Study 2: XYZ, a 21 year old woman, about to get married soon came in with her mother for the first consultation. She had her first seizure at the age of 14 years and was seizure-free for the preceding four years while on tab. Levetiracetam, 750 mg bid.

Doctor: Hello. All ok?

XYZ: I am getting married three week from now.

Doctor: Good News. And how is your seizure control?

XYZ: Good.

Doctor: What do you do?

XYZ: I work as a teacher in a primary class.

Doctor: What is your education?

XYZ: MA, B.Ed (Bachelor of Education).

Doctor: So, have you told your prospective marriage partner about your epilepsy?

Father (interjects): No, we have not told her partner or any of his family members that she has epilepsy.

Doctor: But then, do you think that the fact that she has epilepsy would remain hidden from the husband or the in-laws? I mean, if she continues to take her epilepsy medications after marriage, and her husband gets the sight of the medicines or her taking medicines, he and his family would get to know that she has epilepsy. On the other hand, it is difficult to hide the medicines and to

continue to take the medications in a secretive manner in any marriage.

Father: See it is very difficult to tell them (In-laws). Who will agree to get married in today's world? See, I think we should be able to tell them or the husband after a few months of marriage.

Brother: Yes? (Do you approve?)

Doctor: See I am no one to decide for you whether you should discuss the fact that you have epilepsy or not with your prospective husband. It is always good to be open and freely discuss all the issues in your mind with your partner but it is also not possible to reveal each and every thing with your partner. You are the best judge about what to reveal and what to conceal. I would leave that decision to you, also when to discuss this issue with your prospective partner. The decision depends on your judgment i.e. what is the best time to reveal the fact.

Doctor (to SJ): Did you consider stopping your epilepsy medications?

SJ: I do not want to stop medications as I do not want to uncover the risk of having a seizure.

Doctor: Fair enough. Do you think you will be able to take epilepsy medications without your husband getting to know after marriage?

Father: At least it will have to be done for the first few months.

Doctor: Well Ok: If that is your decision.

A discussion on contraceptives, pregnancy, erotogenic effects, transmission of epileptic traits- all information was given.

Case Study 3 VXY- female, 31 years: The patient came to clinic with her brother, was first seen in clinic at the age 19 years, at which point she commenced AED treatment. She remained seizure free for the next 3 years and hence, she discontinued her epilepsy medications on her own without medical consultation. She got married soon thereafter and had a seizure one year after marriage, then she visited clinic again with her parents. She was started on Levetiracetam and her seizures have been well-controlled since then.

She is a graduate, primary school teacher, lives with her in-laws and has 2 children. She comes

to clinic very sporadically. Her husband runs a shop.

Doctor: Seizures under control?

VXY: Yes.

Doctor: Any side effects?

VXY: Well, it is very difficult to take these medicines. It has been a very long time.

Doctor: I understand, but you need to realize that you are seizure-free because of the medicines.

Doctor (to brother): Are you her husband?

Brother: No I am her brother.

Doctor: Oh I remember, you usually accompany her to clinic.

Brother: Yes mostly.

Doctor: Do her in laws and husband knows that she has epilepsy? And that she is taking epilepsy medications.

Brother: Yes, she stopped her medications prior to marriage but she had a seizure after marriage, at which point of time, we consulted you and you started her on treatment again.

Doctor: How soon after marriage did she have a seizure?

Brother: One year.

Doctor: Ok. Do you buy her medications?

Brother: Yes, we do.... purchase her medications and give it to her.

Doctor: Did her in laws want it that way? I mean that you purchase medications for her.

Brother: Not exactly. They were somewhat upset at the time, she had a seizure after marriage. So we offered to take her to you for medical treatment and have been buying her medications since then. It is not a problem for us. We are quite happy with this arrangement.

Doctor (to VYX): Are you happy with this arrangement?

VYX: Not really. My in laws are always complaining.

Doctor: Why? What do they complain about?

VYX: Well they say I am not gaining weight and not active because of the medications.

Doctor: Oh.

VYX: Basically, they really want me to stop my medications. I am fed up with their repeated nagging. Doctor please stop my medications.

Case Study AMN- female, 33 years: The patient had epilepsy from last 18 years. She has 12 years of marriage, with 2 children, aged 10 and 7 years, she was on Tab. Valprin Chrono 400 mg twice daily. She was a housewife and lives in a joint family, was seen by me 15 years ago and initiated on valproate. Since then, she has had rare seizures, only when she stops taking her medications, on a couple of occasions after marriage. She has studied upto Class XII, her husband was a farmer, also studied upto Class XII. She came in with her brother. She has made a total of 3 visits since her diagnosis.

Doctor: Hello! How are you? Any seizures? AMN: Not lately. Doctor: Are you tolerating medications well? AMN: Yes, indeed.

Doctor: No side effects?

AMN: None.

Doctor: Are you taking your epilepsy medications regularly?

AMN: Well, mostly yes.

Doctor: What do you mean by that?

AMN: Well you see, I have to take the medications secretly, so on rare occasions, I miss the medications.

Doctor: Oh! Does your husband not ask you what these medications are?

AMN: Well! I tell him that these medicines will improve my weakness.

Doctor: ok. Your husband and in laws do not know that you have epilepsy.

AMN: No.

Doctor: And you have not had any seizures after marriage.

AMN: Well I did have n 1-2 occasions that was whenever I missed my medications.

Doctor: So did they not enquire what went wrong?

AMN: Well! We offered to get her checked up and took her home for a few week. And then we told them that it was all weakness only.

Doctor: How do you rate your level of satisfaction in your marriage?

AMN: Well, I'm quite satisfied

3. RESULTS

Four PWE's were studied deeply for this research paper. The patients were selected on the basis of their age group. Those cases were in marriageable age. In majority of cases seizures were controlled while taking AED's majority of them were about to get married in coming time Results showed that all four PWE's denied to reveal the fact of having epilepsy to their would be in laws and perspective life partners. Two of them also denied to reveal about taking AED's to their partners and their families. Both of them and their families were afraid of cancellation of engagement if they reveal the epilepsy fact. This shows the level of stigma attached with epilepsy in Indian society. The conversations depicted that in most of the cases people tend to hide the fact of epilepsy as the breakdown of matrimonial negotiations becomes main cause for families of PWE to hide epilepsy in arranged marriage. Hiding the fact of having epilepsy not only exist in marriage negotiations, but PWE also hide it in a range of social interactions like within kinship, in workplace, in peer groups, strangers and even in intimate relationships.

4. MARRIAGE AND EPILEPSY

Practices, customs, rituals and attitudes towards marriage vary considerably from one region to another and these variations need to be factored in consideration of the impact of epilepsy on marriage. A distinctive tradition, the arranged marriage is widespread in much of South Asia but also observed in smaller numbers in the rest of the world [8,9]. Over 95% of those who get married in India, Pakistan and Bangladesh and over 50% of those in Sri Lanka aside from the enormous expatriate populations from these countries in Western as well as Arabian countries do so by way of arranged marriages. Arranged marriage is defined as one where parents choose marital partners for their children and arranged marriage is a norm in many parts of

Asia, Africa and Middle East On the other hand, non arranged marriages are common in the Western part of the world. In the modern world there is co-existence of both types of marriage system [10,11].

The stigma attached to epilepsy becomes more pronounced, especially when it comes for marriage; even though the word epilepsy has been removed from the Hindu Marriage Act 1955 and Special Marriage Act long ago. In a study it was reported a lower marriage rate, delayed marriage especially among females, suspended marriage, and higher divorce rate in PWE as compared to general population. The disease status of PWE is usually not disclosed in most of India at the time of marriage due to fear of failure of marriage negotiations [12]. It was observed that nearly 55% of people with epilepsy have concealed their disease status at the time of marriage. There was an increased demand for dowry or cancellation of engagements following disclosure [13].

Marital disharmony ensues when the presence of epilepsy becomes evident. Among those who concealed their epilepsy status at the time of marriage; 18% were divorced, 20% were separated, and 45% were disturbed have reported adverse treatment outcome due to marital disharmony among the PWE. Due to the long fought battle of Indian Epilepsy Association (IEA), the Indian judiciary has in recent times pronounced that epilepsy should not be equated to mental illness and the practice of divorce among married individuals due to epilepsy should be strongly discouraged [14].

5. HIDING OR REVEALING THE FACT OF EPILEPSY

Patients with epilepsy who entered in marriageable age tend to feel more pressure and depression in traditional societies because of not fulfilling the social aspirations of his/her society have more depression.

Except when epilepsy is either severe or associated with psychiatric comorbidity or neurological handicap, the disorder is concealable. Other than during brief periods of seizures or convulsive activity, it goes unnoticed and in this manner, it is different from physical disorders, e.g., limb disability. This feature is permissive to hiding epilepsy during marital negotiations in arranged marriages. There are certain factors responsible which forces PWE not

to reveal the fact like: 1) less social acceptability of PWE's 2) unawareness among the people regarding epilepsy 3) social stigma attached with epilepsy 4) social rejection towards PWE. The family seems to have already considered the advantages and risks of hiding epilepsy during the marital negotiations and the consequences thereof while at the same time appear to have an understanding of the implication of stopping epilepsy medications for the fear of revelation after marriage. It might be pertinent to point out the potential consequences of hiding epilepsy during marital negotiations in arranged marriages. While divorce rates are comparatively low in arranged marriages, the likelihood of PWE divorcing increases in arranged marriages in comparison to love marriages. In these arranged marriages, divorce is associated with hiding epilepsy during marital negotiations.

As far as the hiding the fact in marriage negotiation is concerned, there are certain causes behind it. Like in traditional societies, people are very protective about their children's life. No parent wants their children to marry a person who himself/herself is living with some uncertainty. Especially in arranged marriage, where the total responsibility of getting the child married to a good person is on parents. Families in traditional societies are society driven families. Where people care more about their social status rather taking care of individual.

In these societies, parents of PWE hide the fact of epilepsy as they also feel social pressure of getting their child married. But this cannot happen if they reveal the epilepsy fact. Another unawareness about epilepsy in these societies are less productivity of PWE and becomes a burden on the family, as earning opportunities and education attaining chances gets limited for PWE's.

6. BEARING EXPENSES OF MEDICATION

In many cases of married women with epilepsy, taking medicine after marriage becomes a major issue of concern as they concealed the fact of having epilepsy at the time of marriage. Sometimes, married women stop taking medicine after marriage due to many factors. In some cases, many subjects keep on taking medicine without telling the partner and in those cases, it was the natal family of the women with epilepsy rather than the conjugal family that bore the responsibility as well as expenses of treatment. While, in many cases hiding epilepsy in married

life might lead to PWE either discontinuing their epilepsy medications only to have seizures or continuing to use medications in a surreptitious manner. Even so, hiding epilepsy might conceivably be a barrier to visit specialist or other health-care providers at a time after marriage when specialist advice is much needed, e.g., regarding contraception, pregnancy planning and monitoring medications during pregnancy. This is clearly illustrated in some subjects, who would have recourse to medical consultation only while visiting their natal homes. Besides, hiding epilepsy has been associated with a poor marital outcome.

7. REPRODUCTIVE ISSUES AND EPILEPSY

Issues regarding reproduction is a major concern in WWE. For females, the issues of child-bearing and child-rearing and for the male the issues of employment and income have become critical during the marriage. It is always said that a healthy mother can give birth to healthy child. Pregnancy after marriage was discouraged due to fear of having a child with epilepsy or other abnormalities. Earlier studies have indicated that WWE have reduced fertility. For females, the issues of child-bearing and child-rearing and for the male the issues of employment and income have become critical during the marriage. A study by Agarwal et al., reported a lower marriage rate, delayed marriage especially among females, suspended marriage, and higher divorce rate in PWE as compared to general population. The disease status of PWE is usually not disclosed in most of India at the time of marriage due to fear of failure of marriage negotiations. Santosh et al. observed that nearly 55% of people with epilepsy have concealed their disease status at the time of marriage. There was an increased demand for dowry or cancellation of engagements following disclosure.

8. CONCLUSION

In conclusion, poor marital prospect and high divorce rate of PWE in many Asian countries reflect the effects of social stigma and many other adverse factors that the PWE have to face, although there are already progresses in some societies. To maintain a balance between marriage and epilepsy, the people with epilepsy need information and psychological and social support. This awareness regarding epilepsy can be provided through the support of epilepsy

specialist community worker, who can be informed, empathetic listener, alleviate fear of the unknown, encourage compliance, and provide information to the people with epilepsy, their family and the community. The epilepsy specialist community worker can also facilitate the establishment of contacts and self-help groups to boost self-esteem and confidence. Moreover the epilepsy specialist community worker can provide right information about epilepsy, and how to maintain a balance between married life and epilepsy. The epilepsy specialist community worker can also help the people with epilepsy in thinking about whether or not to disclose, local regulations for driving, insurance, and in contacting other people with epilepsy. Moreover, one needs to educate the family of PWE regarding epilepsy, they should motivate the PWE's to empower themselves with other aspects of life.

CONSENT

Informed written Consents were obtained from every parent/surrogate of patients.

COMPETING INTERESTS

Author has declared that no competing interests exist.

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