

Intimate Partner Violence in Persons With Parkinson's Disease

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Abstract

Recent studies have reported that older adults with cognitive or physical disabilities are at risk to suffer intimate partner violence. This article investigates the intimate partner violence among caregivers and persons with Parkinson's disease (PD). We used qualitative methods to investigate whether the presence of violence was related to the type of couple relationship before the disease onset. We used a survey, in-depth interviews, and focus groups in 20 dyads of caregivers and patients. Twelve (60%) persons with PD and nine (45%) caregivers reported receiving violence. Considering their relationships previous to disease onset, we describe three typologies of violence in PD: (a) disease and history of violence, (b) disease as a buffer of violence, and (c) the burden of disease as an inductor of violence. Previous relationships and the couple's biographical trajectories influence the types of violence and its nature. This study is relevant as it considers time as a crucial factor in both the violence and suffering of PD and its caregiving.

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Introduction

In Mexico, older adults live in contexts characterized by poverty, gender inequality, and poor access to health services (Salgado-de Snyder & Wong, 2007). Domestic domain is the principal area where they are cared for even when they have special needs associated with chronic diseases. Recent studies (Cooper et al., 2010) have reported that older adults with cognitive or physical disabilities are at risk to suffer violence from their caregivers. Some of the risk factors are stress and depression in caregivers, cognitive decline in patients, and being a recipient of abuse in childhood (Cooper et al., 2008; Pot et al., 1996).

Violence in the context of caregiving can be a continuity of mistreatment that was present before the onset of the disease among the couple. It can also begin as the caregiving requirements become more demanding. So, the dynamics of the previous relationships can be of relevance for caregiving outcomes. At least some violence in caregiving relationships is part of an evolving trajectory. The study of the relationship history can help understand the roles of the caregiver and the patient in the domestic domain (Pickering et al., 2014).

According to the American Academy of Neurology, there is evidence that suffering from or caring for someone who has a neurological disease may be a risk factor for domestic violence (Schulman & DePold, 2012). Older adults with neurocognitive disorders are a population with a high risk to suffer abuse in the context of caregiving (Cooper et al., 2008).

After Alzheimer's disease, Parkinson's disease (PD) is the most common neurodegenerative disorder (Lee & Gilbert, 2016). Its clinical motor presentation is bradykinesia, rigidity, tremor, and postural instability. People with Parkinson's disease (PP) may also have nonmotor symptoms (falls, freezing of gait, language, difficulty swallowing, and sialorrhea). Also, neuropsychiatric symptoms (depression and anxiety) and cognitive disorders (cognitive impairment, dementia, and psychosis; Cooney & Stacy, 2016). Nonmotor symptoms, neuropsychiatric disorders, and cognitive decline are part of PD appearing and increasing in severity as the disease progresses. All these facts make PD more susceptible to violence display than other entities with physical disabilities.

Informal care is crucial in PP as social, physical, and psychological support are delivered through it. Few caregivers exerting this type of support receive appropriate training even when they devote approximately 50 hr

per week for these chores (McLaughlin et al., 2011). There is literature on the impact of PD in its different stages in primary caregivers. For example, the leading causes of stress and overload are the general disability of patients and their depressive symptoms (Santos-García & De la Fuente-Fernández, 2015).

A diagnosis of an incurable and disabling disease such as PD generates various adverse social events that disrupt the patients' personal lives. The chronicity of the disease and the characteristics of the symptoms undoubtedly interfere with the patients' quality of life and the relationships they establish with their immediate social environment (Lim et al., 2017). Also, the disability associated with PD adds to the age-related vulnerability of older adults, increasing the risk of becoming victims of violence (Nazir & Thomson, 2011).

Some challenging aspects of PD are progressive physical disability and loss of independence, of high value in contemporary societies. High levels of uncertainty also characterize PD. The presence of symptoms and its severity fluctuate among patients and through the disease course (Barken, 2014). Patients and caregivers continuously need to adapt to changing disabilities that need different supports, including medical, familiar, professional caregiving, and sometimes hospital admissions (Plouvier et al., 2015). Uncertainty disrupts the experience of time and the biographies of patients and caregivers. These are related to violence that is neither a static phenomenon and interconnects to several factors, including age and gender. Women with disabilities are 3 times more prone to suffer couple violence (Band-Winterstein, 2013; Frazão et al., 2014).

Even that PD is epidemiologically relevant and can cause stress and overburden, few studies have approached mistreatment among PP and their caregivers. Violence in older adults with neurodegenerative disorders or PD is a complex, multidimensional, and frequent circumstance. However, a sound theory about it is lacking. In a literature review, Fang and Yan (2018) found that of the few studies available, almost none used an empirical method or qualitative methodology. Of these, the approaches utilized were: caregiver stress model (McCubbin & Patterson, 1983), communal relationships theory (Mills & Clark, 1982), risk vulnerability model (Rose & Killien, 1983), and ecological framework model (Schiamberg & Gans, 2000). None of these considered contextual and interpersonal elements or specific risk factors such as chronicity of illnesses, stigma, caregiver burden, and the characteristics of previous relationships.

Due to the complexity of factors that influence the presence of violence in PD, in this study, we approached the types of maltreatment than can be present in the illness-care context: psychological, physical, sexual, and

economical. Our focus was primarily at the couple's relationships. We understand violence as a continuum and also cyclical. It can arise in several moments of life (i.e., infancy, adolescence, old age) and several settings, that is, work, home (Castro & Frías, 2010).

Our research aimed to study the intimate partner violence among PP and their caregivers. More specifically, we explored whether the presence of violence was related to the type of couple relationship before the disease onset.

Method

We used qualitative methods to investigate whether the presence of violence was related to the type of couple relationship before the disease onset. The study was conducted at the National Institute of Neurology and Neurosurgery, (NINN-MVS), a national referral center for care and research of neurological, neurosurgical, and neuropsychiatric disorders in Mexico (Espínola-Nadurille et al., 2014). The results are part of broader research that addresses three more diseases: multiple sclerosis, stroke, and epilepsy (Sánchez-Guzman et al., 2015).

Sample and Procedure

The intentional sample of participants was recruited from the cognitive and movement disorder clinics. Forty-nine dyads (98 participants) composed of parent-child, couples, and siblings participated in the overall research. For the current study, we only selected the 20 dyads that were comprised of couples. The inclusion criteria were as follows: PP regardless of the stage of the disease, without dementia or cognitive impairment assessed through the Pfeiffer test (1975), and older than 18 years of age. The couple of the PP was considered a caregiver if he or she was responsible for basic care, instrumental care, and supervision needs at home. The general sample was recruited from the clinic of movement disorders of the NINN. The dyads that were considered cases of violence according to the National Survey of Violence Against Women (ENVIM per its abbreviation in Spanish). This questionnaire includes 19 items. According to this instrument violence is present when one or both of the members exhibit psychological, physical, or sexual violent behaviors in more than one occasion (Olaiz et al., 2009; Valdez-Santiago et al., 2006). In this study ENVIM obtained a Cronbach $\alpha = .86$.

To analyze the violence narratives, we used participant observation, semi-structured depth interviews, and focus groups:

Table 1. Participants in the In-Depth Interviews.

Patient or Caregiver	Gender	Age (years)	Amount of Time Suffering From Illness/Caring (years)
Patient	Female	62	20
Patient	Female	60	6
Patient	Male	70	9
Patient	Female	52	11
Patient	Female	57	7
Patient	Female	64	10
Caregiver	Male	60	6
Caregiver	Female	56	9
Caregiver	Male	80	12
Caregiver	Male	60	4
Caregiver	Male	64	10

Note. Own elaboration table.

Participant Observation

For 12 months, the participants were observed in the support group sessions for caregivers and PP that are held at the NINN monthly. The purpose of these groups is psychoeducational; to inform participants about the medical characteristics of PD and its treatment. The objectives of the observation phase were: (a) become familiar with the study population and (b) collect data for the development of the guides for the in-depth interviews and focus groups of Phase 3. Observation was performed by two researchers through a descriptive and reflective diary in which they investigated: (a) environment in which caregivers and PP develop at a daily basis, (b) type of relationship and interactions among the dyads, (c) behavior patterns and decision-making, (d) kind of conflicts and form of resolution, and (e) knowledge (health literacy) about PD.

In-Depth Semi-Structured Interviews

We performed in-depth individual interviews to obtain the narratives about the process of illness–care and the experience of violence. The interview guide contained general data, history of illness, descriptions of their daily life, and their emotional state. Meaning and practices related to PD, violence experience, and economic context were also evaluated. We conducted six interviews with PP and five with caregivers (Table 1). The interviews lasted an average of 50 min, with a range of 45–60 min. Caregivers and PP were interviewed separately.

Table 2. Focus Groups.

Group Type	Participant Number	Gender	
		Female	Male
Patients	10	5	5
Caregivers	10	7	3
Mixed	10	5	5

Note. Own elaboration table.

Focus Group

We directed three focus groups (Table 2), with an average duration of 70 min (range of 60–90 min). To organize the groups, we developed a guide that included the following topics: PD (definition and meaning), characteristics of the relationship (PP–caregiver), and expressions of violence (motives, forms, meanings, and how it is addressed).

We intended to explore the group construction of reality through everyday language, values, and practices associated with PD and violence.

The Institutional Research Committee revised and approved the protocol before sampling. The Ethics Committee approved the research project of this study. It conforms to the provisions of the Declaration of Helsinki in 1995 (as revised in Edinburgh 2000). Informed consent was obtained from all patients, and patient anonymity was preserved in all cases.

Data Analysis

We used the biographical method, specifically the life trajectories, to evaluate through a sequence of events how the practices and meanings of the dyads (PP–caregivers) and their relationship with violence are socially constructed.

As a technique of data analysis, we used grounded theory, having as its theoretical framework the *symbolic interactionism* that indicates that *human interaction takes place through the exchange of symbols and meanings* (Castro, 2010). We also return to Mead's interactionist theory (Barken, 2014) to understand the relationship between domestic violence in the disease process and its relation to previous stories of violence in the dyad. Studies of life histories in chronic diseases have showed that these represent a biographical break. It means that patients and caregivers must restructure their daily life to interpret it from their new circumstances (Bury, 1982). Studies of women's life trajectories caring for spouses suffering from PD showed that the interpretation they make of the past

impinges on the experience of the present and the expectations of the future. According to this approach, memories can be a tool to address daily difficulties; the symbolic creations of the past are used by the people to manipulate the present interactions (Barken, 2014).

Two researchers carefully transcribed the interviews. Data were analyzed inductively and comparatively. Coding was done using a codebook after a careful reading of the interviews. The four researchers reviewed the transcripts, discussed differences, and adjusted the codes according to the research objective. Two teams were then created to organize the results through key categories, in which the different dimensions, consequences, and relationships were identified and discussed (Coffey & Atkinson, 2003).

Results

Magnitude of Violence

Of the 20 dyads, 17 (85%) caregivers were women. Interviewees had approximately 8 years of suffering from or caring for someone with PD. Other relevant sociodemographic data are presented in Table 3.

We found that 12 (60%) PP and nine (45%) caregivers reported receiving violence. Only three (15%) PP and seven (35%) caregivers received severe abuse. As for the directionality in 13 (65%) dyads, violence was mutual, and the severity of PP that attacked caregivers (5%) was mild. The most prevalent type of violence was psychological: caregivers six (37.5%) and PP 13 (86.7%), see Figure 1.

Typology of Violence in PD Context

In this study, we included dyads with a marital relationship (Table 4). In the literature about conflicts within caregiving, it has been found that couple relationships are the most susceptible to violence (Davis et al., 2014). Their previous relationships and their couple biographical trajectories influence the type of relationship that they will have in future circumstances. Within couples, the symbolic reconstruction of the past is fundamental to understand the present. Taking on account this assumption, we present these types of violence.

To approach the narratives of suffering from both PP and their caregivers, we must first realize that diseases are not only biological processes but also expressions of metaphorical codes within a cultural system, where social representations are expressed around the body, mind, and suffering. Thus, these codes reflect the different aspects of social life through emotions, feelings, and thoughts (Scheper-Hughes & Lock, 1987).

Table 3. Characteristics of the Survey Sample ($n = 20$).

Characteristics sociodemographic	PWPD		Caregiver	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age	59.55	9.53	55.65	11.61
Education	10.45	4.65	10.05	3.52
Time with the illness/providing care	8.35	6.06	7.8	4.71
Hours of care per day			13	7.95
Children	2.9	1.62	2.95	1.54
Pfifer	0.2	0.41		
Short Zarit			12.4	9.32
Sex	<i>N</i>	%	<i>n</i>	%
Female	3	15	17	85
Male	17	85	3	15
Job				
Employee	7	35	9	45
Not work	13	65	11	55
Pensioner				
Yes	6	30	1	5
No	14	70	19	95
Economic aid				
Yes	6	30		
No	14	70		
Income				
None	9	45	10	50
Variable	0	0	1	5
Less than US\$225	5	25	8	40
US\$226–US\$370	5	25	1	5
More than US\$371	1	5	0	0
Directionality of violence dyads				
Mutual violence			13	65
The patient violent toward the caregiver			1	5
The caregiver violent toward the patient			3	15

Note. Data are expressed as mean \pm SD or n (%). Own elaboration table. PWPD = people with Parkinson's disease.

Typology 1: Disease and History of Violence

Generally, violence is performed by the male and directed at the female representing a gender violence expression. It is related to a social order of gender that constructs opposing and excluding gender identities, in which there is social inequality characterized by compulsory heterosexuality, oppression of

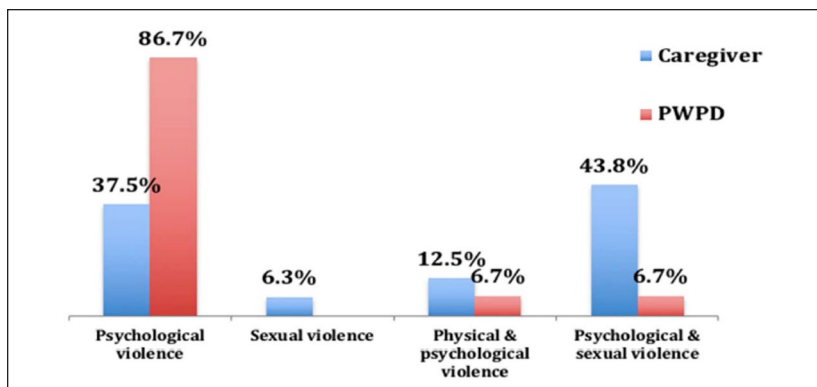


Figure 1. Type of received violence.

women for the benefit of men, and the sexual division of labor where domestic work is unrecognized (Castro, 2012). It usually affects both the couple relationship prior to the disease and after it. In the marital relationship before the illness, the patient assaulted their spouse. Now the spouse has become the primary caregiver and attacks him verbally and through negligent acts. The PP continues to be violent, but the current violence is less severe than before the disease.

To exemplify this typology, we show narratives before PD of a couple in which there was physical and psychological violence, mainly from the male (now PP) toward his spouse (now caretaker):

He has always been very aggressive, but he says that I have always provoked him. I don't know . . . he used to hit me; I was very subdued. He controlled me with money, with everything . . . he has always been very jealous, he says dancing is provocative. (Caregiver, woman, 56 years, 7 years of care)

From the PD perspective, the patient complains of negligence and psychological abuse of their partner. In the following testimony, the caretaker narrates how the authorities called her for her mistreatment against the patient:

He sued me, barely a year ago. I got a paper. But when I'm tired, he does not let me sleep; so, I grab his feet, and I lower them down with force, it's the truth; then he leaves me alone . . . And no, I do not mistreat him, I only did that once a month, or I don't know, when I'm so tired . . . I just treat him badly. [The authorities] asked me, "Do you mistreat him?" and I answered well yes, at that moment I agreed that I had mistreated him, but every day, every week, every month, no. (Caregiver, woman, 56 years, 7 years of care)

Table 4. Relationships and Violence in Parkinson's Disease.

Typology	Violence	Directionality	Severity	Type
1. Disease and history of violence	Without PD			
	Yes	Performed by the male and directed at the female	Severe	Physical and psychological Gender violence
	With PD			
	Yes	Mutual mistreatment	Mild	Physical, psychological, and negligence Gender Violence
2. Disease as a buffer of violence	Without PD			
	Yes	Performed by the male and directed at the female	Severe	Psychological No gender violence
	With PD			
	No			
3. The burden of disease generates violent relationships	Without PD			
	No			
	With PD			
	Yes	Performed by the caretaker (male/female) and directed at the patients with Parkinson's disease (male/female)	Mild	Psychological and negligence No gender violence

Note. Own elaboration table. PD = Parkinson's disease.

. . . I think that what I miss or what has hurt me is that they do not help me as they should . . . My wife is very inconsistent with my medicine schedule: sometimes she gives it to me at ten, nine-thirty, at nine. Why does it have to be this way? No! (Crying). (PP, male, 70 years, 11 years with PD)

Also, the PP continues the mistreatment

. . . the last time we had a small problem, my wife and I . . . I covered my ears, and she got so annoyed that she wanted to hit me, and I tried to defend myself—and I said: you know what? I do not intend to hit you, but if you start it, if you try, I am also going to raise my hand, and I'm not going to stop. One day she hit me for real. (PP, male, 70 years, 11 years with PD)

There is also mutual mistreatment, as this caregiver story shows:

Then, he got up and told me it didn't seem I wanted to leave, and I said: no, look, I'm not going; whoever is leaving is going to be you because here, I am useful. It's you that is useless, you could be helpful, but you don't want to be. And then . . . he hit me, he hit me like that, in the face, and said: "I'm going to break your entire . . . " (Caregiver, woman, 56 years, 7 years of care)

Typology 2: Disease as a Buffer of Violence

In these cases, the patient did not exerted violence, but was mistreated by the couple before the disease. Generally, violence is performed by the man and directed at the woman. It's usually a psychological, not severe form of violence and not related to gender. At the onset of the disease, the abuse disappears, as the PP becomes more vulnerable the aggressor stops maltreatment:

Well, because of the illness. As the doctor has told us, we need to try to be calmer; so, I try to do that, to not let things go as they had before. (Caregiver, male, 64 years, 10 years of care)

Well, well, I think, for example, it is normal to have fights with my husband, right? No more fights like before, and I did say to him: "We came down here, it's all over" . . . I have seen that if I over-exert myself, I get sick. So, I said to my husband, "the fights are now finished." (PP, female, 66 years, 10 years with PD)

Typology 3: The Burden of Disease Generates Violent Relationships

It occurs in women and men. In this typology, there were no aggressions in their marital relationship before the PD. This type of violence is not related to gender. Violence starts from the onset of disease and its care in forms as negligence, infantilization, or verbal abuse:

Well, frequently, she has her way. But she complains that sometimes I impose myself and I say: "it is done because it is done." But sometimes it is necessary to treat her like a child: "you know this is not open for discussion, it's done and period." (Caregiver, man, 60 years, 9 years of care)

At first, if I was angry with her, I would say, "hey move," I got angry not by saying things to her but by making faces, being more abrupt with my movements. (Caregiver, man, 64 years, 10 years of care)

For any reason, he shouts at me, "Because of you I'm not going to be there on time!," "Because of you and because of you . . . "He does not understand that for me it's hard to do things." Even if I put on a pair of pants, my hands do not respond. (PP, woman, 59 years, 6 years with PD)

Discussion

Various studies suggest that the magnitude and characterization of violence cannot be known but rather, the complexities of specific populations can be

approached (Castro & Riquer, 2003). Hence, it is important to explore this issue in PD, which is increasingly prevalent in the Mexican context and in the world and is a condition that ultimately changes the daily lives of those who suffer from it. This study contributes to the knowledge of violence in this neurodegenerative disease through empirical methods. From our results, we found out that multiple categories of violence exist among patient-caregiver dyads of PD.

Quantitative results of our study are similar to those reported at the National Survey on Violence regarding maltreatment among dyads. In both settings, psychological violence is the most prevalent (Instituto Nacional de Estadística, Geografía e Informática, 2017 [National Institute of Statistical Geographic e Informatics, INEGI]). This is relevant because of the degree of vulnerability of PP (Nazir & Thomson, 2011).

Other typologies of violence in disease contexts have been defined from studies done in general population settings. Social learning and sociological and psychological theories have been the approaches used (Cameranesi, 2016). Some psychological approaches have studied aggressor's personalities, substance abuse, violence experiences in infancy, and so on (Cameranesi, 2016).

As in our study, Johnson's (2006) typology to interpersonal violence is based in the dyadic control context of violence. Her typologies are the following: intimate terrorism (gender violence), violent resistance, in-situational couple violence, and mutual violent control. Other investigations have concluded that the study of previous relationships is essential (Isham et al., 2019). As an example, Band-Winterstein (2013) developed a typology about elder and abusive men that live in chronic intimate violent relationships. Through the study of life trajectories, she surmised that the nature of violence can change over the years, analyzing how the abuse patterns change over time. The following dimensions were considered: construction of violence over the years, the perception of the spouse, losses accompanying the violent relationship and the meaning of violence in old age. Our results are consistent with both studies. As Band-Winterstein (2013) we found that violence can change over the years, and that diseases as PD, represent a biographical rupture that change the patterns and forms of violence. Johnson's typology is of use to understand these changes. In our Typology 1, the abuse that the patient exerted previous to the disease onset could be considered an expression of terrorist control. It does involve not only the systematic use of violence, but also, economical subordination, threats, isolation, and other tactics that imply power. Although this type of violence does not stop, it decreases in relation with the patient's disabilities

that prevent the use of physical violence. As well, the response of the caregiver can be described as violent resistance. Our Typology 2 is similar to Johnson's common couple violence. It is characterized by minor forms of violence, not related to gender inequalities as happens in intimate terrorism. The latter could explain why the onset of the disease can induce the disappearance of violence. Finally our third typology could also be an example of common couple violence that emerges in relation with the caregiving difficulties and the complexity of symptoms.

Regarding intimate partner violence the typologies proposed by Johnson (2006) have generated an interesting debate about the diverse causes of mistreatment, suggesting that depending on the type of violence different phenomena can be elucidated. This distinction is important as it underscores diverse cases, development patterns, and consequences. Therefore adequate interventions are needed.

The typologies aforementioned can be used to complement ours in other forms. Although we propose the emphasis in the distinction between the aggressor and the victim in relation to the disease; Johnson (2006) uses power and control as the key factors. Both proposals are of help to understand the complexity of violence in the context of chronic diseases. Given that relationships change over time, a transversal view based on the current violence, enables us to understand the trajectories of violence and the threat that implies the maintenance of behaviors to exert control. In the victimization and perpetrations domains, complex patterns emerge that cannot be understood simply by describing the presence or absence of violence.

This study is relevant as it considers time as a crucial factor in both violence and suffering of PD and its caregiving. Moreover, it considers types of violence and its nature as well. Our main limitation is our sample size. Also, studies that consider different populations are needed, such as homosexual couples, economic status or, diverse stages of the disease. However, our data are relevant because they reveal the role of violence in health contexts as a serious problem that requires further examination.

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