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# BURDEN AMONG CHILEAN CAREGIVERS OF PEDIATRIC PATIENTS DIAGNOSED WITH EPILEPSY

# SOBRECARGA EN CUIDADORES CHILENOS DE PACIENTES PEDIÁTRICOS CON DIAGNÓSTICO DE EPILEPSIA

# SOBRECARGA EM CUIDADORES CHILENOS DE PACIENTES PEDIÁTRICOS COM DIAGNÓSTICO DE EPILEPSIA

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## ABSTRACT

**Introduction:** Informal caregivers of pediatric patients with epilepsy confront a myriad of challenges that may adversely affect their health, with one prominent challenge being the magnitude of the burden they experience. Objective: This study aims to ascertain the level of burden, sociodemographic characteristics, and caregiving attributes among informal caregivers of pediatric patients diagnosed with epilepsy. **Methodology:** A descriptive, quantitative, and cross-sectional study was conducted, involving the participation of 89 caregivers of pediatric patients diagnosed with epilepsy in 2021. A survey was administered to gather sociodemographic and caregiving-related information, along with the application of the Zarit Scale to quantify the caregiver burden. Descriptive statistics were employed to present the findings. **Results:** Among the caregivers of pediatric patients with epilepsy, 97% were female. The majority of caregivers had a low income, dedicated more than

8 hours to caregiving responsibilities, and lacked consistent support in their caregiving role. Six out of ten caregivers reported experiencing some degree of burden. **Conclusions:** Caregivers of pediatric patients diagnosed with epilepsy encounter varying degrees of burden, ranging from mild to intense. The prevalent caregiver profile is characterized by females, often single, with incomes below the Chilean minimum wage, high rates of absenteeism, and insufficient support in their caregiving responsibilities. Gender disparities in caregiving are evident, emphasizing the urgent need to reform current public policies on caregiving, with a particular focus on bolstering support for informal caregivers.

**Keywords:** Caregiver Burden; Child; Epilepsy; Caregivers; Child Care.

## RESUMEN

**Introducción:** Ser cuidador informal de pacientes pediátricos con epilepsia, implica una serie de desafíos que pueden repercutir en su salud, uno de ellos es el nivel de sobrecarga que experimenta. **Objetivo:** Determinar el nivel de sobrecarga, características sociodemográficas y de cuidado del cuidador informal de pacientes pediátricos con diagnóstico de epilepsia. **Metodología:** Estudio descriptivo, cuantitativo, transversal. Participaron 89 cuidadores de pacientes pediátricos con diagnóstico de epilepsia durante el 2021. Se aplicó una encuesta que consultaba datos sociodemográficos, del cuidado y la Escala de Zarit para medir el nivel de sobrecarga del cuidador. Se utilizó estadística descriptiva para presentar resultados. **Resultados:** Existe predominio del género femenino en un 97% para el cuidado del paciente pediátrico con diagnóstico de epilepsia. La mayoría de las cuidadoras perciben bajos ingresos económicos y dedican más de 8 horas al cuidado, además de no tener apoyo permanente en el rol de cuidado. Seis de diez cuidadores poseen algún nivel de sobrecarga. **Conclusiones:** Los cuidadores de pacientes pediátricos con diagnóstico de epilepsia están sometidos a sobrecarga, ya sea ligera o intensa. El perfil de los cuidadores es género femenino, estado civil de soltera, ingreso económico por bajo el sueldo mínimo de Chile, alto porcentaje de ausentismo laboral y falta de apoyo para el cuidado. Se identifica desigualdad de género en materia de este cuidado y la imperiosa necesidad de reformar las actuales políticas públicas de cuidado enfatizando el apoyo a los cuidadores informales.

**Palabras claves:** Carga del Cuidador; Niño; Epilepsia; Cuidadores; Cuidado del Niño.

## RESUMO

**Introdução:** Ser um cuidador informal de pacientes pediátricos com epilepsia envolve uma série de desafios que podem ter repercussões em sua saúde, sendo um deles o nível de sobrecarga experimentado. **Objetivo:** Determinar o nível de sobrecarga, as características sociodemográficas e de cuidado dos cuidadores informais de pacientes pediátricos com diagnóstico de epilepsia. **Metodologia:** estudo descritivo, quantitativo e transversal. Oitenta e nove cuidadores de pacientes pediátricos com diagnóstico de epilepsia durante 2021 participaram. Foi aplicada uma pesquisa que consultou dados sociodemográficos e de cuidados e a Escala Zarit para medir o nível de sobrecarga do cuidador. Estatísticas descritivas foram usadas para apresentar os resultados. **Resultados:** 97% dos cuidadores eram do sexo feminino, e 97% eram do sexo feminino quando cuidavam de pacientes pediátricos com epilepsia. A maioria dos cuidadores tem baixa renda e gasta mais de 8 horas no cuidado, além de não ter apoio permanente na função de cuidador. Seis em cada dez cuidadores apresentam algum nível de sobrecarga. **Conclusões:** Os cuidadores de pacientes pediátricos com diagnóstico de epilepsia estão sujeitos a sobrecarga, seja ela leve ou intensa. O perfil dos cuidadores é do sexo feminino, solteiros, com renda inferior ao salário-mínimo chileno, uma alta porcentagem de absenteísmo e falta de apoio para o cuidado. É identificada a desigualdade de gênero no cuidado e a necessidade urgente de reformar as políticas públicas atuais sobre o cuidado, com ênfase no apoio aos cuidadores informais.

**Palavras-chave:** Fardo do Cuidador; Criança; Epilepsia; Cuidadores; Cuidado da Criança.

## INTRODUCTION

People who are caregivers of ill individuals may experience a series of difficulties that affect their health in various aspects, one of which is their level of burden.[1] The term "informal caregiver" refers to an individual who undertakes the task of caring for sick, disabled, or elderly persons who cannot carry out activities of daily life by themselves.[2] At the international level, informal caregivers are characterized as female adults who simultaneously perform household duties.[3] Between 2015 and 2020, in the United States, the number of caregivers increased from 43 to 53 million, with 61% of them being women.[4] In Chile, 97.7% of informal caregivers are women, and 68% of them experience severe burden.[5]

Zarit, Reever, and Bach-Peterson define burden as the extent to which the caregiver perceives that caregiving has impacted different aspects of their health, social life, personal life, and economic situation.[6] Among the instruments used to measure burden, the Zarit Burden Scale is the most widely used and validated in Latin American countries, both in its full and abbreviated versions.[7]

Epilepsy is defined as a brain disorder characterized by unprovoked seizures.[8] In Chile, its non-refractory type is included in the Explicit Health Guarantees (*Garantías Explícitas de Salud*, or GES), and it covers ages ranging from 1 to 15 years in pediatric patients.[9] Additionally, state policies have been established to provide support to caregivers, with the most recent being the creation of *Sistema Nacional de Cuidados* (National Care System) in 2022.[10]

The age of informal caregivers of pediatric patients diagnosed with epilepsy typically ranges between 30 and 40 years,[11] which may extend up to 50 years in adulthood, fulfilling their caregiving role for an average of 7 to 11 years when extended into adulthood.[12] The predominant gender is female, with a very high proportion corresponding to the patient's mother, who usually shares a marriage and lives with others.[16] In the United States, these caregivers incur higher expenses compared to the general population, with expenditures of up to USD$2000 per person on healthcare consumption and potential productivity losses of up to USD$5000.[12] Similarly, a high percentage are unemployed, dedicating an average of 11 hours per day[16] and up to 70 hours per week to caregiving, often for more than one individual.[17]

On the other hand, caregivers of epileptic patients may receive support to fulfill their role;[16] the main source of emotional support is family, while another percentage seek support online or from healthcare teams.[17] The support networks of caregivers, whether male or female, tend to predominantly consist of females.[18]

A literature review revealed that caregivers of pediatric patients diagnosed with epilepsy are subject to a high human and financial burden,[19] with women experiencing a more severe burden in their role as informal caregivers, having a greater impact than men.[20,21] In Latin America, García-Galicia et al. showed that there is a statistically significant relationship between caregiver burden and having an intact family nucleus through marriage,[22] while other studies found that variables such as income and education do not have a statistically significant relationship with caregiver burden.[13] Additionally, it has been determined that age and weekly caregiving hours are directly proportional to caregiver burden, and have a negative relationship with the presence of more family members who can assist with caregiving.[16] Another study by Edelstein et al. shows that caregiver burden and social support have a statistically negative relationship.[11]

Regarding other neurological diagnoses, an international study conducted on pediatric patients with Spinal Muscular Atrophy asserts that the presence of another child with a disability affects the needs of the family nucleus, thereby having a moderate correlation with caregiver burden.[23] On the other hand, a study conducted on caregivers of adult patients with Alzheimer's disease revealed a significant relationship between the presence of burden and the years spent as a caregiver.[24] Similarly, a higher prevalence of burden was observed in a group of caregivers of pediatric patients with disabilities, when fulfilling this role for more than five years, although no statistically significant relationship was observed.[25]

Based on the aforementioned, the objective of this research is to determine the level of burden, demographic characteristics, and caregiving characteristics of informal caregivers of pediatric patients diagnosed with epilepsy.

## METHODOLOGY

This study employed a descriptive, quantitative, and cross-sectional design. The population consisted of 118 informal caregivers of pediatric patients diagnosed with epilepsy, who had consultations or follow-ups at the neuropsychiatry outpatient clinic of a high-complexity healthcare facility in Chillán, between July and December 2021. The sample comprised 89 caregivers. A non-probabilistic convenience sampling technique was used, based on availability and access to information.

Direct caregivers of patients diagnosed with epilepsy, covered by GES, and actively attending follow-ups at the Neuropsychiatry Outpatient Clinic of the Ñuble hospital were included. Caregivers of hospitalized patients and patients for whom an epilepsy diagnosis was ruled out, who were discharged or deceased at the time of data collection were excluded.

After defining the sample, participants were contacted via telephone to introduce the project to them. Upon contact, they were requested to provide an email address where they could receive the informed consent form and questionnaires via Google Forms. Socio-demographic data about the caregiver and caregiving characteristics were collected through 11 questions addressing variables such as age, gender, relationship with the patient, marital status, income, education, employment status, hours devoted to caregiving, years dedicated to caregiving, additional individuals under their care, and support in caregiving tasks.

The Zarit Scale was used to measure the level of burden of the caregivers. This is an instrument comprising 22 questions with five response options: Never, Rarely, Sometimes, Frequently, and Nearly Always. These alternatives are scored from 1 to 5, resulting in a total score that ranges from 22 to 110. Different levels of burden are determined based on the obtained score: No burden ($\leq 46$), mild burden (47-55), and severe burden ($\geq 56$). The Zarit Scale was validated in Chile in 2009 through a study where construct validity was achieved by a strong correlation between the burden and depression indicators (Pearson correlation coefficient = 0.51 – 0.7; $p < 0.05$) and criterion validity with an almost perfect correlation between the original and abbreviated versions (Pearson correlation coefficient = 0.92; $p < 0.001$). Regarding reliability, high internal consistency was achieved (Cronbach's alpha = 0.87), along with stability reliability of 0.91 (test-retest Kappa) and inter-observer reliability of 0.86 (intraclass correlation coefficient), with a value >0.8 being almost perfect between the two evaluations.[27]

This research was approved by the Scientific Ethics Committee of the healthcare facility where the study was conducted on December 27, 2022 (CEC-HCHM 32-2022). Subsequently, the required information was requested from the Ñuble Health Service through the Transparency Law platform (*Ley de Transparencia de la Función Pública y de Acceso a la Información de la Administración del Estado, Law 20.285*), which allows any individual to access public information held by any Public

Institution. This included requesting data on pediatric patients diagnosed with epilepsy who were treated at the main healthcare facility in Ñuble between July and December 2021.

To safeguard information and ensure confidentiality, a Gmail address was created with the sole purpose of receiving the response forms of the participants. The researchers were responsible for safeguarding this information.

All analyses of variables were conducted using Excel. Descriptive statistics with numbers and percentages were utilized for categorical variables.

## RESULTS

The sample comprised 89 informal caregivers, predominantly aged 35 years or older, with 97% being female, specifically mothers of pediatric patients diagnosed with epilepsy, who fulfilled the primary caregiving duties. Regarding marital status, half of the respondents were single, and one-third were married. Concerning monthly income, a quarter of the sample reported earnings above the minimum wage in Chile, which is currently CLP$460,000, approximately equivalent to 540 USD. Half of the caregivers had completed secondary education, and nearly two-thirds were unemployed. Table 1 presents the socio-demographic characteristics of the caregivers.

**Table 1.** Socio-demographic characterization of caregivers of pediatric patients diagnosed with epilepsy.

| Socio-Demographic Characteristics | n (%) |
|---|---|
| **Age** | |
| 20-34 | 40 (44.9) |
| 35 and older | 49 (55) |
| **Gender** | |
| Woman | 86 (96.6) |
| Man | 3 (3.37) |
| **Relationship** | |
| Mother | 83 (93.2) |
| Father | 3 (3.3) |
| Grandparent | 3 (3.3) |
| **Marital Status** | |
| Married | 27 (30.3) |
| Separated | 8 (8.98) |
| Single | 52 (54.4) |
| **Monthly Income** | |
| CLP$0-145,631 | 31 (34.8) |
| CLP$145,631-476,253 | 38 (42.6) |
| CLP$476,523 and higher | 20 (22.4) |
| **Education Level** | |
| Primary Education | 9 (10.1) |
| Secondary Education | 49 (55) |
| Higher Education | 31 (34.8) |
| **Employment Status (Active)** | |
| No | 59 (66.2) |
| Yes | 30 (37.7) |

Source: Elaborated by the Authors

Table 2 presents the caregiving duties' characteristics. It is important to highlight that six out of ten caregivers dedicated more than eight hours to caring for pediatric patients diagnosed with epilepsy, and four out of ten had been caregivers for more than eight years. Additionally, half of the caregivers cared for two or more additional individuals. Finally, one-third of the caregivers did not receive support in their caregiving tasks.

**Table 2**. Characterization of the caregiving duties of caregivers of pediatric patients diagnosed with epilepsy.

| **Characteristics of Caregiving Duties** | **n (%)** |
|---|---|
| **Hours Devoted to Caregiving** | |
| Under 8 hours | 17 (19.1) |
| 8 hours and more | 52 (58.4) |
| **Years Dedicated to caregiving** | |
| 1-4 | 29 (32.5) |
| 5-7 | 27 (30.3) |
| 8 and more | 33 (37.0) |
| **Additional People Under their Care** | |
| 0 | 14 (15.7) |
| 1 | 28 (31.4) |
| 2 and more | 47 (52.8) |
| **Support in Caregiving Duties** | |
| Sporadic | 37 (41.5) |
| No | 31 (34.8) |
| Permanent | 21 (23.5) |

Source: Elaborated by the Authors

In relation to the detected level of burden (Table 3), it was found that four out of ten caregivers did not experience burden. However, it is important to highlight that one-third of the sample experienced a severe level of burden. Added to those who experienced mild burden, they represent 70.6% of the group. This is crucial to note considering the caregiving responsibilities they undertake.

Furthermore, within the group of caregivers experiencing severe burden, 94% were mothers of pediatric patients diagnosed with epilepsy, 35% were employed, and 39% had a monthly income lower than CLP$476,253. Additionally, it is noteworthy that nine out of ten caregivers with the same level of burden dedicated more than eight hours to patient care, and only 13% were supported in their caregiving tasks, while 49% were responsible for caring for more than two additional individuals.

**Table 3**. Level of burden experienced by informal caregivers.

| **Level of Burden** | **n (%)** |
|---|---|
| No Burden | 35 (39.3) |
| Mild Burden | 23 (25.8) |
| Severe Burden | 31 (34.8) |

Source: Elaborated by the Authors

## DISCUSSION

The higher prevalence of caregivers who do not experience burden is noteworthy and is consistent with international studies.[13,15,20,22] However, one-third of the sample reports severe burden and therefore are at risk of greater mental health complications[13] such as anxiety, headaches, insomnia, and pronounced depressive symptoms, a situation that could lead to increased public healthcare expenditure.

The average age of caregivers was 37 years, similar to what international studies in the same field reveal. [13,15,20] In Chile, this value is slightly lower compared to studies on caregivers of pediatric patients with other diagnoses.[29]

Similar to international studies, women predominate in the role of caregiver for pediatric patients with epilepsy,[13,15] with up to three-quarters feeling that their lives are subordinated to their caregiving role, often leading to the neglect of their own plans and hobbies. Additionally, they report that their children's condition has a detrimental impact on parental, familial, and peer relationships, a pattern that may persist into the adulthood of patients with this diagnosis[14,16,31] and other neurological conditions.[32] This pattern is also observed among caregivers of pediatric patients with other diagnoses in Chile.[28,33] Culturally, there is a stereotyped view where women are considered naturally suited for caregiving, a stance that, according to a literature review by Gascella Carbó and García-Orellan, inevitably fosters gender inequality in our society.[34]

As in the present study, evidence shows that it is typically the mother of the patient who assumes the role of caregiver.[13,15] Moreover, the number of single mothers, representing more than half of the sample, is notable. This is a pattern that differs from evidence found in other countries, where there is a greater prevalence of married couples.[20] In addition, a study carried out in Latin America reveals that single mothers face significant disadvantages, including social criticism, lack of support, and economic repercussions.[35] This highlights the scenario in which the caregiving role unfolds and underscores the lack of recognition that women receive when performing this function, emphasizing how important it is that the state offers opportunities for preparation, training, and compensation to female caregivers.

The monthly income observed in the sample did not show a clear trend; however, the highest percentage was concentrated in the lowest income range of CLP$145,631-476,253 (157 to 513 USD). This figure approximates the minimum wage in Chile, which corresponds to CLP$460,000 (540 USD) monthly.[36] This factor may also be related to the high percentage of caregivers who are not currently employed, a figure that differs from international studies where the proportion of caregivers who are actively employed exceeds half of the sample.[14,16]

Of the caregivers who are currently unemployed, just over half have completed secondary education, a figure similar to that reported in a Chilean study[28] and one carried out in another Latin American country.[20] In this context, according to data from the National Employment Survey (*Encuesta Nacional de Empleo*) conducted by *Instituto Nacional de Estadística de Chile* (Chilean National Institute of Statistics) between November 2021 and January 2022, there is a lower female labor force compared to men, one of the main reasons being permanent family responsibilities such as childcare.[37] The situation is similar at the international level, as exposed in a literature review by Yu et al., which shows that caregivers of epilepsy patients abandon their studies and/or jobs.[38] There also seems to be a higher tendency towards unemployment, as reported by Sullivan et al.[21] Some authors propose expanding the perception of the caregiver role to consider it a job, which would increase the professional and social value of those who undertake it.[29]

Regarding caregiving characteristics, a high percentage of the sample dedicates more than eight hours per day to this function, similar to what is found in international studies[15] and also applicable to adult patients diagnosed with epilepsy.[16] The majority of caregivers have been fulfilling this role for less than eight years, which can be explained by a greater tendency to assume this role from the early stages of the patient’s life.[28]

A noteworthy fact is that this research, like other studies in Latin America, revealed that caregivers of patients diagnosed with epilepsy also fulfill this role for other individuals.[29] Additionally, two-thirds of caregivers receive support, either permanent or sporadic, which is also observed in caregivers of adult patients with epilepsy.[16,29] However, approximately one-third are not supported in their caregiving role, thus highlighting another gender-related inequality. This is relevant, considering that almost the entire sample comprises women and that men tend to receive more support in their caregiving role[18] and experience less social, familial, and health impacts compared to women.[21]

Considering the aforementioned, together with the limited experience in Chile regarding caregiving,[6] it is important to implement public policies that focus on supporting caregivers and follow the model of European countries like Germany and Spain, which prioritize the well-being of caregivers of older adults and strive to keep them engaged in the labor market by adapting labor laws.[39]

There are some limitations in this research that serve as reflection points and could be addressed in further studies. The small sample size is one of them, which hindered analysis and the establishment of statistically significant differences between some of the variables, such as the gender of the caregivers. Furthermore, the preventive measures implemented during the COVID-19 pandemic restricted certain aspects of the logistics. For example, there were difficulties with transportation for conducting in-person surveys, leading to the adoption of a self-administered online instrument and a convenience sample.

The methodology used for data collection allowed direct access to the population, making it possible to present the proposed research to them and therefore collect the necessary data while adhering to the timeline outlined in the study’s Gantt chart. However, it is suggested to consider replicating this research using additional variables, different populations, clinical aspects, and psychosocial factors of the caregivers. This would require an observational analytical design with a larger sample size and appropriate statistical analysis to assess associations and/or relationships.

Another methodological limitation was the difficulty in understanding the context in which the individuals had the opportunity and feasibility to answer the instrument.

## CONCLUSIONS

This research successfully characterized the socio-demographic aspects of caregivers and characteristics of their care of pediatric patients diagnosed with epilepsy, while also assessing the level of burden they experience in this role. Notably, there is a high presence of women in the caregiver role. These women, despite having a minimal income, leaving employment, and receiving little support from others, fulfill a vital role for pediatric patients, which impacts various aspects of their health.

Caregivers of epilepsy patients can experience burden at any stage of their life cycle. This affects the performance of daily activities and the personal, occupational, and health development of the caregiver. It is imperative for nursing professionals to detect caregiver burden early and provide ongoing support to the patient's family, as well as to develop strategies with multidisciplinary teams to prevent additional problems such as anxiety, sleep disturbances, or even depression.

Furthermore, this research highlights the gender inequalities faced by women regarding financial, labor-related, and support network aspects, as they are virtually the only individuals who undertake the caregiving role in both the studied pathology and other conditions. It is crucial that state policies recognize the caregiving duties performed by women as labor, and that governments take an active supportive role, providing training, financial resources, and the recognition caregivers deserve.

This research prompts reflection on strategies implemented as public policies, the importance of improving the allocation of financial resources, the need to strengthen early interventions in primary healthcare, and bolstering the caregiver role from a gender-based approach.

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**POM:** Supervision, manuscript writing, critical review of the manuscript, validation, and approval of its final version.

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