

## Review

## The psychosocial impact of epilepsy on marriage: A narrative review



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## ABSTRACT

There have been many studies exploring quality of life as well as the impact of epilepsy on the affected individual. However, epilepsy affects more than the patients themselves, and there seems to be a paucity of data regarding the impact of epilepsy beyond the person with epilepsy (PWE). In particular, it is uncertain what the impact of epilepsy on marriage may be. We therefore performed a narrative review to evaluate work measuring the psychosocial effect of epilepsy on marriage.

We reviewed the literature on epilepsy and marriage by searching PubMed (Medline) and EMBASE and thoroughly examining relevant bibliographies. Forty-two papers were identified that addressed the issue of the psychosocial effect of epilepsy on marriage.

The different approaches used to assess the impact of epilepsy on marriage can be broadly grouped into three categories: assessment of the social effect of living with epilepsy, which includes the marital prospects of PWEs and how changes in marital status associate with seizure frequency; assessment of quality of life (QOL) of PWEs; assessment of the association of social support with the disease burden of epilepsy. Within each of these approaches, different research methods have been employed including questionnaires, qualitative methods, and scales.

The studies reviewed indicate that epilepsy has a severe impact on individuals and their families. While many quality-of-life surveys do comment on the marital status of the patient, there is little expansion beyond this. The impact that seizures may have on the partner of a patient with epilepsy is barely addressed. With increasing incidence of epilepsy in older populations, potential changes in the dynamic of a long-term marriage with the development of epilepsy in older age are not known. Similarly, the impact of marriage on concordance with medication or proceeding to, for example, surgical treatment for pharmacoresistant epilepsy has not been studied in detail. We suggest ways in which to address these aspects in order to better deliver holistic care to patients with epilepsy and their partners.

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## 1. Introduction

Epilepsy is a chronic neurological disorder characterized by recurrent seizures affecting 50 million people worldwide [1,2]. However, simply classifying epilepsy as a neurological disorder discounts the many social aspects of the condition [3]. Epilepsy significantly influences a person's social experience, emotional functioning, and quality of life (QOL) [4]. Indeed, although the severity of the epilepsy is an important factor in QOL, it has been suggested that the most debilitated persons with epilepsy (PWEs) are not necessarily those who have the highest seizure rates but rather those who do not have adequate social support [5]. Further, it has been suggested that high quality social support can enhance resilience to stress and even reduce medical morbidity and mortality [6].

Marital relationships can be a primary source of social support and a predictor of health status. Spouses may be the primary caregivers of

married PWEs because of their central role identity and fundamental position for social support. For example, it has been shown that married PWEs have a higher quality of life compared with PWEs who are unmarried [7]. In exploring the role marriage plays in a PWE's life, we are able to gain greater insight into the role of the spouse as a caregiver and support system and potentially gain greater insight into the stigma PWEs may experience.

In this narrative review of the available literature, we hope to highlight existing data on the topic and suggest research opportunities for future studies to improve targeted support for PWEs and their long-term partners.

## 2. Methods

A literature search of all studies published between January 1, 1980 and December 31, 2015 was conducted. Computerized databases PubMed (Medline) and EMBASE were searched. Published studies, case reports, and literature reviews of the effects of epilepsy on marriage were identified by using the following search terms: "stigma",

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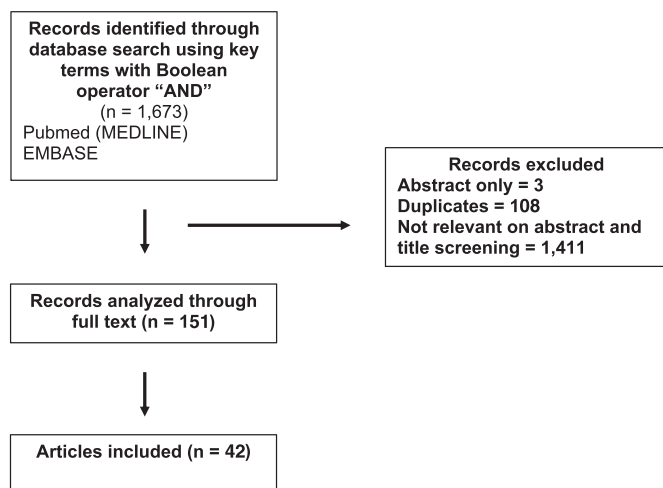
“quality of life”, “psychosocial impact”, “knowledge”, “attitudes”, and “practice” using the Boolean operator “AND” for retrieving articles related to “epilep\*” and “marriag\*” (an asterisk indicating that the search was not inhibited by a fragment of a word) (Tables 1.1 and 1.2). The ancestry method – using the references of included studies – was employed to identify other studies reporting on the effect of epilepsy on marriage.

Criteria for inclusion in the review were primarily that the studies had to report on marriage and/or the relationship between family factors and epilepsy and be in English. Articles which focused on knowledge, attitudes, and perceptions of a small subset of the population (e.g., teachers) were excluded. We eliminated articles which did not mention marriage as a measure for QOL. We also excluded articles focusing on fertility of patients with epilepsy and those that commented on marriage as a component of families that care for pediatric patients with epilepsy, as the main purpose of this work was to examine the interplay within marriage when one of the partners has epilepsy.

Relevant data to marriage and epilepsy from a variety of studies on populations with epilepsy and data pertaining to attitudes towards patients with epilepsy were extracted. Outcomes of the individual studies within a systematic review were then pooled and presented as summary outcome or effect.

### 3. Results

A thorough search yielded 42 publications that met the necessary criterion.



A summary table detailing the studies included in the Results section is provided (Table 2, [7–48]). The different approaches used to assess the psychosocial impact of epilepsy within the context of marriage can be broadly grouped into three categories:

**Table 1.1**  
PubMed (Medline) searches to identify potentially relevant primary data.

Search term	Citations reviewed	Articles retrieved	Duplicates
“epilep*” AND “marriag*”	226	35	8
(((epilep*) AND marriag*)) AND social support	34	1	0
(((epilep*) AND marriag*)) AND psychosocial effect	4	3	3
(((epilep*) AND marriag*)) AND quality of life	25	2	2
(((epilep*) AND marriag*)) AND stigma	32	10	6
(((epilep*) AND marriag*)) AND knowledge	39	8	6
(((epilep*) AND marriag*)) AND attitudes	56	13	11
(((epilep*) AND marriag*)) AND practice	30	7	6
Totals	446	79	42
Number of studies included: 37			

**Table 1.2**  
EMBASE searches to identify potentially relevant primary data.

Search term	Citations reviewed	Articles retrieved	Duplicates
“epilep*” AND “marriag*”	733	19	16
(((epilep*) AND marriag*)) AND social support	40	0	0
(((epilep*) AND marriag*)) AND psychosocial effect	14	0	0
(((epilep*) AND marriag*)) AND quality of life	126	11	11
(((epilep*) AND marriag*)) AND stigma	83	7	6
(((epilep*) AND marriag*)) AND knowledge	93	8	8
(((epilep*) AND marriag*)) AND attitudes	89	14	14
(((epilep*) AND marriag*)) AND practice	49	12	12
Totals	1227	71	66
Number of studies included: 5			

1. Experience and social effect of living with epilepsy: People with epilepsy are interviewed about significant social parameters which may include marital status, level of education, patient’s profession, and/or marriage duration.
2. Quality of life for patients living with epilepsy: A standardized questionnaire is typically administered in order to gauge the QOL of PWEs.
3. Social support and its impact on PWEs: PWEs are interviewed about disease burden, level of support, and/or marital status.

Within each of these approaches, different research methods have been used including questionnaires, qualitative methods, and scales. Major trends that emerge within the studies are the social attitudes for marriage of PWEs, rates of marriage of PWEs, gender rates, and marriage difficulties relating to PWEs.

#### 3.1. Social attitudes for marriage of PWEs

Fourteen studies within the existing literature have surveyed the general public of a specific region in order to gauge the social acceptance of epilepsy (Table 3) [8,9,19,21,25–27,30,32,36–39,41]. Questions within these surveys would often include whether the respondent would consider epilepsy to be a hindrance to marriage. Twelve of these studies indicated negative views within the general public for PWEs to marry (Table 2) [9,19,21,25–27,30,32,36,37,39,41]. For example, a study of 800 respondents in Iran found that only 28% of respondents were willing to accept the marriage of a family member to someone with epilepsy, while a Turkish study found attitudes towards social acceptance and employment of PWEs to be generally negative, especially with regard to marriage [21,26]. Another study administered to 219 students in India found that nearly 67% of the respondents stated that epilepsy was a hindrance to marriage [27]. Lim et al. compared perceptions of marriage by gender in China and showed that gender did not have a significant association with awareness of or familiarity with epilepsy [37]. In this study, 43% of the 379 adults would object to their children marrying people living with epilepsy [37]. Negative attitudes towards PWEs were particularly associated with older age, married females who had higher numbers of children, and those who lived in rural areas. Men, particularly young, single, less well-educated males, had a tendency to have negative attitudes towards PWEs being employed, owing to an inclination to believe that epilepsy is a form of insanity [37].

However, there are trends that attitudes towards PWEs may be improving. This is perhaps due to an increased understanding of epilepsy as a health condition. Mirnics et al. conducted a longitudinal study in Hungary in which a total of 1000 randomly selected subjects were interviewed [38]. They found that there was a significant decrease in prejudice rate towards PWEs regarding all attitude aspects (marriage, children, work) when comparing results from 1994 with those obtained in 2001 [38]. Similarly, a 1997 study conducted in Madagascar of 1392 respondents found that the respondents generally

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