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RESEARCH ARTICLE

Vulnerability in women primary caregivers of children in palliative care due to intimate partner violence in a pediatric hospital in Mexico

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Abstract

Background: *Women are the primary caregivers of children in palliative care. Research has shown that the presence of intimate partner violence at home exacerbates the vulnerability of the caregiver. Current statistics indicate a high prevalence of violence in Mexico present in the intersectionality between intimate partner violence and the role of the primary caregiver. This study aimed to describe the frequency of intimate partner violence among primary palliative caregivers at the Hospital Infantil de México Federico Gómez.* **Methods:** *We conducted a cross-sectional and prospective study with convenience sampling; no sample calculation was performed. All female primary caregivers of children in the palliative care unit were invited to participate. The Scale of Violence and Index of Severity of Violence was used as the measuring instrument.* **Results:** *One hundred women participated in the study by submitting their survey in a designated mailbox. No sociodemographic data or patient diagnoses were collected. The frequency of intimate partner violence was 28%, of which 16% were considered severe cases. Women reported psychological violence (36%), sexual violence (23%), and physical violence (22%).* **Conclusions:** *Almost one-third of female primary caregivers of pediatric patients at the Hospital Infantil de México Federico Gómez have been victims of some form of violence by current partners. This study highlights a previously unreported problem and opens the door for studies to correlate intimate partner violence among primary caregivers and the quality of life of children in palliative care.*

Keywords: *Intimate partner violence. Palliative care. Pediatric patients. Primary caregivers.*

Vulnerabilidad en mujeres cuidadoras primarias de menores en cuidados paliativos debida a violencia de pareja en un hospital de niños en México

Resumen

Introducción: *Las mujeres son las principales cuidadoras de los niños en cuidados paliativos. Las investigaciones han demostrado que la violencia de pareja en el hogar exacerba la vulnerabilidad del cuidador. Las estadísticas actuales sobre violencia en México indican una alta prevalencia presente en la interseccionalidad entre la violencia de pareja y el rol de cuidador principal. El objetivo de este estudio fue describir la frecuencia de violencia de pareja entre los cuidadores primarios*

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del Hospital Infantil de México Federico Gómez (HIMFG). **Métodos:** *Se llevó a cabo un estudio transversal y prospectivo con muestreo por conveniencia; no se realizó ningún cálculo de muestra. Se invitó a participar a todas las mujeres cuidadoras primarias de niños en la Unidad de Cuidados Paliativos. Se utilizó como instrumento la Escala de Violencia e Índice de Severidad de la Violencia.* **Resultados:** *Cien mujeres participaron en el estudio; no se recogieron sus datos sociodemográficos ni diagnósticos. La frecuencia de violencia de pareja fue del 28%: 16% se consideraron casos graves. Las mujeres reportaron violencia psicológica (36%), violencia sexual (23%) y violencia física (22%).* **Conclusiones:** *Alrededor de la tercera parte de las mujeres cuidadoras principales de pacientes pediátricos del HIMFG han sido víctimas de algún tipo de violencia por parte de sus parejas actuales. Este estudio destaca un problema no informado previamente y abre la puerta a estudios para correlacionar la violencia de pareja íntima entre los cuidadores primarios y la calidad de vida de los niños en cuidados paliativos.*

Palabras clave: *Violencia de pareja. Cuidados paliativos. Pacientes pediátricos. Cuidadores primaries.*

Introduction

Palliative care is defined as a medical approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses. It prevents and relieves suffering through early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems[1]. Pediatric palliative care addresses life-threatening or life-limiting illnesses in children and involves a multidisciplinary team focusing on the patient's entire social environment. Most primary caregivers are women[2]. Society assumes that caring for a sick family member is part of the so-called "domestic work" and, as such, is associated with a particular gender role: "a woman's job"[3]. Caregivers may face challenges in daily caregiving that place them in a situation of multidimensional (emotional, economic, and structural) vulnerability.

The caregiver's experience is related to training, information, emotional and social support, financial assistance, coping strategies, and the availability of relief care and assistance at home[4]. Deficits in these factors lead to caregiver burnout, which is defined as a state of emotional exhaustion, stress, and fatigue that interferes with leisure activities, social relationships, freedom, and emotional balance. Fatigue can cause anxiety and depression, trigger interpersonal changes, and directly or indirectly affect the caregiver's physical and mental health and subjective well-being[4-7]. In addition, burnout interferes with the management of the patient's disease and its clinical course, leading to episodes of physical and psychological abuse of the patient[8].

Violence against women refers to any harmful act against a female due to their gender, whether done in public or privately[6]. Yugueros García identified three types of intimate partner violence: direct, structural, and cultural[9]. Direct violence can be seen through physical, verbal, or psychological abuse. Structural violence is caused by the social environment, while the cultural dimension is based on symbolic violence originating from traditional values.

Among the traditional values are the belief that women should live for others through multiple duties, including caring for people, and that others should be the priority over the women's well-being.

Violence also results in Years of Healthy Life loss for large segments of the population, particularly women[10,11]. In Mexico the prevalence of women who have experienced violence from their current intimate partner is estimated at 33.3% (2006), of those who have experienced violence from their intimate partner at some point in their lives at 42.9%, and of all forms of domestic violence at 60%[12]. Exposure to gender-based violence in the domestic sphere has a negative impact on the sons and daughters of the abused women, exposing them to direct physical and psychological abuse by both parents or indirect abuse through witnessing acts of violence against their mothers[13]. There is also a relationship between family violence and non-adherence to treatment[14].

Research on professionals' knowledge, barriers, and attitudes toward gender-based violence shows that it is a common and serious problem surrounded by myths and beliefs, but difficult to detect[15]. Among the difficulties cited by professionals as impeding their active participation in recognizing this problem are the lack of training on the subject and the lack of time due to excessive workloads[15].

Studies documenting the relationship between palliative care and violence have focused on caregiver abuse toward patients but have not addressed the gender-based violence experienced by caregivers.

Considering that mostly women take the role of primary caregiver or are forced into this role, it is important to examine the areas that affect their health, including violence. Based on current statistics regarding violence in Mexico, we think that there is a connection between

being a primary caregiver and experiencing intimate partner violence. We view intersectionality as a useful tool for examining and comprehending how gender intersects with other aspects of identity and how these intersections can lead to distinct experiences of privilege and oppression[16].

There are no reports in palliative care on the population of female caregivers of pediatric patients who are abused by their intimate partners. Therefore, we considered documenting this issue to fully address the needs of these women and their children and follow-up with further research sensitive to this issue.

Therefore, we conducted this exploratory study to describe the self-reported frequency of intimate partner violence perpetrated against the primary caregivers of patients in the Palliative Care and Quality of Life Unit of the Hospital Infantil de México Federico Gómez.

Methods

We conducted a cross-sectional and prospective study between May and November 2021. As a convenience sample was used, no calculation was performed. All female primary caregivers of children who attended a palliative care appointment at the Hospital Infantil de México Federico Gómez were invited to participate under anonymity. The study's purpose, data confidentiality, and voluntary participation were explained to them, and verbal informed consent was obtained when their partners were not present to protect them from possible aggression.

Participants then received a printed version of the Scale of Violence and Index of Severity of Violence questionnaire, which included 19 questions with four possible answers, to be completed at a convenient time and place. On completion, the surveys were placed in a mailbox in the palliative care unit and then collected and analyzed.

No sociodemographic characteristics, patient names, or diagnoses were collected to maintain confidentiality, given the potential risk that responding to this survey posed to the participants.

Surveys that were not (fully) completed were eliminated.

Instrument

The Scale of Violence and Index of Severity of Intimate Partner Violence was used as the measuring instrument, which has been validated in a Mexican population[17]. This scale measures intimate partner violence with a severity index composed of four factors: psychological violence, sexual violence, physical violence, and severe physical violence (Supplementary data).

For this study, we defined intimate partner violence as any behavior within an intimate relationship that causes or is likely to cause physical, psychological, or sexual harm to its members[18]. The definitions on which the scale used is constructed are the following:

- Psychological violence. Any of the following: insulting, belittling, or humiliating the partner; frightening or intimidating her (for example, by destroying things); threatening to harm her or someone important to her; threatening to abandon her, take her children away, or withhold financial support.
- Sexual violence. Any of the following: forcing the partner to have unwanted sexual relations, forcing her to perform other unwanted "sexual acts," forcing her to have unwanted sex because of fear of what the husband/partner will do if she refuses.
- Physical violence. Any of the following: slapping, shaking, throwing objects at the partner, pushing, twisting her arm, or pulling her hair; hitting her with a fist or an object that could hurt her; kicking, dragging, or striking her; choking or burning her (actually doing so or attempting to do so); threatening or injuring her with a knife, gun, or other type of weapon.

The violence scale consists of 19 validated questions grouped into four factors: psychological violence, physical violence, severe physical violence, and sexual violence. These factors measure the frequency of violent acts in the past 12 months on a Likert scale: never, once, a few times, and many times. Each of the possible answers to the 19 questions has a weight that was previously assigned during the validation of the instrument by expert judgment (Appendix 1). The questions were scored as follows: 0 for "never", 4-9 for "once", 8-18 for "a few times" and 12-27 for "many times".

The final assessment was made using an overall index of the severity of intimate partner violence, considering the different dimensions assessed: psychological, physical, and sexual. This index allows for the inclusion of dimensions of severity, such as the frequency with which acts of violence are perpetrated against women over a year and the severity of such acts.

The severity index was constructed based on the results of the sample studied. We calculated the mean and standard deviation to obtain the value of the Index of Severity of Partner Violence, grouping the cases as follows:

Table 1. Values of categorization for defined cases

Values	Non-case (nc)	Case (c)	Severe case (sc)
Sexual violence	< 5.95	5.95-18.16	> 18.16
Psychological violence	< 15.01	15.01-35.6	> 35.6
Physical violence	< 9.2	9.2-28.37	> 28.37
Index of Severity of Intimate Partner Violence	< 30.16	30.16-78.19	> 78.19

Cutoff points for the categorization: Non-cases (nc): as any score less than the mean of the factor studied in our population; Cases (c): any score greater than or equal to the mean of the factor studied; Severe cases (sc): any value greater than the mean plus one standard deviation of the factor studied.

Table 2. Frequencies by type of violence and by the Likert scale of responses

Type of violence	Never	Once	A few times	Many times
Sexual violence	236 (78.66%)	37 (12.33%)	16 (5.33%)	11 (3.66%)
Psychological violence	315 (63%)	84 (16.8%)	45 (9%)	56 (11.2%)
Physical violence	414 (82.8%)	57 (11.40%)	17 (3.40%)	12 (2.4%)
Severe physical violence	579 (96.5%)	19 (3.16%)	0	2 (0.33%)

Number of responses that were given in the surveys grouped by types of response. The corresponding frequency of responses is provided next to the total.

- Non-cases: values from 0 to below the mean.
- Cases: values from the mean to one standard deviation.
- Severe cases: values greater than one standard deviation above the mean.

Results

One hundred women participated in the study by delivering their survey in the mailbox described in the methodology section. Due to the nature of the study, in which confidentiality was essential to ensure the women's safety and the data quality, sociodemographic characteristics and diagnoses of the children in their care were not collected for correlation.

After scoring the surveys using the weights assigned to each question, we identified three groups: "non-cases," defined as any score less than the mean of the factor under study in our population; "cases," defined as any score greater than or equal to the mean of the factor under study in our population and up to one standard deviation; and "severe cases," defined as any score greater than the mean plus one standard deviation of the factor under study. Cases were defined according to the values shown in table 1.

As we can see in table 2, which describes the frequencies by type of violence using the Likert scale of responses, the most common types of violence were as follows: 36% of the women underwent psychological violence, of which 17% was classified as severe and 19% as non-severe. The frequency of sexual violence was 23%, of which 10% were considered non-severe and 13% severe. The frequency of physical violence was 22%, with a marked difference between severe 17% and non-severe 5% (Table 3).

An estimated 28% of participants reported experiencing intimate partner violence, of which 12% were considered cases and 16% severe cases.

Discussion

In this study, the incidence of intimate partner violence among primary caregivers of children in palliative care was 28%, indicating a prevalent problem among female primary caregivers.

The frequency found in this study was higher than that reported in the general population in Mexico according to a 2020 national survey, which reported an overall prevalence of 25.6% of women who had experienced intimate partner violence[19]. Similarly, the National Survey on Violence against Women (ENVIM 2003), reported a prevalence of 21.5% of current intimate partner violence[20], suggesting that despite the

Table 3. The Index of Severity of Intimate Partner Violence based on the information collected in the surveys and their analysis

Types of violence	Total	Non-severe	Severe
Psychological violence	36.00%	19%	17%
Sexual violence	23%	10%	13%
Physical violence	22%	5%	17%
Index of Intimate Partner Violence	28%	12%	16%

Frequencies obtained following the analysis of data regarding the construction of indices of severity in each factor and the Index of Severity of Intimate Partner Violence constructed from the sum of the factors.

limitations of this study, intimate partner violence is a major problem. The difference of 6.5% between the ENVIM 2003 and our results could be explained by the additional vulnerability experienced by women in the role of caregivers. Our study found a frequency of psychological violence of 36%, compared to a prevalence of 19% reported in the ENVIM 2003, a difference of 17%, which could be explained by the stress generated in families with a child facing a life-threatening diagnosis.

The most significant differences between severe and non-severe violence were observed in physical and sexual violence. The frequency of severe physical violence was higher than non-severe physical violence, at 16% and 12%, respectively; the frequency of sexual violence was similar, with 10% experiencing non-severe violence compared to 13% experiencing severe violence. Such figures should alert us to the danger in which these women find themselves because they live in a stressful and violent environment and experience violence that puts their lives in imminent danger.

Assigning the role of caregiver to women is considered one of the main structural barriers to economic stability for a significant portion of the population. Thus, the fact that economic violence against women was not measured in the instrument used leads us to believe that intimate partner violence has been underestimated since economic violence has a prevalence of up to 4.4% in Mexico[13].

Furthermore, women may have underreported situations of violence due to shame, fear, reprisals, or the phenomenon known as the normalization of violence. This phenomenon is defined as predispositions consistent with subjection to a social context favored by being predominantly male and tolerant of various forms of misogyny[21].

Furthermore, vicarious violence against women is underreported. This type of violence is directed at people, objects, and possessions important to women to harm them vicariously. Unfortunately, the ultimate expression of it is the murder of their daughters and sons. The perpetrator knows that by harming her children, the mother will never recover from this trauma. This extreme level of harm[22] could be an important reason why women do not dare to speak out about or report the violence they experience. In addition, the children they care for are already in such a vulnerable situation that they would not be able to survive without their care if their abusers were to separate them.

Limitations

This study has some limitations. First, its cross-sectional design. In addition, given the inability to measure sociodemographics or support network variables, among others, it was not possible to identify other factors associated with violence. Second, the type of instrument used, which could explain the underestimation of intimate partner violence. The Scale of Violence and the Index of Severity of Intimate Partner Violence lacks items that can provide information on economic violence, which were excluded due to validation problems in the original study.

Despite the limitations, our results provide evidence for the creation of specific interventions in the health sector, as current legislation prioritizes interventions in the legal and criminal fields. Routine monitoring of this issue and, better yet, creating a service to address gender-based violence in hospital units, such as the palliative care unit, would be considered a priority strategy to address this problem. Awareness-raising and training of healthcare personnel for the detection, early intervention, or, if necessary, referral to facilities for timely treatment of this type of violence should also be prioritized[23].

It is known that the greater the number of questions asked about violence and its various manifestations, the higher the prevalence in the female population studied. In this case, we preferred to protect the integrity of women by using a short scale as a preliminary approach to the problem to later create a network of timely care.

Based on our findings, we conclude that three out of ten female primary caregivers of pediatric patients at the Hospital Infantil de México Federico Gómez have been victims of some form of violence by their current

partners. Having a patient in the palliative care program represents an enormous emotional burden for women caregivers. One of the fundamental difficulties in providing adequate help is that society tends to ignore the existence of aggression. Therefore, we emphasize that these results should set a precedent for further research to estimate the prevalence of violence against this population, and also to correlate it with the quality of life of children in palliative care and with the repercussions of their treatment.

Ethical disclosures

Protection of human and animal subjects. The authors declare that no experiments were performed on humans or animals for this study.

Confidentiality of data. The authors declare that no patient data appears in this article.

Right to privacy and informed consent. Due to confidentiality and the difficulty of emotional openness, a mailbox strategy was implemented to submit anonymous surveys. For this reason, direct informed consent was not obtained, although verbal consent was obtained. In addition, women signed an informed consent form when they entered the palliative care service as part of research projects.

Conflicts of interest

The authors declare no conflicts of interest.

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Supplementary data

Supplementary data are available at DOI: 10.24875/BMHIM.23000040. These data are provided by the corresponding author and published online for the benefit of the reader. The contents of supplementary data are the sole responsibility of the authors.

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