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RESEARCH ARTICLE

Burden and means of support for family caregivers of patients with chronic diseases

Sobrecarga y apoyos en el cuidador familiar de pacientes con enfermedad crónica

Sobrecarga e apoio no cuidador familiar de pacientes com doença crônica

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5 National University of Colombia, School of Nursing, Bogotá, Colombia. E-mail address gmcarrillog@unal.edu.co https://orcid.org/0000-0003-4513-104X Introduction: An increase in chronic noncommunicable diseases has been observed worldwide in this century as patients have highly complex longer-lasting pathologies that generate dependency, making necessary to have a caregiver at home with a set of different means of support to ensure proper care. Objective: To identify means of support used by family caregivers of patients with chronic noncommunicable diseases to analyze how these are related to caregiver burden. Materials and Methods: A quantitative cross-sectional analytical study was conducted using the tools "Characterization of the patient-caregiver dyad" and "Zarit Caregiver Burden Interview" and comprising 62 population dyads. ORs were calculated using logistic regression. Results: 19.35% (12) of caregivers showed an intense level of burden, 20.97% (13) showed mild burden, and 59.68% (37) had no burden. Caregivers with intense burden referred zero psychological and social support. The relevant variables related to the burden level were number of daily care hours OR = 1.14 (95% CI: 1.01; 1.33), the higher the level of computer knowledge, the lower the possibility of increase in the burden level through crude OR = 0.14 (95% CI: 0.02; 0.91) and adjusted OR = 0.07 (95% CI: 0.007; 0.68). **Discussion:** It is fundamental to continue examining aspects to reduce caregiver burden, keep caregivers healthy in proper conditions to perform their role. Conclusions: Strengthening the different means of support for family caregivers is necessary to reduce their work-derived burden levels.

Keywords: Patients; Caregivers; Chronic Diseases; Social Support.

Resumen

Introducción: En el presente siglo se evidencia un incremento de la enfermedad crónica no trasmisible a nivel mundial, los pacientes presentan patologías con mayor duración y complejidad generando dependencia, requiriendo de un cuidador en el hogar; necesitando contar con diferentes medios de apoyo para mejorar la competencia de cuidar. Objetivo: Identificar los medios de apoyo que utiliza el cuidador familiar de paciente con patología crónica no trasmisible y su relación con el nivel de sobrecarga del cuidado. **Materiales y Métodos:** Estudio de abordaje cuantitativo, transversal y analítico, aplicando los instrumentos de "caracterización diada paciente-cuidador y la Encuesta de Percepción de Sobrecarga del Cuidador de Zarit". La población correspondió a 62 Diadas. Se calcularon OR en regresión logística. **Resultados:** El 19.35% (12) de los cuidadores presentaban un nivel de sobrecarga intensa, el 20.97%(13) leve y el 59.68%(37) no tenían sobrecarga. Los cuidadores con sobrecarga intensa refieren 0% de apoyo psicológico y social. Las variables relevantes en el nivel de sobrecarga fueron las horas diarias de cuidado OR = 1.14 (IC 95%: 1.01; 1.33), a mayor nivel de conocimiento del computador disminuye la posibilidad de aumento en el nivel de sobrecarga con OR crudo= 0.14 (IC95%: 0.02; 0.91) y OR ajustado = 0.07 (IC95%: 0.007; 0.68). Discusión: Es básico continuar indagando en aspectos que permitan disminuir la sobrecarga del cuidador, mantenerlo sano y en condiciones para su rol. **Conclusiones:** Es necesario fortalecer los diferentes medios de apoyos en el cuidador familiar para disminuir el nivel de sobrecarga relacionada con su tarea.

Palabras clave: Pacientes; Cuidadores; Enfermedad Crónica; Apoyo Social.

Introdução: No presente século, tem se evidenciado um aumento das doenças crônicas não transmissíveis no mundo inteiro e que os pacientes apresentam patologias com maior duração e complexidade, gerando dependência de um cuidador em casa ou de vários deles para melhorar a competência de cuidar. Objetivo: Identificar os meios de apoio utilizados pelo cuidador familiar de pacientes com patologia crônica não transmissível e sua relação com o nível de sobrecarga do cuidador. Materiais e Métodos: Estudo de tipo quantitativo, transversal e analítico, aplicando os instrumentos de "caracterização díade paciente-cuidador e a Sondagem de Percepção de Sobrecarga do Cuidador de Zarit". A população correspondeu a 62 díades. A razão de possibilidades (OR) foi calculada em regressão logística. Resultados: 19,35% (12) dos cuidadores apresentaram sobrecarga intensa, 20,97% (13) leve e 59,68% (37) não apresentaram sobrecarga. Os cuidadores com sobrecarga intensa relatam apoio psicológico e social de 0%. As variáveis relevantes no nível de sobrecarga foram as horas diárias de cuidado OR = 1,14 (IĈ 95%: 1,01; 1,33), quanto maior o nível de conhecimento de informática diminui a possibilidade de aumento do nível de sobrecarga com OR bruto = 0,14 (IC 95%: 0,02; 0,91) e OR ajustado = 0,07 (IC95%: 0,007; 0,68). Discussão: É fundamental continuar estudando aspectos que permitam diminuir a sobrecarga do cuidador, mantê-lo saudável e apto para a execução do seu trabalho. Conclusões: É necessário fortalecer as diferentes formas de apoio do cuidador familiar para reduzir o nível de sobrecarga relacionado à sua tarefa.

Palavras chave: Pacientes; Cuidadores; Doença Crônica; Apoio Social.

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INTRODUCTION

Being the main leading cause of death worldwide, Chronic non-communicable diseases (NCDs) have significantly increased by 5.8% between 2015 and 2010, which corresponds to 9 million deaths. From a pathological point of view, NCDs are also considered among the leading causes of morbidity and mortality as these are responsible for 63% of deaths¹.

Cardiovascular diseases, respiratory diseases, diabetes, and cancer are classified as NCDs. It is estimated that 62% of deaths and about 50% of disease burden worldwide in 2008 were due to this group of diseases. The World Health Organization (WHO) states that by 2020 75% of global deaths will be attributable to this type of diseases¹. A similar situation occurs in the Americas as Chile, Canada and Colombia have made efforts to achieve ten of the 19 proposed indicators. According to the Colombian Ministry of Health and Social Protection, chronic conditions are similar in the country: 76% of morbidity has been caused by NCDs over the last 20 years, becoming one of the main public health problems in which neuropsychiatric disorders, hypertensive cardiopathy, diabetes, and some heart diseases are mostly suffered by adults age 45 and over².

NCDs are complex pathologies of long duration and slow progression that in most cases generate total or partial dependency in those individuals experiencing them. In light of this, it is necessary to rely upon a caregiver, who regularly is a close relative, for which preparation and support are required to prevent morbidity in caregivers due to the burden imposed by the newly adopted role³.

Thus, individual or group programs and interventions, which are managed by healthcare professionals and different sector areas, are being created in different countries to provide support to informal caregivers on how to improve knowledge about the disease and its treatment management, care skills and competencies required so that the burden generated by this role can be reduced3. Therefore, different means of support are now being used in different scenarios such as Information Technology tools (IT)⁴, support networks⁵, discharge programs⁶ for both patients and family caregivers in order to reduce the burden generated by the caregiver role. This study was aimed at identifying the means of support used by family caregivers of patients with chronic non-communicable diseases to reduce care-related burden.

MATERIALS AND METHODS

Design and Sampling

A quantitative cross-cutting analytical study was conducted on a population composed of 62 patient-family caregiver dyads. These patients with chronic diseases had been hospitalized in the Internal Medicine and Emergency Room departments of a second-level healthcare hospital in the metropolitan area of Bucaramanga between 2016

and 2017. A sample of 157 dyads was calculated based on the burden prevalence estimated at 88.5% in caregivers of hospitalized patients, in which alpha (0.05), power (80%) are adequate using the EpiData 3.1² software. A convenience sampling was conducted in which family caregivers of patients with NCDs that had a minimum care time experience of three months over the age of 18 years were included, but caregivers with physical and mental disabilities were excluded as they had limitations to respond to questionnaires.

Tools Used

The GCPC-UN-D©, an instrument created by the Group of Care to the Chronic Patient and their Family of the School of Nursing at the National University of Colombia, was used to create sociodemographic records for the characterization of the patient-caregiver dyad. This tool includes items for the exploration of socio-demographic aspects of caregivers, their time and dedication to care, support networks, relationship with the patient, the level of patient dependency assessed using the PULSES profile and the mental state of patients and caregivers assessed through the SPMSQ test.

As for social support with the use of IT, caregivers were asked if they had a high, medium or low level of knowledge, access and use of television, radio, computer, telephone, internet and other means that support the management of the patient's disease. The ZARIT scale was used to assess caregiver burden, which consists of 22 LIKERT-type questions ranging from rarely to almost always. The score ranges from 22 to 110 under the following categories: absence of burden (\leq 46), mild burden (47-55) and intense burden (\leq 55). It also has inter-observer reliability (IOR) of 0.71 to 0.85, internal awareness measured using Cronbach's alpha of 0.85 to 0.938.

Data Analysis

For the analysis, Excel and STATA V-12 statistical software (StataCorp College Station, TX, USA) were used. The description of the variables was made through proportions, absolute frequencies, averages, standard deviation, median and interquartile range, according to the nature of each variable. There were no missing data in the variables studied. In order to identify differences between the three groups (no burden, mild burden, and intense burden), the following statistical tests were used: Kruskal-Wallis test (continuous variables with non-parametric or normal distribution), chi-squared and Fisher's test (categorical variables). For multivariate analysis, Ordinal Logistic Regression models were constructed, following the steps proposed by Hosmer and Lemeshow to include variables in the model with p-values less than 0.25 or variables that change coefficients greater than 25%. The fit of the model and analysis of influential data were both reviewed.

Ethical Aspects

This research complies with the ethical guidelines for biomedical research established by the Council for International Organizations of Medical Sciences (CIOMS), the Guides to Good Clinical Practices and Resolution 8430 of 1993 issued by the Ministry of Health of the Republic of Colombia. This research is classified as minimal risk research due to the fact that although no interventions were carried out, the application of surveys involved sensitive questions. This project was approved by the school's research committee, that for the School of Health is known as the MASIRA Institute of the University of Santander (UDES). The project was also submitted and approved by the ethics committees of the University of Santander and the partner institution where we worked.

RESULTS

Intense caregiver burden was identified in 19.35% (12), mild burden in 20.97% (13) and no burden

in 59.68% (37). According to the level of burden perceived by caregivers, some differences were identified in patients in relation to schooling, the zone where they live and the mental state of patients, with p-values < 0.05. See Table 1.

As for the level of schooling, the highest prevalence was primary school in 83.33% (10) in caregivers with intense burden, no school in 61.54% (8) of caregivers with mild burden, and primary school in 75.00% (27) of caregivers with no burden. In relation to the zone where they live, no patient lived in rural areas in caregivers with intense and mild burden, while 27.03% (10) of the patients lived in rural areas in caregivers with no burden. As for patient's mental state, patients of caregivers with no burden had a median on the SPMSQ mental scale score of 0 (IQR: 0 - 1), while patients of caregivers with mild and intense burden had a median of 2 (IQR: 1-2) and 2 (IQR: 0.5-3) respectively.

No significant differences were identified in the remaining variables based on the level of burden identified in caregivers, p-value > 0.05.

Table 1. Caregiver burden level according to patient characteristics

Patient characteristics	No burden n= 37 (59.68)	Mild burden n=13 (20.97)	Intense burden n= 12 (19.35)	p-value*
Median age (IQR)	76(66-76)	77(73-79	79.5(68-83.5)	0.89
Female #(%)	45.95(17)	53.85(7)	50(6)	0.88
Schooling #(%)				0.02
None	22.22(8)	61.54(8)	1(8.33(1)	
Primary school	75.00(27)	38.46(5)	10(83.33(10)	
Secondary school	2.78(1)	-	-	
Technical education	-	-	1(8.33)	
Socioeconomic classification #(%))			0.35
1	21.62(8)	23.08(3)	50(6)	
2	64.86(24)	61.54(8)	33.33(4)	
3	13.51(5)	15.38(2)	16.67(2)	
Zone where they live #(%)				0.01
Rural area	27.03(10)			
Urban area	72.97(27)	100(13)	100(12)	
N. of hours/days for patient care.	12(6-24)	20(10-24)	24(16-24)	0.09
Median (IQR)				
Sole patient caregiver #(%)	47.22(17)	69.23(9)	58.33(7)	0.37
Patient's PULSES score	2 (1-3)	3(1-3)	3(1-3)	0.15
Patient's SPMSQ score	0 (0-1)	2 (1-2)	2 (0.5-3)	0.01

^{*} P-values of continuous variables in Kruskal-Wallis test and chi-squared and Fisher's categorical tests.

Perceived Support

Caregivers with intense burden do not perceive any psychological or social support, those with mild burden do not perceive psychological support, and only 37.5% (11) of those categorized with no burden receive psychological support. Family, religious and economic support are perceived by caregivers of the different burden levels in percentages ranging from 50% to 100%. See Figure 1.

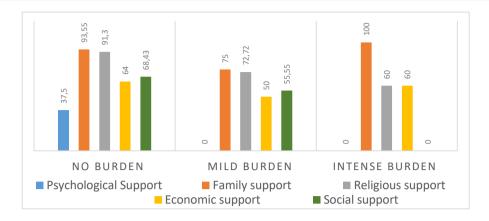


Figure 1. Perception of caregiver support based on their burden level

Use of IT Tools

When asking caregivers about knowledge, access and use of IT tools for patient management support, they were asked to refer to whether it was high, medium or low. Among those who responded with low levels of knowledge, access and use, it was identified that caregivers with intense burden showed higher percentages compared to those with mild burden and with no burden and in all IT in general. In addition, it was 100% for computer and internet use. See Figure 2.

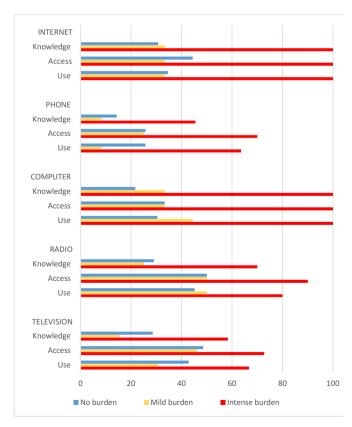


Figure 2. Low levels of knowledge, access and use of IT tools based on the caregiver burden level

In the multiple analysis, one of the characteristics identified with the greatest influence on caregiver burden is the daily number of care hours as it increases for each additional care hour with a crude OR = 1.10 (95% CI 1.03, 1.18) and an adjusted OR = 1.14 (95% CI 1.01, 1.33). Patient's mental

state was relevant in the crude analysis with an OR of 2.00 (95% CI 1.26, 3.17) and the adjusted model with an OR of 1.15 (95% CI 0.56, 2.38). The level of caregivers' computer knowledge was relevant to the crude and adjusted level as shown in Table 2.

Table 2. Ordinal Logistic Regression Model. OR (95% CI)

Characteristics	Crude Analysis	Adjusted Analysis		
Number of daily care hours	1.10 (1.03; 1.18)	1.14 (1.01; 1.33)		
Patient's SPMSQ	2.00 (1.26; 3.17)	1.15 (0.56; 2.38)		
Caregiver's computer knowledge level				
Low	1	1		
Middle	0.17 (0.03; 0.88)	0.14 (0.02; 0.91)		
High	0.09 (0.01; 0.63)	0.07 (0.007; 0.68)		

DISCUSSION

In this study, the number of hours dedicated to patient care and their mental state was significant in the Zarit scale scores, similar to the study conducted by Black et al. in 2018⁹ but different to the study published by Mestrinelly et al. in 2018 as their study population was caregivers of patients with Parkinson's disease with a sample size of 21 dyads in which no statistical significant variables were found in the multivariate analysis¹⁰.

When checking the sociodemographic characteristics of the caregiver-patient with NCDs dyad, similar results are found in other studies in Colombia¹¹ with regard to the profile, coinciding that caregivers are female homemakers aged between 36 and 59 years old that live in urban areas without any type of mental disorder, conditions

that support family caregivers to perform their role.

It was observed that caregivers with intense burden show high percentages in the use, knowledge and access to television, telephone and radio, although internet and computer use, knowledge and access rates are lower compared to caregivers with mild burden or no burden. Similar data are found in studies where the use of support means such as telephone increases care wellbeing and diminishes anxiety generated by the new role¹². Caregivers are interested in receiving information about in-home disease management, for which IT tools are very useful to obtain social support through groups where they can share their emotions and experiences related to care¹³.

In addition, it can be observed the importance that social support generates in people with chronic diseases and their caregivers, which allows tackling appropriately this work that, if uncontrolled, it can have adverse consequences and generate burden-related stress¹⁴. The design and implementation of psychosocial interventions should be considered as these have been identified to have positive effects on quality of life and care burden¹⁵. It has also been reported that including caregivers in computer training courses and using internet bring social benefits, good communication and improvement of care skills according to the study published by Dow et al.¹⁶.

This study retrieved information on patients and caregivers' characteristics that can be related to caregiver burden, but it did not assess aspects such as quality of life, presence of affective disorder and sleep disorders in both patients and caregivers. The study conducted by Crespo et al. consider these variables as relevant in caregiver burden¹⁷, for which it is recommended to include instruments to assess these variables in future studies aimed at determining the caregiver burden level¹⁸⁻²⁰.

CONCLUSIONS

Caregivers assuming the role of caring for their family patients with chronic diseases need to increase their knowledge in the use of IT tools, especially the use of computers and internet, so they can join groups of psychological and social support to improve care and reduce the burden generated by this role.

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Conflict of interest: The authors declare that they have no conflict of interest.

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