



Review

In focus: The everyday lives of families of adult individuals with epilepsy



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ARTICLE INFO

Article history:

Received 9 March 2015

Revised 26 May 2015

Accepted 30 May 2015

Available online 17 June 2015

Keywords:

Coping

Family

Epilepsy

Quality of life

Seizures

Siblings

Spouses

ABSTRACT

Epilepsy is a multifaceted chronic neurological disorder with diverse effects on a patient's psychosocial well-being. The impact on quality of life has been well documented, and many studies have addressed the detrimental influences epilepsy has on an individual. However, the emotional impact and the influence of the condition on family members have not been well studied. Furthermore, the majority of the studies on this topic have been confined to childhood epilepsy, and there is only scarce literature that discusses the effects on family members caring for adult patients. The purpose of this literature review was to examine the influence of adult epilepsy on the psychological and social well-being of individual family members. We explored the psychological and physical well-being, satisfaction with social circumstances, and perceived level of support in families of adult patients with intractable epilepsy. The paper also suggests best practices on how to improve the family's quality of life, as well as future directions for research.

Superior medical care and a positive family support system are important conditions that can help adult individuals with epilepsy best deal with their condition.

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1. Introduction

Epilepsy is a chronic neurological condition that affects 5 to 10 per 1000 people [1]. Persons with epilepsy (PWEs) have a wide range of devastating medical, social, and economic disadvantages. These result in a significant burden to both patients and family members [2]. Studies on the psychological effects of epilepsy have focused primarily on PWEs. However, it has also been shown that having a family member with epilepsy is an unfavorable predictor for a successful family life primarily because family members bear much of the caregiving responsibility and its accompanying stress [3]. Somatic and psychological health, emotional health, quality of life, and well-being have all been shown to deteriorate among caregivers of those with epilepsy [2,4]. The negative impact of caring for a loved one with epilepsy on family members is widespread and has been seen across a variety of cultures [4–6].

Because epilepsy affects both individuals with epilepsy and their families, most psychosocial interventions should include both PWEs and their relatives [7]. Understanding how families are affected by epilepsy allows caregivers to address specific family needs, help families improve medical management, and practice strategies for maintaining their own well-being.

The aim of this review was to examine the existing literature on the impact of epilepsy on family members, with a focus on those who care

specifically for adult PWEs. It is important to identify gaps in knowledge, identify avenues for research, and propose best practices. By doing so, we hope to ultimately help improve the quality of life of PWEs and their families.

2. Methods

We performed a literature search with the aim of determining the impact of epilepsy on the quality of life of family members of adult PWEs. We excluded articles that focused on the quality of life of patients with epilepsy per se, on families that care for only pediatric patients with epilepsy, and on those who focused on nonfamily member caregivers.

Published case series, case reports, and literature reviews of the psychosocial effects of epilepsy in the family were identified by using the search terms “epilepsy and family,” “impact of epilepsy on family,” “family perception of epilepsy,” “epilepsy family and quality of life,” and “epilepsy and siblings” in the existing PubMed and BIOSIS databases. We searched only the English literature; therefore, the possibility of reported cases in the remaining world literature could not be excluded.

An exhaustive search yielded 14 publications in PubMed and 7 in BIOSIS. We excluded 4 nonrelevant articles and ended up with 17 publications that were specifically related to family members caring for adult PWEs (Table 1). The nonrelevant articles that were excluded contained studies focused mainly on the quality of life of family members caring for only pediatric patients with epilepsy [19,20], a study that included nonfamily caregivers [21] and a study that focused on

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Table 1
Studies reviewed.

Article	Year	Summary
Cianchetti et al. [8]	2015	Utilized a questionnaire that assessed the quality of life (QoL) of adolescents with epilepsy and their family members. It concluded that epilepsy impairs all aspects of QoL.
Chen et al. [9]	2013	Explored the issue in marriage involving PWEs. The study demonstrated that people with epilepsy (PWEs) encountered more marital discord compared with controls.
Duncan et al. [1]	2006	The article noted an increase incidence of epilepsy syndrome among the elderly and discussed an innovative approach to diagnosis and treatment.
Elliott et al. [10]	2011	A survey was conducted to examine the impact of marriage and social support on self-rated health status and life satisfaction in persons with active epilepsy and their partners.
Ellis et al. [7]	2000	Review of literature of family and epilepsy.
Fernandes et al. [11]	2005	Performed a questionnaire survey to assess the level of knowledge of children living with PWEs.
Grant et al. [12]	1985	Indicated that strong social support results in significantly less debilitation from epilepsy.
Jacoby et al. [13]	2011	Increased seizure breakthroughs result in a decreased QoL.
Kobau et al. [14]	2007	Examined the prevalence of self-reported epilepsy and impaired health-related QoL in the state of California.
Lua et al. [15]	2011	Study assessed general awareness, knowledge, and attitudes of PWEs.
Mahrer-Imhof et al. [6]	2013	Study investigated factors that influence QoL in hospitalized adult patients with epilepsy and concluded that the patient's QoL also depended on the QoL of family members.
Saburi et al. [5]	2006	Study reviewed the perceived family reaction in response to epilepsy. It concluded that epilepsy education of family members is associated with an enhanced quality of life.
Thompson et al. [4]	1992	Study concluded that families having a family member with epilepsy generally have more restricted activities.
Thompson et al. [16]	2014	An online, qualitative international survey conducted to examine the impact on those who care for a family member with epilepsy.
Tsuchie et al. [17]	2006	Prospective study that reviewed the psychosocial impact on siblings of PWEs.
Wittenberg et al. [2]	2013	Systematic review of literature that provided an estimate of and summarized approaches for the spillover disutility of illness on family members, relatives, and caregiver with PWEs.
Zhao et al. [18]	2011	Study found that higher educational level and economic status are protective factors in the QoL of adult patients in China.

the quality of life of patients with epilepsy rather than the family member [22].

From our literature review, we organized this article into sections detailing the impact on family members caring for adults with epilepsy (negative or positive) as well as the effects of epilepsy on siblings and spouses.

3. The negative effects on families caring for patients with epilepsy

The existing literature indicates that many of the negative consequences of epilepsy are likely to extend to families caring for individuals with the condition. Thompson and Upton [4] surveyed 44 families of PWEs and determined that the level of stress and dissatisfaction with their social situation was high among primary caregivers. To a significant extent, there was poor emotional adjustment among caregivers, which correlates with the severity of seizures and episodes of status epilepticus. Saburi and colleagues interviewed adults with epilepsy and determined that fear, individual isolation, secrecy, and concealment were negative strategies often used by PWEs and family members in the course of their interactions [5].

Many caregivers and parents caring for PWEs have unfounded concerns about the condition, which leads to the formation of overly negative attitudes. Additionally, social stigmas associated with epilepsy result in a sense of pessimism [8]. A study by Ellis demonstrated that stigma within the family is responsible for triggering some of the behavioral problems in PWEs [7]. Negative mindsets among families and caregivers may lead to reduced expectations for the PWEs, thereby unconsciously influencing the patient's behavior. Thompson and colleagues conducted an online, qualitative, international survey to examine the caregiving impact of those who support family members with epilepsy. Their article showed that financial concerns, scheduling issues, and the burden of care diverted attention from other family members. Social isolation is also a significant burden for family members [16].

A stressor unique to families of PWEs is the unpredictability of when seizures occur [16]. This makes it difficult for families to reliably plan activities such as group outings. Another consequence of caring for PWEs is the tendency of family members to become overly protective. Unfortunately, this has the deleterious effect of heightening the feelings of depression, emotional immaturity, and poor social skills among PWEs [7].

In summary, the literature shows that caring for PWEs can have significantly negative effects on the caregivers. Factors that result in stress are related to the financial costs incurred in the day-to-day medical care,

the impact of the disease on the employment status of caregivers due to difficulty finding and maintaining jobs that accommodate their family member's care needs, and the unpredictability of seizures resulting in difficulties when it comes to scheduling activities as well as heightening safety concerns. Some family members report being unable to go on vacations or spend time with others; this eventually leads to social isolation. As a consequence, the rising emotional burden among family members results in considerable exhaustion and stress.

3.1. The impact of epilepsy on siblings

Aside from looking at the effects of epilepsy on the family as a whole, it is important to examine the impact of the condition specifically on the lives of the patient's siblings. A prospective study by Tsuchie and colleagues [17] evaluated the effects of the disorder on 127 siblings of PWEs. The siblings were provided a questionnaire to gauge their level of understanding about their brother's/sister's illness and how much effect the disorder had on their own lives. The study indicated that the impact of epilepsy on the lives of siblings of PWEs is severe. Although many siblings knew how to act during a seizure and were willing to care for the patient, many admitted to being worried and frightened. This concern often results in anxiety and other psychological problems among siblings that may be often missed by the parents who are focused on the care of their adult child with epilepsy.

3.2. The impact of epilepsy on spouses

Spouses are the primary caregivers of married patients with epilepsy. A good marital relationship is an important predictor of health status in married patients with epilepsy. Chen and colleagues interviewed a total of 136 married PWEs and 145 healthy control subjects. Using the Dyadic Adjustment Scale to compare the two groups, there was a significantly lower score in people with active epilepsy than in controls. Depression and lack of social support satisfaction were significant predictors for the low Dyadic Adjustment Scale. Their results indicated that people with active epilepsy are more likely to have marital problems than the control group. Among PWEs, those who were depressed, jobless, of female gender, or had convulsive seizures of long duration had increased marital stress [9]. Another publication by Elliott and colleagues also confirmed that increased marital stress was more frequently reported among families with a spouse who has epilepsy [10].

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