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ORIGINAL ARTICLE

Domestic violence in patients and caregivers dyads in neurological diseases

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Abstract

Introduction: *Patients with neurological diseases are susceptible to abuse and neglect. Studies on violence in this context have mainly focused on abuse perpetrated by a caregiver to the patient directionally. In this study we describe violence in dyads of caregivers and patients with neurological disorders according to frequency, directionality, and type of relation.* ***Methods:*** *One-hundred-and-eighty-five caregiver-patient dyads were assessed by means of the National Survey of Violence Against Women (NSVAW) guidelines and the Zarit and Pfeiffer questionnaires. Bivariate analysis and Spearman correlation tests were performed.* **Results:** *Violence was reported by 32.5% of caregivers and 33.5% of patients. In both groups, psychological abuse was the most common. Mutual violence (54.5%) is the most common type of abuse and the caregiver reported as having more violent behavior is the intimate partner. Epilepsy was the neurological disorder where violence was more prevalent (47.6%).* ***Conclusions:*** *The prevalence of violence in our sample is higher than the one for the general population of 21%, as reported by the NSVAW. Clinical neurologists and healthcare services are key elements for the detection of abuse in this context.* (Gac Med Mex. 2015;151:422-7)

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Introduction

According to the American Academy of Neurology, patients with neurological disorders are susceptible to be abused[1], both due to the characteristics of the disease (it can generate dependence, be progressive, etc.) and the social setting. Although violence produced within the context of disease and care occurs from caregivers to patient and vice versa, studies on the subject focus on one-way violence, mainly caregiver-to-patient[2,3].

Research on violence by dyads (patient-caregiver) reports that depresion and anxiety in patients[4], living with relatives without the spouse[5], cognitive functional deterioration of the patient[4], poor quality of current relationship[6], reduced perception of help, overload, stress[7], child abuse and lack of economic and human resources are variables associated with abuse.

Health systems, as a whole, should aspire to provide high quality care to victims of all kinds if violence, as well as the rehabilitation and support services necessary to prevent further complications. According to the

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World Health Organization (WHO), priorities include, among others: – improving urgent response systems and capacity of the health sector to treat and rehabilitate the victims; – recognizing the symptoms of violent incidents or continuous violence situations, and referring the victims to adequate organizations to offer them follow-up and support; – warranting that health, judicial, police and social services avoid "revictimization" and efficaciously disuade violent acts perpetrators from repeating the offense; – offering social support, prevention programs and other services in order to protect families at risk of violence and reduce caregivers' stress; – incorporating modules on violence prevention to the programs of medicine and nursing students.

For these reasons, the purpose of this study is to describe the violence that is exerted and received in ND patient-caregives dyads with regard to the frequency, directionality and type of relationshp in the dyad (couple, parents and children).

Material and methods

A cross-sectional study was conducted in purposive sample of 185 dyads from December 2009 to March 2011, at the Instituto Nacional de Neurología y Neurocirugía (INNN), a ND reference center in Mexico. Using a face-to-face structured interview (not dependent on the interviewer's subjectivity), different variables were retrieved in order to collect data to explore the violence self-report by using the ENVIM *(Encuesta Nacional sobre Violencia contra las Mujeres* – National Survey on Violence against Women) instrument[8]. Additionally, variables of the caregiver (overload, age, education, time in charge of care and hours of daily care) and the patient (age, education, cognitive status and time with the disease) were assessed.

The patients were referred by the outpatient clinics of the INNN (multiple sclerosis [MS], cerebrovascular disease [CVD], Parkinson and epilepsy). Selection criteria were: patient-caregiver dyads diagnosed with ND, or epilepsy, or CVD, or MS or Parkinson disease, and no report of cognitive deterioration in the medical history or when assessed using Pfeiffer's test[9]. The caregiver was defined as a person who spends time with the patient and who expressed to the investigator his/her responsibility in providing care (basic and instrumental needs) and supervision at home. Caregivers were not required to be family members or to live with the patient. Only one ND patient caregiver older than 16 years participated, and had to have been involved with this task for a period not shorter than 12 months before being interviewed. In order to know the caregivers' degree of burden, they were applied the short version of the Zarit scale questionnaire.

Patients and caregivers were separately interviewed, and the survey took from 30 to 45 minutes. At the initial contact, the purpose of the study was explained and confidenciality and anonymity were guaranteed. The interviewers cleared up any doubts of those persons who had problems answering the questionnaire but were willing to participate, as well in the case of illiterate persons; if interwiewees had only primary education, they were offered assessment in things they didn't understand, and if they had secondary or higher level of education, doubts were clarified in case there were any. Verbal and written consent was asked for (informed consent) to participate, as established by the Declaration of Helsinki. Interviewers were healthcare professionals (psycologists and a Gender Studies Master's Degree holder) with experience applying this type of instruments, who received a training course on the biomedical definitions of the diseases and social and cultural characteristics of violence and its measurement; this basic training included the supervision of the interviews' conduction in order to avoid biases in data collection. Approval was received from the research and bioethics committee prior to the conduction of the survey.

The characteristics of the applied scales are the following:

- ENVIM[8]. It measures different degrees of violence on its different modalities: physical, emotional and sexual violence. It is a questionnaire comprising 19 items. It has a reliability of 0.99 when all test items are used. It comprises four factors with values higher than 0.40, identified as: psychological violence, physical violence, severe physical violence and sexual violence. The combination of all four factors explains 62.2% of variance. In addition, childhood abuse and economic violence subscales were also applied.
- Short Portable Mental Status Questionnaire[9] (Pfeiffer test). It is a cognitive deterioration screening test, validated in Spanish through a transcultural adaptation that has demonstrated acceptable parameters and similar to those of the questionnaire's original version[10]. It is useful in older and illiterate persons. Test-retest reliability ranges from 0.82 to 0.85. It comprises 10 items referring to general or personal issues. It

is interpreted by counting mistakes in all 10 test items. From 0 to 2 is considered normal; from 3 to 4, mild intellectual deterioration; from 5 to 7, moderate, and from 8 to 10, severe. Cut-off point for dementia is established at 5 mistakes. Sensitivity ranges from 68 to 82%, and specificity from 92 to 96%.

- Zarit caregiver burden scale[11] (BI). It is the most widely used instrument to assess overload in caregivers, translated into different languages. Twelve-item short version is best to assess the burden in caregivers; a 0 to 48 score can be obtained, it has a reliability of 0.85 and discriminating capacity with ROC curve results (0.99, 95% confidence interval [CI]: 0.98 to 0.99). The scales applied in this research showed adequate reliability rates, above the recommended 0.70[12].

Spearman's test was used to describe relationships between the groups' continuous variables. A bivariate analysis was performed for prevalences. Version 18.0 of the SPSS software program (Chicago, IL) was used.

In this study, self-reports from both the patient and the caregiver on violent behavior were used (specifically, the occurrence of one or more acts of psychological/physical and/or sexual aggression, to classify the dyadic relationship) in an attempt to explain how violence can be generated in the new control and power arrangements appearing within the disease-care context, where, qualitatively, different types of relationships occur. Thus, categories were created using the ENVIM[8] methodology to define cases of violence for dyads where one or both members (patient and/or caregiver) have psychological/physical and/or sexual aggressive behaviors; occasional violence for dyads where an aggression episode (psychological/physical and/or sexual) has occurred, but that according to the ENVIM[8] methodology it did not reach the score to be considered a case of violence, and without violence in dyads not reporting having used or received violent behavior in the applied survey.

In addition, the directionality of violence category was created according to the orientation it presents within the dyad's structure. Hence, the following categories were established: violence to the caregiver (the patient psychologically/physically and/or sexually abuses in the relationship), violence to the patient (the caregiver psychologically/physically and/or sexually abuses in the relationship) and mutual violence (where both members of the dyad psychologically/physically and/or sexually abuse). Similarly, categories such as child-to-parent violence (where mainly the son/daughter psychologically/physically and/or sexually abuses in the relationship), parental violence (where mainly the father/mother psychologically/physically and/or sexually abuses in the relationship) and intimate partner violence (where one of the members of the couple [husband/wife] psychologically/physically and/or sexually abuses in the relationship), were also created.

Results

The dyads' sample comprised 185 out of 269 (69%) eligible surveyed subjects, the non-eligible 31% (84) are patients and caregivers that failed to form a dyad, i.e., only one person participated; out of these, 46 are patients and 38 caregivers. The reasons that prevented the dyad from being interviewed were: cognitive deterioration of the patient, physical impairments (language and/or motor problems), not having a caregiver available and/or not being accompanied to the medical appointment.

Table 1 shows their sociodemographic characteristics. Violence was reported by 32.5% of caregivers and 33.5% of patients according to the ENVIM methodology[8]. In both, the most commonly reported type of abuse is psychological (45.4%), followed by violence comprising simultaneous physical and psychological abuse with 20.5%. Having experienced at least one event of violence was reported by 78.4% of participants. Most participants report childhood abuse, mainly psychological. Patrimonial or economic violence was very low, with less than 10%. The prevalence of abuse sometime in life reported by condition was: CVD 19%, MS 32%, Parkinson 33.3% and epilepsy 47.6%. In turn, by disease, caregivers reported: CVD 22.8%, MS 29.2%, Parkinson 33.9% and epilepsy 45%. With regard to directionality, we found that 54.1% of patients and caregivers report mutual abuse, 12.4% of patients report abusing their caregiver and 11.9% of caregivers abuse their patient. The most representative relationships in the sample are couple and child-parent relationships. More violence is reported in the first ones, with 25.4%. As for the child-to-parent violence, it reaches 17.8%, and parental violence 21.6% (Table 2). The relationship found in self-reported violence between patients and caregivers is high ($r = 0.67$; $p = 0.001$), whereas between Zarit and self-reported violence by the caregiver ($r = 0.43$; $p = 0.001$) and by the patient ($r = 0.32$; $p = 0.001$) is

Table 1. Characteristics of the surveyed sample*

	Patient		Caregiver	
	M	SD	M	SD
Age	44.85	12.62	49.31	14.29
Education	10.67	4.05	10.34	4.13
Time of disease/care	8.94	7.46	7.43	6.34
Hours of daily care			9.34	6.83
Sons/daughters	1.66	1.64	2.58	2.05
Pfeiffer	0.46	0.78		
Zarit short-form			11.09	8.30
Sex	n	%	n	%
Female	112	60.5	136	73.5
Male	73	39.5	49	26.5
Marital status				
Married/civil union	86	46.5	132	71.4
Separated/divorced/widowed	18	9.7	21	11.4
Single	81	43.8	32	17.3
Relationship				
Couple	56	30.3		
Parent-child	53	28.6		
Child-parent	41	22.1		
Sibling	21	11.4		
Other	14	7.6		
Dyad relationship				
Female taking care of female			69	37.3
Female taking care of male			67	36.2
Male taking care of female			43	23.2
Male taking care of male			6	3.3
Disease				
Parkinson	49	26.4		
CVD	44	23.8		
MS	45	24.3		
Epilepsy	47	25.4		

CVD: cerebrovascular disease; MS: multiple sclerosis.
*Answers are expressed as M: means ± SD: standard deviation; n: frequencies and %: percentages.

moderated; time of care shows weak but significant relationships with self-reported violence by the patient (r = 0.16; p = 0.034) and the caregiver (r = 0.17; p = 0.021).

Discussion

In Mexico, there are not enough formal and informal support networks for the care of chronic diseases, even less if they are degenerative. We also lack spaces for the detection and care of violence in these cases. Hence the importance of the specialist physician as a key element for prevention, detection and care, since as established by the WHO, agents of health have the opportunity to perform this task, especially when the patients have any kind of disability or deterioration.

Considering the diseases that were reviewed in this investigation, neurologists have a very special place in the patients' contact, either because they are the first contact or because they are the only ones who examine them. However, some neurologists are not necessarily sensitized or informed on violence within the

Table 2. Violence reported in the dyads

	Patient		Caregiver	
	n	%	n	%
Violence report				
No violence	123	66.5	125	67.6
Violence	62	33.5	60	32.5
Childhood violence	112	60.5	134	72.5
Disease				
Epilepsy	23	47.6	21	45
Parkinson	16	33.3	17	33.9
MS	14	30.2	11	29.2
CVD	9	19.6	11	22.8
Directionality	Patient-caregiver dyad			
Violence towards the patient	22		11.9	
Violence towards the caregiver	23		12.4	
Mutual	100		54.1	
Relationship				
Couple	47/56		83.9	
Parent-child	40/53		75.5	
Child-parent	33/41		80.5	
Care relationship				
Female taking care of female	52/69		75.4	
Female taking care of male	51/67		76.1	
Male taking care of female	38/43		88.4	
Male taking care of male	4/6		66.7	

CVD: cerebrovascular disease; MS: multiple sclerosis.

process of health, disease and care, and/or lack the time or resources to detect it. On the other hand, there is also the important work carried out by other healthcare system members (nursing, social work, psychology and psychiatry), along with whom this serious problem should be multidisciplinarily addressed. All this, trying to minimize the impact of violence and its cost for public health and social services, without forgetting that putting the victims at risk of new violent acts, criticism by the family or lack of support by the community should be avoided.

In Mexico, we have different legal instruments addressing the problem of abuse; within the health care setting, the Mexican Official Standard (NOM-046-SSA2-2005) "Familial violence and violence against women, criteria for prevention and care" can be applied. NOM 046 applies to males and females attending healthcare services and establishes minimal action guidelines for each healthcare provider for the detection, diagnosis, assessment and reference of possible victims who are attended to in outpatient services, both in public and private settings.

Although violence has been studied in patients with ND, mainly with dementia, only few studies address the analyzed diseases: epilepsy, Parkinson, MS and CVD.

Prevalences found are higher than those reported by the ENVIM, where there is 21% of prevalence at the national level. However, they are consistent with those found in works on violence in dyads[4,5].

As in other investigations, we found that violence in childhood can be a risk factor for perpetrating and suffering abuse, but it is specially a precedent that can explain the normalization of abuse, which drives these relationships to turn into a way of life. This might explain, for example, the fact that not only prevalences are high but most part of this abuse is mutual.

The health-disease and care process might explain why in our sample we have many women who commit abuse, i.e., the role changes that can be generated by having or taking care of a disease could be the reason why males receive more abuse than in other contexts. However, it remains a fact that abuse by males is always more severe; in this study, 18.9% of women are subject to more than one type of violence simultaneously (e.g., physical and psychological).

The epidemilogical change, characterized by an increase in chronical diseases and populational aging, can be one of the reasons for the increase in violence perpetrated by sons/daughters on their parents that, although it has not reached too high levels, it may reflect situations that will be common in the near future.

The frequency of abuse against patients with epilepsy could be related to the stigma of the disease[13]; in addition, sometimes abuse is used as a form of discipline that is culturally accepted in our country. As with patients with epilepsy, those who suffer from MS are generally young and violence against them could be due to age-associated social expectations that are not being met because of their disease.

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