The dilemma of arranged marriages in people with epilepsy. An expert group appraisal.

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Bullet Points

- Arranged marriages are very common in South Asia but also take place among South Asian expatriates and sporadically in non-Asian populations across the world.
- Arranged marriages pose a psychosocial challenge to people with epilepsy (PWE) because parents/elders initiate, negotiate and contractualize the marriage of their wards, which presents little opportunity for the prospective partners to interact before marriage.
- Concealment of epilepsy is common during negotiations in arranged marriages.
- Counselling PWE regarding arranged marriages is complicated but should ideally begin preemptively much before marriage is contemplated and should emphasize their empowerment through education and employment and disclosure of epilepsy during marital negotiations.

Abstract

Introduction: Matrimony remains a challenging psychosocial problem confronting people with epilepsy (PWE). PWE are less likely to marry; however, their marital prospects are most seriously compromised in arranged marriages.

Aims: To document marital prospects and outcomes in PWE going through arranged marriage and to propose optimal practices for counselling PWE contemplating arranged marriage.

Methods: MEDLINE search and literature review followed by a cross-disciplinary meeting of experts to generate consensus.

Results: PWE experience high levels of felt and enacted stigma in arranged marriages but the repercussions are heavily biased against women. Hiding epilepsy is common during marital negotiations but leads to many adverse consequences including poor medication adherence, reduced physician visits and poor marital outcome. Although divorce rates are generally insubstantial in PWE, divorce rates appear to be higher in PWE undergoing arranged marriages. In these marriages, hiding epilepsy during marital negotiations is a risk factor for divorce.

Conclusions: In communities, in which arranged marriages are common, physicians caring for PWE are best-equipped to counsel them about their marital prospects. Marital plans and aspirations should be discussed with the family of PWE in a timely and proactive manner. The benefits of disclosing epilepsy during marital negotiations should be underscored.

Key Words: Epilepsy; Marriage; Divorce; Outcome

Introduction

Epilepsy, one of the most common neurological disorders, literally means “to be seized with”. Although epilepsy appears relatively straightforward to treat, the management of psychosocial issues associated with it is considerably complex. People with epilepsy (PWE) are more often ‘seized by’difficult social environments and negative attitudes than by epileptic seizures. Negative attitudes lead to stigmatization in education, employment and marriage.

Until recently, marriages were either forbidden or could be invalidated because of epilepsy.[1] Western industrialized countries have experienced positive legislative reform and improvements in public attitudes in relation to marriage and epilepsy. [2, 3] However, in many Oriental, and south- and west-Asian communities, the stigmatization potential of epilepsy during matrimony is immense, only insufficiently documented.[4-8] The stigma leads to reduced prospects of marriage, marital discord and possibly an increased likelihood of divorce following marriage.[4,5,9]

Arranged marriage refers to parental/elder control in choosing marital partners.[10] Elders track down marital partners through their social contacts or print and electronic media, and base the search on considerations of religion, caste, socio-economic status, physical characteristics and horoscopic predictions. Traditionally, arranged marriages afford little opportunity for prospective partners to meet and develop rapport. Hence, PWE fail to disclose the fact that they have epilepsy during matrimonial negotiations while those who disclose upfront are often faced with rejection. Professionals in epilepsy care frequently face the challenging task of providing counsel regarding the optimal way to deal with the situation. Very few studies have examined marital prospects and outcome in PWE and there is little scientific data on which to base guidance to PWE seeking partners through arranged mar-

riage.[4,5,11,12] Here, we report the outcome of a meeting of experts in epilepsy, social science, and legal and administrative services in order to consider optimal practices for caregivers (including physicians) contending with arranged marriage in PWE.

Material and Methods

A MEDLINE search undertaken (by GS) using the search terms "Epilepsy"and"Marriage"yielded 213 abstracts. Of these, 132 were excluded (28, in languages other than English; 53, unrelated to epilepsy; 51, not alluding to marriage). Full papers of the remainder (Table 1) were reviewed (GS, VSS and ST).

A round-table meeting of experts comprising 19 epileptologists from across India (except JSD - overseas), social scientist (RA), neuropsychologists (CS, US), administrative (VM), legal (VS) and media (GT) experts was organized. The meeting included didactic talks by selected experts, a debate [To conceal (epilepsy) or not to (during marital negotiations)] and discussions on transcripts of conversations between PWE and their neurologists (GS, MMM, PSK) regarding marital plans or experiences (paper submitted elsewhere) and focus group meetings (conducted by US). Recommendations drafted by GS circulated prior to the meeting (via email) to all experts were discussed in order to arrive at a consensus.

Arranged marriages: Global perspective and overview

Arranged marriages are rare in the post-industrialized western nations and probably declining in many parts of the world (e.g., China) (Table 2).[13] However, arranged marriages are common in South Asia and probably Far-East Asia.[10-12,14-16] Over 95% of marriages in India, Pakistan and Bangladesh are arranged.[10] Besides, there exist large expatriate Asian

communities in many western nations, in which, arranged marriage is the norm. The enormous scale of arranged marriages can be measured by the sizeable native as well as emigrant South Asian population.

The choice of the marital partner in arranged marriages is typically made by parents/elders. However, in the recent times, although parents or family initiate the process, but the prospective bride and grooms are now consulted during the match-making. A population survey in India noted that 25% of parent-arranged marriages in a birth cohort from the 1970s took place with the consent of prospective partners.[14] Even so, 57% who got married through parent-arranged marriages to which they had consented; and 86% of those who were married without their consent, admitted meeting their partners for the first time on their wedding day. This feature of an arranged marriage allows little opportunity for the prospective bride and groom to discuss consequential past and future matters. Another feature involves the bride moving in to an extended family of the groom with patriarchal authority (patrilocal residence; female exogamy).

Implications for PWE

Since epilepsy is a sensitive and profoundly stigmatizing issue, a certain degree of familiarity, which develops only over time, is required before disclosing it to the prospective spouse. The limited pre-marital contact between the couple is an impediment to disclosure of epilepsy. Besides, the patrilocal settlement in arranged marriages deprives the bride of her existing social and family support, which might be an important mechanism to cope with epilepsy.

Does epilepsy influence marital prospects?

Epilepsy limited marital prospects in PWE in the early nineteenth century prior to the eugenic legislation in the United States and European Countries.[1] Only few studies examined marriage prospects in PWE more recently and found an excess of never-married PWE in comparison to the general population.[17-19] Curiously, studies from western countries documented lower marriage rates in men with epilepsy, particularly if seizures in them commenced before 10 years of age. Small clinic-based studies from Far-East Asia likewise documented that PWE had an increased likelihood of remaining single. [11, 12]

The connection between stigma of epilepsy and arranged marriage

The stigma associated with epilepsy is particularly intense for PWE with psychiatric comorbidities, poorly-controlled epilepsy and those living in resource-poor countries.[20] Although debatable, stigma is associated with poor quality of life and impaired psychosocial functioning.[21]

Several authors propose different theories regarding the basis of stigma.[20,22,23] Early impressions of seizures as being dramatic, threatening and unpredictable as well as ignorance about the nature of epilepsy lead to bizarre explanations such as demonic possession.[24] Epilepsy was considered a hereditary disorder with relentless progression till the early nineteenth century and is still considered to be a contagious disorder in many resource-poor countries.[20] In several countries, it is equated with mental illness and hence, often treated by psychiatrists (and since neurologists are in small number in these countries).[20,25] In India, the Hindu (dominant religious order) matrimonial statute clubbed epilepsy with insanity, both being grounds for divorce prior to 1999. [26] Because epilepsy is equated with mental illness, the reaction of people to PWE is one of pity rather than sympathy.[20] Finally, the desire to procreate normal healthy offspring, fears of having to deal

with partner's seizures and potential loss of the partner's life due to seizures might be factors associated with stigma in relation to matrimony.

The stigma of epilepsy in arranged marriages is both felt and enacted.[9,27] The felt stigma manifests in PWE in the form of forebodings of rejection by prospective partners. The trepidation leads to postponing attempts to find a prospective marital partner by families of PWE. Enacted stigma is experienced by unmarried PWE when families of prospective partners spurn them during marital negotiations.

One redeeming feature of epilepsy is that unlike visible traits or physical illnesses, it remains undetectable except during brief periods of occurrence of seizures. This renders epilepsy concealable and hence, concealment is the most frequent strategy adopted by PWE to deal with felt stigma.[27,28]

Why do people conceal having epilepsy during marital negotiations?

Concealment is a response to felt stigma across a range of social interactions with strangers, in-laws, friends and professional acquaintances.[28] The decision to conceal or not is influenced by the balance between the perceived chances of detection (e.g., by the social contact witnessing a seizure) and anticipated social consequences of disclosure.[28] In arranged marriages, the anticipated consequences of disclosure can be devastating, leading to breakdown of matrimonial negotiations and hence override the perceived chances of detection.

Some PWE might not disclose for other reasons. They might believe that epilepsy is too trivial a condition to be disclosed. Others might have the erroneous belief that marriage cures epilepsy and enter a marital arrangement in the hope of getting cured.

What are the consequences of concealing a diagnosis of epilepsy during marital negotiations?

People with epilepsy who hide their illness during marital negotiations either discontinue their epilepsy medications at the time of marriage or continue to take the medications covertly. Some choose to stop their medications on their own only to risk having seizure/s at the time of, or soon after marriage. However, majority take their epilepsy medication/s in a clandestine manner to avoid the risk of having a seizure. The regular use of medications surreptitiously within the intimate environment of marriage is challenging and some PWE report disguising their epilepsy medications as vitamin pills by putting them in vitamin-labeled bottles. Perhaps the limited communication between the bride and the groom before marriage persists in the early period after marriage and this allows the use of medications without many questions being asked.

The covert use of epilepsy medications potentially leads to poor compliance, which cannot be monitored and leads to breakthrough seizures. Hiding a diagnosis of epilepsy from the spouse and in-laws makes visits to health care providers difficult and less frequent at times (post-marriage, pregnancy and post-pregnancy) when specialist advice is much required for issues such as fertility, contraception, and teratogenesis. Hiding might also be associated with increased anxiety. Felt stigma is often the reason for not disclosing epilepsy but when epilepsy is revealed due to a seizure happening or unintended disclosure by self or others, it leads to enacted stigma. Finally, failing to disclose epilepsy might impact marital outcome (see below).

Divorce in people with epilepsy

It is hard to attribute divorce to epilepsy alone in couples with a partner having epilepsy. Often there are multiple circumstances that build up to culminate in divorce. Western studies examining long-term psychosocial prognosis in PWE did not find higher divorce rates except in situations when there was a dramatic change in the seizure frequency (e.g., following surgery for intractable epilepsy).[17-19] In contrast, observational studies from Asia, albeit involving highly-selected samples, found higher rates of divorce in PWE in comparison to the general population.[4,5,12] In these studies, divorce was more common in arranged marriages, particularly in marriages wherein the affected partner concealed epilepsy during marital negotiations. The higher divorce rate in PWE who opt for arranged marriages is noteworthy as divorce rates is considered to be rare in arranged matrimony in Asian communities. Moreover, at least one study documented a gender-bias with married women with epilepsy experiencing divorce more frequently as compared to men.[29]

Statutes regarding divorce in couples with a partner having epilepsy vary from country to country. In many South Asian countries (e.g., Sri Lanka and Nepal), in which arranged marriages are common, epilepsy is a legally valid reason for divorce.[6,7] In India, epilepsy was equated to insanity and hence a ground for divorce prior to 1999, but is no longer so.[26] However, a divorce petition may be taken up in court because of failure to disclose epilepsy during marital negotiations. Whether concealing a diagnosis of epilepsy at the time of marital negotiations amounts to fraud or not is debatable as it can be argued that every small matter cannot be possibly disclosed to prospective marital partners. From a medical perspective, well-controlled epilepsy is essentially a benign condition with excellent prognosis. On the other hand, poorly controlled epilepsy, or epilepsy associated with psychiatric, neurological, cognitive comorbidities, constitutes a serious condition that should perhaps not be hidden.

The compounded problem: Epilepsy stigma added to gender bias in impoverished communities

The stigma associated with epilepsy is probably more profound in traditionally disempowered sections of the society. Many oriental societies still are patriarchal with a gender-based power bias. The gender-bias is perceptible during childrearing, feeding, education and employment.[30,31] Epilepsy experts from many South Asian countries contend that matrimony in PWE is a heavily gendered issue, impacting women disproportionately more in comparison to men and is compounded by the prevailing gender-power inequality.[5-8] Unfortunately, this gender bias has not been objectively documented in studies of felt stigma associated with epilepsy in these communities**.** Surveys in western countries in comparison have not observed any significant gender bias in felt stigma associated with epilepsy.[32-34]

Proposed interventional approaches to improving marital prospects and outcome in PWE

The stigma associated with epilepsy, particularly relating to marital prospects is deep-rooted and a turn-around of people's attitudes might take a generation to occur. In the interim however, certain measures might be considered in optimizing marital prospects for PWE (Table 3). The approach should be multidisciplinary, at many levels and involving different sectors. Interventions are required at individual (PWE), family, interpersonal, administrative and societal levels and should involve the health care system, health care providers, and legal, administrative, education, advocacy, social and media sectors.

Recommendations to physicians caring for PWE

Who should counsel people with epilepsy regarding marriage?

Although physicians caring for PWE have limited time and resources to engage in extensive discussions and counsel about matrimonial prospects, they are still the best professionals to deal with this sensitive topic. In following-up their patients, they are likely to have a good understanding of their psyche, personality and aspirations. In resource-poor countries, marriage counsellors are scarce and hence PWE depend upon treating physicians for discussions on marital aspirations.[35] Moreover, where counsellors are available, they might not have the requisite experience or expertise to counsel PWE. Counselling PWE regarding their matrimonial prospects is a sensitive topic and hence should be undertaken by someone who has a fair deal of experience and expertise.

When should counselling be ideally undertaken in the clinic?

Often, families of matrimony-inclined PWE consult the physician after initial marital negotiations (or betrothal) in which, they were unable to disclose the fact that their dependant has epilepsy. The social ramifications of this situation are immensely complex. However, the situation can be averted if physicians following-up PWE bring up the topic of matrimony at an early and appropriate time, ideally before the legal-minimum marriageable age (Table 2).[36]

How should PWE and their families be counselled about matrimony as they approach marriageable age?

The physicians should inquire about the views of the patient and his/her family regarding plans for marriage and age at which they contemplate marriage. Their views about disclosure during marital negotiations should also be gauged. They could be asked to list ways in which epilepsy poses barriers to their matrimonial plans. Many of the barriers might originate from inaccurate information acquired from acquaintances, elders and family doctors

or from previous experiences about epilepsy and may not be based on facts, e.g., someone with a family history of epilepsy might assume that all epilepsies are inherited and this might constitute a mental block to consider matrimony. Such misconceptions can be allayed by providing basic information in the clinic.

During discussions about disclosure during marital negotiations, the patient and his/her family should be counselled about the consequences of concealment on marital outcome, seizure control and general health. The importance of continued care after marriage should be emphasized. It is pertinent to discuss issues related to women with epilepsy, e.g., contraception options, planned pregnancies and optimizing epilepsy medications before, during and in post-partum phase, pre-conceptional folic acid supplementation, teratogenic risks associated with epilepsy medications, risk of seizures during pregnancy, and recommendations regarding breast-feeding practices.[37] Finally, legal provisions about marriage, separation/divorce in PWE, that vary from country to country, should be discussed.

Although underscoring the benefits of disclosure of epilepsy during marital negotiations is appropriate, the choice whether to disclose or not to and when to disclose should be left to the patient and his/her family. “When to disclose?”might depend on the severity of epilepsy and the presence of comorbidity. When epilepsy is severe or associated with neurological or psychiatric disorders, disclosure should be imminent at first meeting during marital negotiations. In milder, well-controlled epilepsy, disclosure might be deferred but should ideally take place before the wedding.

If the family chooses not to disclose the condition at the time of marital negotiations, the physician should refrain from becoming a “partner to non-disclosure”(e.g., by suggesting

methods such as disguising epilepsy medications in vitamin bottles for clandestine use after marriage) as this might have legal implications for the physician.

Early counselling of parents of the girl child with epilepsy

Many parents of young teenage girls with epilepsy express concerns about impact on matrimony in the distant future. For these parents, managing epilepsy and finding a cure before the marriageable age is of prime concern and takes priority over other upbringing issues. The best counsel for these parents is to ensure appropriate education of the girl child, to empower her to support herself financially, emotionally and socially in the years to come, i.e., education and employability should be prioritized over simply controlling seizures.

Post-betrothal counselling to non-disclosing families

Not uncommonly, families of just betrothed PWE approach physicians for counsel regarding how to deal with non-disclosure of epilepsy during marital negotiations. These are usually stand-alone consultations with little rapport between the doctor and family. Initial discussions should focus on medical aspects of management of epilepsy after marriage including contraception, pregnancy management and bone health. These form a good prelude to subsequent discussions and serve to convince the family for regular physician visits after the marriage and also rethink about non-disclosure. In these circumstances, physicians should neither coerce the family in to disclosure nor should be a party to non-disclosure.

AUTHORS' STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Table 1: Marital statistics (legal minimum age for marriage, singulate mean age at marriage and estimated proportion of arranged marriages;) from selected countries (Gabriella R, personal communication)

Country	**Legal minimum age for marriage (in years)**		**Singulate mean age at marriage [50]**		**Proportion**
	Males	**Females**	**Males**	**Females**	**Year of publicatio**
Pakistan	18 [51,52]	16 [51,52]	26	23	1982-198
Bangladesh	21[53]	18 [53]	25	19	1972-1
India	21 [54]	18 [54]	25	21	1979-1
Cambodia	20 [55]	18 [55]	25	22	1981-1
Nepal	18 [56]	18 [56]	24	20	1986-1
Korea	18 [57,58]	16 [57,58]	32	29	1977-1
Turkey	18 [59]	18 [59]	23	24.2	1974-
Sri Lanka	18 [60]	18 [60]	24	28	1980-1
Togo	-	-	27	21	1980
Indonesia	19 [61]	16 [61]	NA	NA	1964-1
Vietnam	20 [62]	18 [62]	NA	NA	1965-1
Malaysia	18 [63,64]	16 [63,64]	28	26	1957-

Japan	18 [65]	16 [65]	31	30	1967-1
China	22 [66]	20 [66]	27	25	1977-1
Taiwan	17 [67]	15 [67]			1977-

Table 2. Categorisation and geographic origin of literature search.

Subject areas	*Geographic regions*				
	Africa	*Asia*	*South America*	*Western*	*Europe*
Impact of epilepsy	5 (14%)	15 (42%)	1 (3%)	14 (39%)	1 (3%)
Knowledge-attitudes and practice studies	9 (32%)	13 (46%)	-	4 (14%)	2 (7%)
Marital outcomes in PWE	1 (12%)	6 (75%)	1 (13%)	-	-
Impact of epilepsy surgery on marriage	-	-	-	2 (40%)	1 (20%)
Impact of marriage on epilepsy	-	-	-	2 (50%)	-

Total	**15 (19%)**	**34 (42%)**	**2 (3%)**	**22 (27%)**	**4 (5%)**

Note: Publications reviewed: 213; excluded: 132 (see text for break up of exclusions)

Figures in parenthesis represent percentages row-wise, i.e., according to geographic origin of the publication, while those in the last column are column-wise, i.e., according to subject area.

Table 3. Suggestions advanced to improve marital prospects and outcomes in PWE in communities, in which arranged marriages are common.

Sr .No.	Sector	Level/s targeted	Existing provisions	Suggested interventions*

1.	High level policy and legislation	Multiple, Health, Judiciary, Societal, NGO, personal	The Hindu Marriage Act, 1955 in India was amended in 1999 as a result of which, epilepsy was delinked from insanity and would no longer be a ground for annulment of marriage or for divorce. Although, the statutes exist now for over a decade, there are plentiful examples of felt and enacted stigma associated with epilepsy in relation to matrimony.	1. Integrate education programs for children (especially girls) with epilepsy into larger national gender-based programs to enhance educational proficiency in the girl child and eventually, employment and self-sustenance in women. 2. Developing national programs for epilepsy with improved access to essential epilepsy medications and greater number of epilepsy surgery centres. 3. Incorporating knowledge and awareness about epilepsy in secondary school (age 10-17 years) curricula.

2.	Judicial sector approaches	Personal, interpersonal, societal levels	1. In Karnataka state, India, an NGO for epilepsy awareness participates in public awareness meetings organised by a Governmental Agency wherein several Departments attaend. This ensures good turnout at the meetings. 2. Judicial officers may be invited to meetings of epilepsy experts to enable cross-disciplinary exchange of ideas.	1. Although there are clear statutes in relation to epilepsy as a ground for annulment of marriage and for divorce in most countries, there are still a number of gray areas, for instance, does failure to disclose epilepsy prior to marriage amount to fraud or willful hiding in divorce litigations. 2. Many courts have stand apart benches for social justice. Epilepsy-related lawsuits can be handled by these benches so that redressal is speedier.

3.	Non-governmental sectors	Community, interpersonal and personal	Organization of public awareness meetings, street plays, etc.	Epilepsy experts should encourage and foster non-governmental agencies to include epilepsy within their scope of concerns.
4.	Media sector	Community, Government, NGOs, interpersonal and personal levels	Media coverage is effective but mostly sporadic.	1. Contemporary modes of communication including electronic media could be employed to educate people about epilepsy. 2. It might be useful to get epilepsy in to the storyline of television soap operas as these are widely followed. The story can then slowly be evolved to convey effectively different messages in relation to epilepsy.
5.	Health sector	Community, interpersonal and personal	Many upcoming comprehensive epilepsy care centres with dedicated personnel who specialize in counseling PWE and their families.	1. Awareness campaigns should target health personnel in LMICs as in these countries, patients often abide unconditionally by the recommendations of health care providers. 2. Incorporation of epilepsy treatment and counseling in school health programs.

6.	Health care providers	Community, interpersonal and personal	In the existing settings, neurologists are the most effective health care personnel to deal with the matter.	Recommendations for counseling based on expert recommendations are discussed in detail in the text.