

Overload on the primary caregiver of patients with chronic kidney disease during the SARS-CoV-2 pandemic

Sobrecarga del cuidador principal del paciente con enfermedad renal crónica durante la pandemia por SARS-CoV-2

Sobrecarga no cuidador primário de pacientes com doença renal crônica durante a pandemia da SARS-CoV-2

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Abstract

Introduction: In times of pandemic, with a significant prevalence of chronic non-communicable diseases in Mexico is associated the risk of contracting viral diseases such as SARS-CoV-2, a risk that can be transferred to primary caregivers and increase the demand for daily life care to sick person. **Objective:** to describe the level of primary caregiver overload of patients with chronic kidney disease who receive renal replacement therapy in a second-level pandemic hospital center. **Methodology:** Descriptive, cross-sectional study with $n = 84$, simple random sampling. **Results:** The age was 54 ± 10 years and the female gender predominated. The majority of people who care for a CKD patient suffer from a chronic disease. A small percentage (23.8%) consider that the overload they have due to functions they perform is intense. **Conclusions:** Most of the primary caregivers of patients with chronic kidney disease (CKD) who receive renal replacement therapy in a second-level hospital in times of pandemic are perceived without overload. It is necessary to study this phenomenon in greater depth, as well as its impact on the health of the caregiver, since most suffer from a chronic disease and are doubly vulnerable to the spread of the SARS-CoV-2 virus.

Key words: Kidney failure; Caregivers; Coronavirus infections; Pandemic (DeCS).

Resumen

Introducción: En tiempos de pandemia, con una prevalencia importante de enfermedades crónicas no transmisibles en México se adjunta el riesgo de contraer enfermedades virales como SARS-CoV-2, riesgo que puede transferirse a los cuidadores primarios e incrementar la demanda de los cuidados de la vida diaria a la persona enferma. **Objetivo:** describir el nivel de sobrecarga de cuidador principal de los pacientes con enfermedad renal crónica que reciben tratamiento renal sustitutivo en un centro hospitalario de segundo nivel en época de pandemia. **Metodología:** Estudio descriptivo, transversal con una $n = 84$, muestreo aleatorio simple. **Resultados:** La edad fue de 54 ± 10 años y predominó el género femenino. Las personas que se dedican al cuidado de un paciente con ERC, en su mayoría, padecen alguna enfermedad crónica. Un pequeño porcentaje (23.8%) considera que la sobrecarga que tienen debido a las funciones que realizan es intensa. **Conclusiones:** La mayoría de los cuidadores primarios de los pacientes con enfermedad renal crónica (ERC) que reciben tratamiento renal sustitutivo en un hospital de segundo nivel en época de pandemia se percibe sin sobrecarga. Es necesario estudiar este fenómeno con mayor profundidad, así como su impacto en la salud del cuidador pues la mayoría padece una enfermedad crónica y es doblemente vulnerable al contagio del virus SARS-CoV-2.

Palabras clave: Insuficiencia renal; Cuidadores; Infecciones por coronavirus; Pandemia (DeCS).

Abstrato

Introdução: Em tempos de pandemia, com uma prevalência significativa de doenças crônicas não transmissíveis no México está associado o risco de contrair doenças virais, como SARS-CoV-2, um risco que pode ser transferido para os cuidadores primários e aumentar a demanda por cuidados de vida diária para a pessoa doente. **Objetivo:** Descreva o nível de sobrecarga do cuidador principal de pacientes com doença renal crônica que recebem terapia de substituição renal em um centro hospitalar pandêmico de segundo nível. **Metodologia:** Estudo descritivo, transversal com $n = 84$, amostragem aleatória simples. **Resultados:** A idade predominante foi de 54 ± 10 anos composta principalmente por mulheres. A maioria



das pessoas que cuidam de um paciente com DRC sofre de uma doença crônica. Um pequeno percentual (23,8%) considera que a sobrecarga que possuem pelas funções que desempenham é intensa. **Conclusões:** A maioria dos cuidadores primários de pacientes com doença renal crônica (DRC) que recebem terapia renal substitutiva em um hospital de segundo nível em tempos de pandemia são percebidos sem problemas. É necessário estudar esse fenômeno com maior profundidade, bem como seu impacto na saúde do cuidador, uma vez que a maioria sofre de doença crônica e é duplamente vulnerável à propagação do vírus SARS-CoV-2.

Palavras-chave: Falência renal; Cuidador(a); Infecções por coronavírus; Pandemia (DeCS).

Introduction

The month of December 2019 was a transcendental moment worldwide, since, in Wuhan, China, a series of similar cases with acute respiratory diseases of unknown origin appeared ⁽¹⁾. After analyzing the conditions of the patients, it was discovered that the disease was caused by a new betacoronavirus called SARS-CoV-2 that spread worldwide ⁽¹⁻²⁾. The SARS-CoV-2 pandemic turned into a global health emergency ⁽³⁾ that affected the entire population. However, it should be mentioned that the SARS-CoV-2 situation poses a special risk for patients with kidney disease due to their immunosuppression condition, advanced age and associated comorbidities ⁽⁴⁾.

There are comorbidities associated with higher mortality from SARS-CoV-2, including chronic kidney disease (CKD) ⁽¹⁾ and, above all, patients with end-stage CKD ⁽⁴⁾, because it is common for patients to have a kidney transplant or undergo renal replacement therapy (1). For this reason, it is necessary for CKD patients to take stricter prevention measures as they are a population at risk ⁽²⁾, because they receive an out-patient treatment; the hospital stay can last up to 6 hours, during which time they are exposed and can be infected and in turn transmit the betacoronavirus. Up to now, it has not been possible to provide the treatment in strict isolation as the conditions of the disease would require ⁽⁴⁻⁵⁾. Additionally, they go to medical centers regularly, increasing the contagion risk between health professionals and patients with CKD ⁽⁴⁻⁵⁾.

Therefore, it is considered that patients with kidney disease are especially vulnerable to greater morbidity and mortality due to COVID-19 infection ⁽³⁾ and they are likely to have more complications ⁽⁵⁾.



When a person suffers from CKD, their kidneys are unable to maintain the internal homeostasis of the body, causing the need to a renal replacement treatment ⁽⁶⁾. This not only affects the person who suffers from the disease, it also affects the person who takes care of him, since it is common for these types of patients to require the support of another person. Thus, the quality of life of the caregiver is compromised to the extent of the overload that he receives, and that burden of the caregiver is defined as "the set of physical, mental, emotional, social or economic problems that can experience caregivers of disabled people" ⁽⁶⁾.

Some studies have found that the overload depends on the age of the patients and their caregivers, the roles that the caregivers play, their educational level, the payment status, their occupation and the lack of support from the health system ⁽⁷⁾. This process of perception of the impact of care and anguish associated with caring for a patient with CKD is what is called caregiver overload ⁽⁶⁾. This is an important aspect, since the SARS-CoV-2 pandemic implies greater self-care of patients with end-stage CKD and, in turn, an increase in the care they receive through their caregivers. Therefore, the work carried out by caregivers in times of pandemic may overload the caregiver. Thus, the present study aims to describe the level of primary caregiver overload of patients with chronic kidney disease who receive renal replacement therapy in a second-level hospital in times of pandemic.

Methodology

The study has a quantitative approach with a cross-sectional and descriptive design. The sample was made up of 84 primary caregivers of people with chronic kidney disease on hemodialysis, estimated using Epi Info Version 7 CDS Atlanta Georgia USA 2013, for a finite proportion of the population, assuming that 20% present what is called the caregiver overload, with a 95% level confidence and a 5% margin of error.

The primary caregivers of patients with chronic kidney disease that were included were older than 18 years and dedicated to this role for three or more months. Primary caregivers who had two or more



chronically ill patients under their care were not considered. Simple random sampling through the generation of a table of numbers was used.

The abbreviated Zarit scale (EZA) was applied to all main caregivers. This instrument is a psychometric test that objectively qualifies and determines the presence or absence of overload perceived by the caregiver and is made up of 7 Likert-type scale items with five response options each, from 1 indicating never to 5 that indicates always. The variability of the score ranges from 7 to 35 points, interpreting that, the higher the score, the greater the overload perceived by the caregiver ⁽⁸⁾. The categories designated to this score are:

- Equal to or less than 16 points: no overload.
- Equal to or greater than 17 points: intense overload.

In 2009, the adapted scale was validated in Chile and had a reliability that yielded a Cronbach's α coefficient of 0.91 for internal consistency and a Pearson correlation coefficient of 0.86 for test-retest reliability ⁽⁸⁾. For the purpose of this research, internal consistency was estimated and in $n = 35$ primary caregivers ⁽⁹⁾, resulting in a Cronbach's Alpha of 0.82.

For data assessment, the Statistical Package for the Social Sciences (SPSS) version 25 program was used. Data treatment was performed using descriptive statistics, frequencies and percentages were used for categorical variables, and for numerical variables mean and standard deviation were used. The approval of the Health Research Committees and the Ethics Committee of Hospital General of Zone number 4 of Celaya city, of Guanajuato was obtained with registration R-2020-1006-014, considering that the present study respected the dignity, well-being, free choice to participate; also, their identity was safeguarded and the confidentiality of the information, as well as the caregivers were informed of the results. Likewise, it was classified as risk-free research in accordance with the Regulations of the General Health Law on Health Research ⁽¹⁰⁾.



Results

In the studied group of caregivers of patients with chronic kidney disease, the age was 54 ± 10 years and the female gender was predominant with a percentage of 84.5%, while only 15.5% of the caregivers were male; the time they have dedicated to the CKD patient care on hemodialysis was 5 years; most of these caregivers suffered from some chronic disease and only 38.1% were disease-free (Table 1).

Table 1. Sociodemographic characteristics of main caregiver of patients with chronic kidney disease during the SARS-CoV-2 pandemic, $n= 84$

Variable	Minimum	Maximum	Average
Age	25	73	54
Time to care for person with CKD on hemodialysis	7 months	15 years	5
Variable	Categories	Frequency	Percentage
Gender	Female	13	84
	Male	71	15
Marital status	Married	50	59,5
	Single	20	23,8
	Widower / Widow	3	3,6
	Divorced	10	11,9
	Not defined	1	1,2
Scholarship	None	2	2,4
	Elementary school	18	21,4
	Junior high school	35	41,7
	High school	20	23,8
	Technician	7	8,3
	Bachelor's degree	2	2,4
Work activity	Worker	10	11,9
	Businessman	15	17,9
	Housewife	53	63,1
	Unemployed	3	3,6
	Professional	3	3,6
Caregiver pathologies	HAS*	15	17,9
	HAS and obesity	2	2,4
	HAS and others	5	7,2
	Obesity	9	10,7
	Obesity and dyslipidemias	1	1,2
	Obesity and retinopathy	1	1,2
	Obesity and others	2	2,4
	None	32	38,1
	Diabetes	9	10,7
	Others	7	8,3

* HAS = High arterial blood pressure

Source: Results of the sociodemographic data card.



The most prevalent comorbidities in the group studied are obesity and high arterial blood pressure. It was identified that a large part of the primary caregivers have a junior high education level (41.7%); married (59.5%); and their main activity was as housewives (63.1%).

According to the results obtained through EZA, it was found that the level of overload in the main caregiver of patients with CKD is perceived without overload, and a small percentage considers that the overload they have is due to the intense activities they perform (table 2).

Table 2. Level of overload of main caregiver of patient with chronic kidney disease during the SARS-CoV-2 pandemic, $n = 84$

Overload level	Frequency	Percentage
Intense overload	20	23,8
No overload	64	76,2

Source: results of the sociodemographic data card.

Discussion

The kidneys play an important role in the regulation of the renin-angiotensin system and are therefore vulnerable to the effects of SARS-CoV-2 viral infection because it targets cells through a receptor transmembrane, the angiotensin converting enzyme 2⁽¹¹⁾. For this reason, CKD is considered an important risk factor for becoming seriously ill from COVID-19⁽¹¹⁻¹³⁾.

Nephrology has been affected by COVID-19 in acute care environment, outpatient dialysis, and organ transplantation settings⁽¹¹⁾; this situation has posed many challenges, such as increased acute renal failure (ARF) in critically ill patients⁽¹⁴⁾. In addition, there has been an increase in the number of dialysis performed in intensive care units (ICU) and the tasks of preventing the spread of SARS-CoV-2 in CKD patients with renal replacement therapy who had the need of going to hospitals several times a week⁽¹⁴⁾.



The situation of CKD patients could increase the overload that the main caregiver of the CKD patient has. However, in our study we found that only 23.8% perceive that the overload is intense while the other 76.2% consider that they are not overloaded by caring for the CKD patient. A similar phenomenon is observed in a study carried out in Paraguay, where 10% of the caregivers who were interviewed stated a slight overload ⁽¹⁵⁾. However, a study from Guatemala differs from these results, since the overload that predominated in primary caregivers was intense, followed by mild, and only three out of ten caregivers did not show any type of overload ⁽¹⁶⁾. In Mexico City, in 2015, the overload of caregivers of patients with CKD on hemodialysis was intense showing a 67% ⁽¹⁷⁾. In 2016, in a Jalisco hospital among these caregivers intense overload prevailed with 45.5% ⁽¹⁸⁾, a situation that contrasts with the results of this study.

Nevertheless, some investigations have reported that in the face of the COVID-19 pandemic, the society has had positive consequences also such as more unity, empathy, solidarity, and social awareness ⁽¹⁹⁾. In this study, the mean years of care for a CKD patient on hemodialysis was 5 years, Velazquez et al. mentioned that those who care for a CKD patient have been doing it full time for more than 5 years and frequently take care of them for affective reasons ⁽²⁰⁾.

Some similar studies that have been carried out found that the majority of caregivers of patients with CKD are women ⁽²⁰⁻²⁴⁾ and their age ranges from 40 to 70 years ⁽²⁰⁻²²⁾, data similar to those found in this study. Like the job characteristics of caregivers, one study found that most caregivers do not have a job or employment relationship ⁽²⁰⁾.

Therefore, it is considered necessary to develop further research where the overload of the primary caregiver is assessed more in-depth with the aim of monitoring the health of the caregivers, using the not abbreviated Zarit scale or the scale of taking roles in caregivers of people with chronic illness (ROL). This approach will make it possible to assess the transition of the family member (husband, mother, father, son or brother) from a healthy person to being a caregiver for a person with chronic non-communicable diseases ⁽²⁵⁾.



One of the limitations of this study was not having a comparison group since all the caregivers were immersed also in the COVID-19 pandemic situation. In addition, the blood bond between the caregiver and the patient was not considered, being a variable that could be studied to determine their behavior in relation to the overload that the primary caregiver may perceive.

Conclusions

CKD is associated with an increased risk of severe COVID-19 infection, which implies greater precautions for this risk group to minimize exposure to the virus and, in case of exposure, to detect early signs of progression of the disease. Being patients who commonly require the support of a caregiver, this could mean a greater overload and in the future represent health problems for the caregiver, since most of them also suffer from a chronic disease, which makes them vulnerable to SARS-CoV-2. However, the results obtained in this study indicated that the main caregivers of patients with chronic kidney disease who receive renal replacement therapy in a second-level hospital in times of pandemic considered themselves without overload. However, it is necessary to study this phenomenon more in-depth, as well as to monitor the health of the main caregivers in this pandemic since most of them present at least one comorbidity, a situation that doubles their vulnerability.

Conflicts of interests

There are no conflicts of interest.

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