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# Prevalence of Caregiver Burden of Patients with End-Stage Chronic Kidney Disease Undergoing Peritoneal Dialysis

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## Abstract

**Introduction**: The final stage of chronic kidney disease is stage V, characterized by the need for life-sustaining renal replacement therapy (1,2). One of these therapies is peritoneal dialysis, which is performed at home. This is where caregivers come in, and the likelihood of them developing a burden. Research studies have been conducted to determine such burden in primary caregivers of patients with chronic kidney disease (9-12).

**Objectives**: To determine the prevalence of intense caregiver burden in primary caregivers of patients with End-stage chronic kidney disease receiving peritoneal dialysis. As well as the degree of burden, the caregiving profile, and its correlation with patient dependency and caregiving time.

**Methods**: Sociodemographic data were then collected using the identification form, which collected general patient information. The Socioeconomic Status Index (SES) of the Mexican Association (AMAI) was applied. This was followed by questions about caregiving data, which included relationship to the patient, total time as primary caregiver, and time spent caring per day. Application of the Barthel scale to determine the patient's level of dependency in care. Zarit scale was applied.

**Results**: The age population was 51.22 years with a SD of ± 14.18 years, 25% male and 75% female. A prevalence of severe caregiver burden was found at 15%. To assess the correlation between the degree of dependency and the level of burden, the variables were recoded as ordinal, and Spearman's rho was used. Spearman's rho coefficient was 0.309 (p = 0.016), indicating significance, and the coefficient is classified as "Moderate."

For the correlation between the degree of burden and the time, in months, spent caring for the patient, Spearman's rho was used, yielding a rho of 0.299 ($p = 0.020$), which is classified as mild and statistically significant. For the correlation between the degree of burden and hours per day dedicated to care, the Spearman's rho coefficient of 0.509 was also used, with a p-value of $< 0.001$, which is classified as significant.

**Discussion and Conclusions**: We found a 15% prevalence of intense caregiver burden among our study subjects in this setting. The prevalent caregiver profile is similar to that described in the literature: the majority are women (75%), married (58.3%), caring for their partner (40%), secondary school (43.3%), and have a socioeconomic status of C-/C+ (21.7%)/21.7%.

## Keywords

Caregiver Burden; Chronic Kidney Disease; Peritoneal Dialysis.

## Introduction

Chronic kidney disease has become a public health problem, given its high incidence rates, morbidity, mortality, and strain on public health systems [1].

This condition, chronic kidney disease, is defined as a decrease in glomerular filtration rate accompanied by albuminuria that persists for at least 3 months and is classified into different stages [1]. The final stage of this disease is stage V, characterized by the need for renal replacement therapy to sustain the patient's life [1,2].

Among renal replacement therapies, kidney transplantation and hemodialysis, peritoneal dialysis is the most frequently accessible to the general population [3].

According to the International Society of Nephrology's Global Kidney Health Atlas (ISN-GKHA), the global average prevalence of peritoneal dialysis in 2018 was 38.1 per million inhabitants, and more than half of the patients receiving peritoneal dialysis live in four countries: China, the United States of America, Mexico, and Thailand [4,5].

One characteristic of this renal replacement therapy is that it can be performed at home; however, this requires some preparation and attention from a caregiver [2].

Informal caregivers are a risk population that may develop what is known as caregiver burden syndrome, which is a set of signs and symptoms that manifest in the physical, mental, and socioeconomic contexts of caregivers, secondary to the time, effort [6,7], and personal context [8] of caring for a chronically ill patient.

Research studies have examined caregiver burden among primary caregivers of patients with chronic kidney disease [9-12], some of which have analyzed caregivers of patients undergoing hemodialysis [13], peritoneal dialysis [14], or both [15].

A general profile of primary caregivers has been identified, highlighting women with primary education, young adults, and older adults who are part of the family unit of the sick patient [15,16].

This is true in the study by Arredondo et al., which found that the primary caregiver is a woman (92.1%), a daughter of the dependent patient (52.4%), with no or incomplete primary education (52.4%), a homemaker (54%), who receives help from other family members (54%), with previous experience as a caregiver (54%), who has been providing care for 3 years and with mild burden [9].

Other studies have attempted to directly relate the degree of patient dependency to the level of burden [10].

The Barthel Index is used to assess a patient's level of dependency. This instrument measures a person's ability to perform basic activities of daily living. These activities include eating, transferring, personal hygiene, toileting, bathing, moving around, climbing and descending stairs, dressing, and continence of urine and feces. Scores range from 0 to 100 and are classified as follows: 0 to 20 points for total dependency; 21 to 60 points for severe dependency; 61 to 90 points for moderate dependency; 91 to 99 points for minimal dependency; and 100 points for independence [4].

The most common instrument used to assess caregiver burden is the Zarit Burden Scale, which has been validated in several studies in its Spanish version [17,18].

The Zarit Scale explores various impacts of caregiving, such as emotional fatigue, impact on personal life, perception of caregiving competence, interpersonal relationships, and symptoms of anxiety or depression. It is a self-administered instrument containing 12 items with five response options on a Likert-type scale (1 point: never, 2 points: rarely, 3 points: sometimes, 4 points: quite a few times, 5 points: almost always). The scale is scored by summing the scores for all the questions. Its interpretation is based on the score obtained: less than 46 points indicates no burden, 47 to 55 points indicate mild burden, and 56 or more points indicate severe burden [18]. Another important factor influencing the degree of caregiver burden is socioeconomic status [9], which is part of family physicians' overall assessment of patients [19].

In Mexico, the Mexican Association of Market Intelligence and Opinion Agencies (AMAI) created the Socioeconomic Level Index, which classifies Mexican households into seven levels based on their ability to meet the needs of their members. This index includes Human Capital, Practical Infrastructure, Connectivity and Entertainment, Health Infrastructure, Planning and Future, and Basic Infrastructure and Space. The questionnaire used to determine the Socioeconomic Status Index is the AMAI 2022 Rule, which examines the head of household's education level, number of bedrooms, number of full bathrooms, number of employed persons aged 14 or older, number of cars, and internet access. These questionnaires are classified as Level A/B with 202 or more points, C+ from 168 to 201 points, C from 141 to 167 points, C- from 116 to 140 points, D+ from 95 to 115 points, D from 48 to 94 points, and E from 0 to 47 points [20].

Caregiver syndrome is a condition that has been little explored in the care of patients with chronic kidney disease and their families. This condition has been studied primarily in caregivers of patients with


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psychiatric illnesses or elderly patients with some dementia. Therefore, this type of research is essential in the field of family medicine, given our biopsychosocial approach [19] to expand knowledge of caregivers' realities, emphasizing the high burden, which underscores the need for multidisciplinary treatment.

Given that Mexico is one of the four countries in the world with the highest number of patients on peritoneal dialysis, it is essential to understand the prevalence of caregiver syndrome in its different degrees in order to identify risk factors and eventually develop prevention strategies and interventions to treat this syndrome.

### Primary objective

To determine the prevalence of intense burden among primary caregivers of patients with end-stage chronic kidney disease on peritoneal dialysis.

### Secondary objectives:

- To determine the profile of primary caregivers of patients with end-stage chronic kidney disease on peritoneal dialysis.
- To relate the degree of dependency of patients on peritoneal dialysis and the length of care provided to the degree of caregiver burden.

## Methods

- **Design:** Quantitative cross-sectional observational study.
- **Study population:** Primary caregivers of patients with end-stage chronic kidney disease undergoing peritoneal dialysis who attend the Nephrology clinic at a University Hospital in Mexico.
- **Inclusion Criteria:** Primary caregivers of patients with end-stage chronic kidney disease undergoing peritoneal dialysis.
- Patients must be 18 years of age or older.
- Patients must not receive compensation for patient care.
- Patients must give their consent to participate in the study.
- **Exclusion Criteria:** Diagnosis of a psychiatric disorder (anxiety, depression, bipolar disorder, schizophrenia, etc.) in the study subject.
- **Elimination Criteria:** Incomplete surveys were eliminated from the study, or if the research subject expressed their desire to stop participating in the study for any reason.

Recruitment took place in the Nephrology outpatient clinic, identifying primary caregivers and inviting them to participate in the study from December 2024 to October 2025. Sociodemographic data, including gender, age, marital status, and educational level, were collected.

The Socioeconomic Status Index (SES) of the Mexican Association of Market Intelligence and Opinion Agencies (AMAI) was subsequently applied. This index, which classifies the study subject's socioeconomic status using six questions, was used.


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An ad hoc questionnaire was administered with specific questions about the care of the sick family member and the management of the peritoneal dialysis procedure.

The 10-item Barthel scale was used to assess the patient's level of dependency in care by examining 10 basic activities of daily living.

The Zarit scale was applied, which uses 22 questions related to patient care to determine the absence or presence and level of caregiver burden.

## Results

The prevalent profile of caregivers is: the majority are women (75%), married (58.3%), care for their partner (40%), attend secondary school (43.3%) and have a socioeconomic level C-/C+ (21.7%) (21.7%). The age of caregivers was 51.22 ± 14.18 years old, with 25% males and 75% females.

A prevalence of 15% of caregiver extreme burden was found, as shown in (Table 1). There is a significant statistical correlation between the intense caregiver overload and the degree of intense dependency. (Table 1).

| Variables | | OVERLOAD LEVEL ACCORDING TO ZARIT SCALE | | | |
|---|---|---|---|---|---|
| | | No overload n=44 | Light overload n=7 | Intense overload n=9 | Total, N=60 |
| **Age in years** | | 50.07 | 50.71 | 57.22 | 51.22 |
| **Time in months caring for the patient** | | 16.75 | 32 | 28.28 | 20.26 |
| **Hours dedicated to care per day** | | 8.55 | 18.71 | 14.89 | 10.68 |
| **Gender (%)** | **Male** | 25.00% | 28.60% | 22.20% | 25.00% |
| | **Female** | 75.00% | 71.40% | 77.80% | 75.00% |
| **Degree of Dependence According to the Barthel Scale (%)** | Total | 0.00% | 0.00% | 0.00% | 0.00% |
| | Mild | 59.10% | 100.00% | 55.60% | 63.30% |
| | Independent | 27.30% | 0.00% | 0.00% | 20.00% |
| | Severe | 13.60% | 0.00% | 44.40% | 16.70% |
| | Moderate | 0.00% | 0.00% | 0.00% | 0.00% |
| **MARITAL STATUS (%)** | Single | 13.60% | 14.30% | 11.10% | 13.30% |
| | Married | 54.50% | 57.10% | 77.80% | 58.30% |
| | Common-law | 29.50% | 0.00% | 11.10% | 23.30% |
| | Divorced | 0.00% | 0.00% | 0.00% | 0.00% |
| | Widowed | 2.30% | 28.60% | 0.00% | 5.00% |
| | Illiterate | 0.00% | 0.00% | 11.10% | 1.70% |


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| | | | | | |
|---|---|---|---|---|---|
| **Educational Level (%)** | Elementary | 31.80% | 0.00% | 22.20% | 26.70% |
| | Middle | 38.60% | 71.40% | 44.40% | 43.30% |
| | High School | 20.50% | 28.60% | 22.20% | 21.70% |
| | Technical | 0.00% | 0.00% | 0.00% | 0.00% |
| | Professional | 9.10% | 0.00% | 0.00% | 6.70% |
| | Posgraduate | 0.00% | 0.00% | 0.00% | 0.00% |
| **Related To Patient (%)** | Father | 4.50% | 14.30% | 0.00% | 5.00% |
| | Mother | 9.10% | 0.00% | 11.10% | 8.30% |
| | Brother | 6.80% | 14.30% | 22.20% | 10.00% |
| | Sister | 6.80% | 14.30% | 0.00% | 6.70% |
| | Son | 2.30% | 14.30% | 0.00% | 3.30% |
| | Daughter | 29.50% | 0.00% | 11.10% | 23.30% |
| | Parner | 36.40% | 42.90% | 55.60% | 40.00% |
| | Friendship | 0.00% | 0.00% | 0.00% | 0.00% |
| | Other | 4.50% | 0.00% | 0.00% | 3.30% |

**Table 1:** Description of the population.

As a partner of a relative with chronic kidney disease, the caregiver spent an average of 20 months as the primary caregiver, dedicating an average of 10 hours per day to care. Correlation between Dependency and Overload was significant (Table 2).

| | | | **Overload** | **Dependency** |
|---|---|---|---|---|
| **Spearman's Rho** | **Overload** | Correlation coefficient | 1 | .309* |
| | | Sig. (bilateral) | . | 0.016 |
| | | N | 60 | 60 |
| | **Dependency** | Correlation coefficient | .309* | 1 |
| | | Sig. (bilateral) | 0.016 | . |
| | | N | 60 | 60 |

**Table 2:** Correlation between Dependency and Overload.

*The correlation is significant at the 0.05 level (two-tailed).

The correlations between the degree of burden and the time spent caring for the patient in months, the hours per day dedicated to caregiving, so the patient's level of dependency were significant. (Tables 3 and 4).

| | **Overload** | | **Time in months has been caring for a patient** | |
|---|---|---|---|---|
| **Spearman's Rho** | **Overload** | Correlation coefficient | 1 | 0.299* |


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| | | | | |
|---|---|---|---|---|
| | | Sig. (bilateral) | . | 0.02 |
| | | N | 60 | 60 |
| | **Time in months that you have been caring for a patient** | Correlation coefficient | 0.299* | 1 |
| | | Sig. (bilateral) | 0.02 | . |

**Table 3:** Correlation between the degree of overload and the time in months caring for the patient.

*. The correlation is significant at the 0.05 level (two-tailed).

| | | | **Overload** | **Hours per day dedicated to care** |
|---|---|---|---|---|
| **Spearman's Rho** | **Overload** | Correlation coefficient | 1 | .509* |
| | | Sig. (bilateral) | . | 0.001 |
| | | N | 60 | 60 |
| | **Hours per day dedicated to care** | Correlation coefficient | 0.509* | 1 |
| | | Sig. (bilateral) | 0.001 | . |
| | | N | 60 | 60 |

**Table 4:** Correlation between the degree of overload and the time in hours caring for the patient.

*The correlation is significant at the 0.01 level (two-tailed).

The Spearman's rho coefficient was 0.309, with a significance level of p = 0.016. The coefficient was significant, and Spearman's rho yielded a coefficient classified as "Moderate."

A Spearman's rho of 0.299 was found, with a p-value of 0.020. The correlation found was weak and statistically significant. A Spearman's rho of 0.509 was found, with p < 0.001. This correlation is strong and highly significant.

## Discussion

Overload is a pathology present in the primary caregivers of patients with chronic kidney disease. Its prevalence varies according to the type of renal replacement therapy the patient is receiving, and it remains understudied.

Among the similar studies found in our country, one recently published (2025) by Serrano Hernández et al. in Mexico City stands out. This study found a prevalence of 37% for severe overload (21), higher than that reported in the literature outside the country and higher than that in this study.


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Comparing the results of our study with those of other studies worldwide on overload, we find slightly different values. This study found that, of the total number of patients, 73.3% had no overload, 11.6% had mild overload, and 15% had severe overload. Compared with a study conducted in Spain (2), a non-overload rate of 72.2%, mild overload of 16.7%, and severe overload of 11% was found.

Regarding the caregiver profile in our study, it is similar to that described by Ana Isabel Aguilera Flores et al. (2016), who found a caregiver profile dominated by women (76.9%), with a mean age of 54.38 years and a SD of 18.5 years, and primarily spouses (4). Other studies show a general profile of primary caregivers of women with basic education, young adults, or older, and who are part of the family unit of the ill patient (15,16).

Also notable is the relationship found between the degree of patient dependency with chronic kidney disease (4) (20), the hours of daily caregiving, and the degree of burden experienced (20). They found that the higher the degree of dependency, the greater the burden experienced. Similarly, the more hours dedicated per day to caring for the kidney patient, the more symptoms of burden the caregiver experiences. This issue has also been highlighted in previous studies.

Among the limitations of this study (and considered causes of the difference in caregiver burden found in this study and the aforementioned one) is the length of time the patients had been on renal replacement therapy, and therefore had a primary caregiver, since a large portion of our population had only been on peritoneal dialysis for a few months, as demonstrated by the standard deviation in our study (20.26 ± 37.03).

Another factor not recorded was the physical health status of the study subjects, as other studies (21) have shown that caregiver health is related to the degree of caregiver burden.

## Conclusion

In our setting, we found a 15% prevalence of intense caregiver burden among our study subjects. Furthermore, the prevalent caregiver profile is similar to that described in the literature, where the majority of caregivers are women (75%).

Caregiver syndrome is a condition present in our setting among caregivers of patients undergoing peritoneal dialysis treatment. It opens the door to developing prevention and care strategies for the primary caregiver.

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