



Clinical Research

Domestic violence among persons with epilepsy and their caregivers



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1. Introduction

According to the World Health Organization violence is the intentional use of physical force or power, threatened or actual, against oneself, another person or a group or community, which either results in or has a high likelihood to cause injury, death, psychological harm, development disorder or deprivation [1]. Domestic violence (DV) is a complex and common social phenomenon that takes place in the private domain: among couples or family members. According to the National Survey on Violence in Mexico 2006 (*Encuesta Nacional de Violencia en México –ENVIM–*) women are primarily attacked by family members, and three out of every 10 users of health services have experienced violence by their current partner [2]. Also, one fourth of these women reported being insulted and humiliated by their caregivers since childhood [3].

Different studies suggest that possessing or caring for someone with a chronic illness can exacerbate abuse in interpersonal relationships [4–6]. For example, Diaz-Lopez et al. reported violence from caregivers toward elderly persons with a disease in forms of verbal or gestural intimidation, infantilization, violation of basic rights such as privacy, decision-making, medical information and socialization with peers [7,8]. These behaviors can be understood through the concept of

microviolence that defines violence as a series of almost normalized, subtle and continuous acts of dominance and power [...], acts that with scarce noticeability, in an insidious and recurrent manner restrict personal empowerment and autonomy. When dependency and need for care among the caregiver and the ill are overwhelming, the co-emergence of maltreatment can go unnoticed or be normalized [9].

The American Academy of Neurology has recently stated that persons with neurological disorders are susceptible to DV due to the characteristics of the pathologies and the ways in which these types of disorders are understood in the social environment [10,11]. The unpredictable nature of seizures, their disruption to social interaction, and their unpleasantness in aesthetic terms are some proposed features of epilepsy that trigger stigmatization to PWE and make them more susceptible to DV [12]. Epilepsy is a chronic neurological medical condition that affects men and women regardless of location, race, or age. It is estimated that 50 million people around the world have this condition [13]. It has serious consequences for the psychological and social lives of individuals, and many studies indicate that persons with epilepsy (PWEs) experience discrimination due to the stigma associated with the illness, which affects the education that they receive, access to employment, and social functioning [14,15]. The stigmatization of PWEs has been studied in various cultures; for example, a study conducted in Mexico concludes that a series of stereotypes regarding contamination, danger and madness are associated to PWE [16]. As Goffman proposed (Goffman, 1963), this type of stereotypes makes the others to see stigmatized persons (such as PWE) as “not quite human”. The problem of stigmatization is that it is not only circumscribed to a labeling issue, but that it turns into marginalization, exclusion and violent acts that are legitimized by the labeling process [17]. As well, several researchers have described how the social discrediting of the stigmatization process not only applies to the affected person, but also threatens familial aspirations and life chances through a process described as “courtesy stigma” [18] subsequently facilitating and justifying DV from family members toward PWE.

The scientific literature addressing violence and epilepsy has approached the issue from two main perspectives: a) epilepsy in children as a consequence of child abuse [19] and b) aggressive behavior by PWEs that can present itself in the context of ictal or post-ictal states [20,21].

The objective of this study is to present the frequency, directionality and type of violence among PWE and their caregivers and explore the

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relationship between DV and the meaning of epilepsy for PWEs and their caregivers. The research questions that guided the study were the following:

What is the frequency of DV among PWE and their caregivers?; What types of DV are carried out: psychological, physical, sexual, economical?; What is the severity of DV?; What is the directionality of DV?; What is the meaning of epilepsy for PWE and their caregivers? and What relationship does DV have with the meaning of epilepsy for PWEs and their caregivers?

2. Methods and analysis

2.1. Study design

A mixed methodology was used due to the complexity that poses the investigation of the multidimensional factors embedded at the convergence of violence and epilepsy. Our objective was to understand the social impact of epilepsy, an illness that involves stigma and marginalization, in association with violence, a common and normalized situation in our context. Even though both phenomena have been investigated, few studies have approached them in conjunction. The combination of quantitative and qualitative data provides us with interpretive richness and an in depth view necessary for the recognition of violence in epilepsy and for the understanding of its meaning.

2.2. Study setting

The study was conducted at the National Institute of Neurology and Neurosurgery (INNN), a major center for research and specialized care for neurological and neuropsychiatric disorders in Mexico.

A cross-sectional study of DV among PWEs and caregivers was conducted from 2009 to 2013. The results are part of a broader study that addresses three more illnesses: multiple sclerosis, cerebrovascular event, and Parkinson's disease [22].

The participants of the quantitative phase included a consecutive sample of 47 dyads (94 individuals in total) of PWEs and caregivers who were referred to the epilepsy clinic at INNN. The inclusion criteria were as follows: being a PWE with any type of epilepsy, being from 18 to 60 years of age, and being without cognitive impairment, as measured by Pfeiffer's test [23]. The caregivers were selected by the researchers and defined as the person who accompany PWEs the majority of the time and cover their basic needs in terms of care, essentials, and supervision in the home. We only included participants who had a pair, that is we only interviewed a PWE only if he/she had a caregiver that met the criteria described above and if both wanted to participate. The quantitative phase of the study was carried out first, followed by the qualitative approach: in depth interviews were done and focal groups were performed at last.

2.3. Quantitative

2.3.1. Instruments

During a 6 month period the structured interviews of the quantitative approach were applied. These interviews were identical for PWE and their caregivers, who were assessed separately. All instruments were self-applied but an interviewer was always available. This assessment had a duration of 30 to 45 min.

The structured interviews included:

- Sociodemographical variables: age, level of education, and marital status were included, in addition to variables related to the disease, such as hours of care per day and years with epilepsy.
- The structured interview of the ENVIM: that contains 19 questions, and measures the presence and severity of psychological, physical, sexual, and economic violence during the year prior to the interview.

According to this instrument violence is defined as a repetitive pattern of maltreatment characterized by a series of coercing behaviors including the following: a) physical violence: pushing, beating, wounds with firearms or "arma blanca"; b) psychological violence: insults, verbal humiliations, threats of physical violence; c) sexual violence: to physically or emotionally coerce the other to have sexual intercourse; d) economical violence: to have power over the other through the control of money [24]. Severity was measured through the frequency of the violent acts during the year prior to the interview as follows: 1 = never, 2 = one occasion, 3 = several occasions y 4 = many occasions [25].

- The Zarit scale: to determine the level of caregiver burden [26].

2.3.2. Analysis

Categories were created using the ENVIM methodology to define a) *case of violence* for the dyads in which one or both members (the PWE and/or the caregiver) displayed psychologically, physically, or sexually aggressive behavior; b) *occasional violence* for the dyads that presented one episode of psychological, physical, or sexual violence but that, according to the ENVIM, did not reach a level that could be considered a case of violence; and c) *no violence* in dyads that stated in the interview that they did not exhibit nor were they subjected to violent behavior.

The category of *directionality of violence* was also created according to the orientation that appeared within the structure of the dyad, with the following categories: a) *violence toward the caregiver* (in which the PWE abuses the caregiver psychologically, physically, or sexually), b) *violence toward the PWE* (in which the caregiver abuses the PWE psychologically, physically, or sexually), and c) *mutual violence* (in which both members of the dyad abuse one another psychologically, physically, or sexually). Similarly, categories were created for a) *child-parent violence* (in which primarily the child commits verbal, physical, or sexual abuse), b) *parent-child violence* (in which primarily the father or mother commits verbal, physical, or sexual abuse), and c) *intimate partner violence* (in which one of the members of the relationship, i.e., either the husband or the wife, abuses the other verbally, psychologically, or physically).

We used descriptive statistics in terms of central tendency and dispersion measures in the case of numerical variables, and we used proportions in relationship to nominal variables. Data were analyzed using SPSS software (version 18; SPSS, Chicago).

In every case, informed consent was sought. The caregivers and patients were interviewed separately. The project was evaluated and approved by the research and bioethics committee of the institute. Cases that were considered cases of violence were referred to a government-run center for victims of violence in Mexico City.

3. Results

3.1. Characteristics of the participants

The average age of PWEs was 31.55 ± 10.65 years and the average age of caregivers was 49.62 ± 15.26 years. The majority of PWEs did not work (this was true for 25, or 53.2%) and were single 33 (70.2%). The caregivers were primarily women 34 (72.3%), and the majority were married or in a domestic partnership 31 (66%). The average score on the short Zarit Burden Interview was of 11.7 ± 8.6 (R, 0–40), representing mild caregiving burden. Caregivers spent an average time of 9.5 ± 6.9 h dedicated to care or accompaniment (Table 1). In table two the relationship of the dyads by parentage and sex can be seen (Table 2). Most of the dyads ($n = 23$ 48.9%) were composed of mothers and children. In this study adult mothers were the caregivers of adult PWE, we did not have cases of adult children taking care for adult PWE (Table 2).

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