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Relationship between Burden and Perceived Social Support in Low-income Caregivers*

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Theme: Chronic care

Contribution to the subject: From the Nursing area, participation in the creation and restructuring of public policies should be fostered in the country to establish strategies for strengthening the social support provided to caregivers of people with chronic diseases, especially those with low income, thus improving their care skills and, simultaneously, preventing or reducing their burden.

Abstract

Objectives: To describe and correlate burden and social support in low-income caregivers of chronic patients. **Material and methods:** A descriptive and cross-sectional study was conducted with 170 low-income family caregivers of people with chronic diseases who answered a survey on sociodemographic and care variables, in addition to the Zarit scale to measure burden and the MOS questionnaire on perceived social support. The analysis was performed using descriptive and differential statistics. **Results:** Most caregivers were female, and the predominant kinship was father-son. A significant and negative correlation ($r_s = -0.307$, $p < 0.001$) was identified between the caregivers' burden and perceived social support, as well as a significant and positive correlation ($r_s = 0.278$, $p < 0.01$) between the time devoted to care and the caregivers' burden. **Conclusions:** Low-income family caregivers require more social support to reduce the burden levels.

Keywords (Source: DeCS)

Caregivers; family caregiver; social support; cost of illness; chronic disease.

4 Relación entre la sobrecarga y el apoyo social percibido en cuidadores de bajos ingresos económicos*

* Este estudio se realizó en el marco del proyecto “Adopción del rol de cuidador familiar de la persona con enfermedad crónica con base en la comunidad” identificado con el código Hermes 50257 y contó con la financiación del Ministerio de Ciencia, Tecnología e Innovación (MinCiencias) mediante la “Convocatoria para el fortalecimiento de proyectos en ejecución de CTel en ciencias de la salud con talento joven e impacto regional”, bajo el convenio o Contrato de Financiamiento de Recuperación Contingente N.º 847 de 2020 celebrado entre el MinCiencias y la Universidad Nacional de Colombia.

Resumen

Objetivos: describir y correlacionar la sobrecarga y el apoyo social de cuidadores de pacientes crónicos con bajos ingresos económicos.

Material y métodos: estudio descriptivo transversal realizado a 170 cuidadores familiares de personas con enfermedad crónica de bajos ingresos económicos a quienes se les aplicó una encuesta sobre variables sociodemográficas y de cuidado, además de la escala Zarit para medir la sobrecarga y el cuestionario MOS sobre apoyo social percibido. El análisis se realizó mediante estadística descriptiva y diferencial. **Resultados:** la mayoría de los cuidadores fueron mujeres y el vínculo filial predominante fue de padre e hijo. Se identificó una correlación significativa y negativa ($rs = -0,307, p < 0,001$) entre la sobrecarga del cuidador y el apoyo social percibido, como también una correlación significativa y positiva ($rs = 0,278, p < 0,001$) entre el tiempo dedicado al cuidado y la carga del cuidador. **Conclusiones:** los cuidadores familiares de bajos ingresos económicos requieren mayor apoyo social para disminuir los niveles de sobrecarga.

Palabras clave (Fuente: DeCS)

Cuidadores; cuidador familiar; apoyo social; carga de las enfermedades; enfermedad crónica.

Relação entre sobrecarga e apoio social percebido em cuidadores de baixa renda*

* Este estudo foi realizado no âmbito do projeto "Adoção do papel do cuidador familiar da pessoa com doença crônica baseada na comunidade" identificado com o código Hermes 50257, financiado pelo Ministério da Ciência, Tecnologia e Inovação (MinCencias), da "Chamada para o fortalecimento de projetos em execução de CTel em ciências da saúde com talento jovem e impacto regional", sob o convênio ou contrato de financiamento de recuperação contingente n. 847 de 2020 celebrado entre o MinCencias e a Universidad Nacional de Colombia.

Resumo

Objetivos: Descrever e correlacionar a sobrecarga e o suporte social de cuidadores de baixa renda de pacientes crônicos. **Material e métodos:** Estudo descritivo e transversal, realizado com 170 cuidadores familiares de baixa renda de pessoas com doenças crônicas, que responderam a um questionário sobre variáveis sociodemográficas e assistenciais, além da escala de Zarit para medir a sobrecarga e do questionário MOS sobre suporte social percebido. A análise foi realizada por meio de estatística descritiva e diferencial. **Resultados:** A maioria dos cuidadores era do sexo feminino e o vínculo filial predominante era entre pai e filho. Foi identificada uma correlação significativa e negativa ($r_s = -0,307, p < 0,001$) entre a sobrecarga do cuidador e o suporte social percebido, assim como uma correlação significativa e positiva ($r_s = 0,278, p < 0,001$) entre o tempo dedicado ao cuidado e a carga do cuidador. **Conclusões:** Os cuidadores familiares de baixa renda necessitam de maior suporte social para reduzir os níveis de sobrecarga.

Palavras-chave (Fonte: DeCS)

Cuidadores; cuidador familiar; apoio social; efeitos psicossociais da doença; doença crônica.

Introduction

Chronic Non-Communicable Diseases (CNCDs) are characterized by progressive long-term consequences and are the leading causes of disability and death globally, given their high burden (1). According to the World Health Organization (WHO), 71% of deaths each year can be attributed to these diseases, with 5.5 million annual deaths in the Americas alone. In particular, CNCDs affect populations in a condition of vulnerability, as they are exposed to risk factors and enjoy limited access to health services. The CNCD burden is estimated through life years lost (LYL) and years lived with disability (YLD). These indicators have increased since 1990 to the extent that, by 2019, YLDs due to CNCDs represented more than half of the entire morbidity burden (2).

CNCDs affect not only the patients but also their caregivers, who are individuals that provide care and receive no economic remuneration in exchange (3). Most of the time, this caregiver role is taken on by a family member, called a family caregiver, who is in charge of providing direct care to the person with a CNCD, making decisions related to the health needs, and supporting the health care system by favoring home-based care (4–6). However, family caregivers are generally not duly prepared to perform a new role and risk developing a burden if low satisfaction with social support and high demand in the care tasks are added (7).

Burden is understood as mental and emotional exhaustion that leads to stress, with repercussions on physical and psychological health and other spheres of everyday life, such as social relationships (8, 9). The burden levels can be determined by socioeconomic conditions, especially when dealing with a low-income context. Family caregivers offer their care services without receiving any remuneration, and, as they devote themselves to these tasks, they find it challenging to earn a livelihood necessary to meet not only care-related needs but also those emerging from everyday life, also limiting access to long-term health services and support (10, 11). In Colombia, most studies assessing burden have evidenced that caregivers have mild or nonexistent burden levels (10–12).

On the other hand, it has been demonstrated that caregivers have higher burden levels when they perceive less social support (13, 14). Social support is the system of formal and informal relationships from which a person receives instrumental and emotional help to face stressful situations (15). The perception of this support exerts an influence on caregivers' responses and adaptation to take on the care experience more efficiently and reduce negative perceptions (16, 17). This perceived social support can be conditioned when the caregivers earn low incomes (18, 19). They and their family enjoy fewer chances of accessing health services and making rapid and early diagnoses, to which difficulties purchasing medications, transportation and mobility limitations to attend medical centers,

and lack of clear and precise information about care and management of the disease are added (20).

In Colombia, various studies have proved that the social support provided to caregivers is insufficient to meet the care demands (21); it has also been reported that 96.1 % of caregivers from different regions of the national territory earn low incomes (12). These variables have been measured independently, and from them, it cannot be determined whether these low-income caregivers perceive sufficient social support or how this impacts caregivers' burden levels. Thus, the present study aims to describe and correlate sociodemographic and care variables, burden, and social support in low-income caregivers of chronic patients.

Materials and methods

Design

A quantitative, descriptive, cross-sectional study was conducted during the first half of 2021 in Bogotá, Colombia.

Inclusion criteria

We included come-of-age caregivers having already cared for a family member with a chronic disease for more than six months, with their mental function unaltered, as verified with the SPMSQ test (22). In addition, caregivers who stated that their homes were classified in strata 1, 2, and 3 based on the Colombian socio-economic classification (22) were included; in other words, the population segment that earns USD 250 or less per month (23).

Exclusion criteria

Caregivers who found difficulties answering the online questionnaire were excluded.

Participants and sample

During the first half of 2021, an open call was made to family caregiving associations linked to the *Cuidando a los Cuidadores*® (Taking care of caregivers) program from Universidad Nacional de Colombia. The caregivers interested in participating wrote to the program's email address. The reply to this email informed them about the study objective and methodology and provided an online Google Forms form for data collection. A total of 120 forms were sent, and 170 answers were received because the individuals that received the email message shared the survey with other interested participants that had missed the first notice. No incomplete forms were received because they were designed for all the questions to be answered mandatorily to enable submission.

Study variables and measurements

The interested caregivers that wrote to the program's email address were sent an online Google Forms form for data collection. This form, comprised of three sections, was designed to be answered by self-reporting, with a prior explanation in the email message.

The first section was devoted to collecting sociodemographic data using the characterization survey for the care of the "person with a chronic disease-family caregiver" dyad, developed and validated to be used in the Colombian context. The survey has 42 items that measure three general dimensions: sociodemographic profile and general conditions of the caregiver, perception of burden and support, and use of Information and Communication Technologies (10).

The following section measured the caregiver's burden with the Zarit burden instrument in its Spanish version validated for Colombia, with 0.92 validity, 0.81 reliability, and a Cronbach's alpha of 0.861. The tool has 22 items, which are assessed on a five-point Likert-type scale: 0 (Never), 1 (Rarely), 2 (Sometimes), 3 (Often), and 4 (Almost always). Its possible score can vary between 0 and 88 points, and, in turn, the burden levels are established according to the range obtained: when below 46, it is classified as no burden; when between 46 and 56, the burden is considered mild; and when above 56, the burden is considered intense (24).

Finally, perceived social support was measured with the MOS questionnaire, validated in Colombia using Confirmatory Factor Analysis, which shows GFI = 0.780, AGFI = 0.713, RMSEA = 0.113, AIC = 566.98, and BIC = 707.22 in addition to a Cronbach's alpha of 0.94 (25). This questionnaire has 20 items scored through a Likert-type scale from 1 (Never) to 5 (Always); the first item evaluates the size of the social network, and the next 19 are grouped into four dimensions that consider affective, instrumental, and emotional/informational support, and positive social interaction. Consequently, the higher the score, the greater the perceived social support.

Data analysis

The information analysis was performed using descriptive statistics for continuous variables, whereas proportions were used for nominal and ordinal variables. Data analysis was conducted in the R Studio statistical program, version 4.0.5. Pearson's correlation coefficient was employed to determine data correlation upon fulfilling the normality requirements tested with the Kolmogorov-Smirnov test. Correlations with p -values < 0.05 were considered significant.

Ethical considerations

This study was approved by the Ethics Committee of the Nursing School at Universidad Nacional de Colombia under Minutes 029/2019. In addition, the current study considered the ethical norms outlined

in the 1973 Declaration of Helsinki at all times. It also met all the respect, autonomy, beneficence, and information confidentiality principles.

The participants received an explanation of the research objectives before expressing their will to participate in the study, manifested in the informed consent included at the beginning of the Google Forms form. Likewise, they were ensured that their data would be handled anonymously and confidentially, solely for research purposes.

Results

Sociodemographic characteristics of the patients with chronic diseases

Information was collected from 170 dyads comprised of caregivers and individuals cared for. The patients' information can be found in Table 1, where it is noted that most people with chronic diseases were female, and their mean age was 69 years old ($SD = 22.7$), in addition to a mean of 136.7 months with the chronic illness ($SD = 126.3$). Regarding marital status, 34.7 % were widowed, and 39.4 % were married. In terms of occupation, 39.4 % were devoted to housework. Among the chronic diseases that most prevailed were cardiovascular diseases with 48.8 %, while others such as cancer, respiratory, neurodegenerative, renal, and mental diseases jointly accounted for 49.4 %.

Table 1. Sociodemographic characterization of the patients with chronic diseases

Variables		N (n = 172)	%
Gender	Male	73	42.9
	Female	97	57.1
Marital status	Married	67	39.4
	Consensual union	3	1.8
	No partner	100	58.8
Schooling	No studies	13	7.7
	Incomplete elementary school	27	15.9
	Complete elementary school	72	42.4
	Incomplete high school	2	1.2
	Complete high school	24	14.1
	Technician or technologist	10	5.9
	Complete higher education	19	11.2
	Incomplete higher education	2	1.2
	Graduate studies	1	0.6
Occupation	Employee	14	8.2
	Student	8	4.7
	Housework	67	39.4
	Freelance job	30	17.6
	Other	51	30

Variables		N (n = 172)	%
Number of chronic diseases	1	101	59.4
	2-3	56	32.9
	3+	13	7.6
Type of chronic disease	Cardiovascular	83	48.8
	Metabolic	38	22.3
	Musculoskeletal	32	18.8
	Other	84	49.4
		Mean	SD
Age in years		69	22.7
Time with the disease in months		136.7	126.3

Source: The authors.

Sociodemographic characteristics of the caregivers

Table 2 presents the information collected from the caregivers, where 87.6 % were female, with a mean age of 52.3 years old. Their mean time in the role was between 88.0 and 119.4 months (95 % CI). Regarding the number of hours devoted to care tasks, the mean was 12.6, varying between 11.7 and 13.5 daily hours (95 % CI); 57.6 % stated sharing the care tasks. Kinship with the patients mainly corresponded to father or mother with 47.6 %, followed by 23.0 % for another type of kinship and 15.9 % for spouses. Regarding the caregivers’ current occupation, 41.2 % stated that they were not working due to their housework, followed by 24 % with freelance jobs.

Table 2. Sociodemographic characterization of the caregivers

Variables		N (n = 172)	%
Gender	Male	21	12.4
	Female	149	87.6
Marital status	Married	70	41.2
	Consensual union	13	7.6
	No partner	87	51.2
Schooling	Incomplete elementary school	4	2.4
	Complete elementary school	21	12.4
	Incomplete high school	12	7.1
	Complete high school	44	25.9
	Technician or technologist	41	24.1
	Complete higher education	37	21.8
	Graduate studies	11	6.5
Occupation	Employee	31	18.2
	Student	7	4.1
	Housework	70	41.2
	Freelance job	42	24.0
	Other	20	11.7

Variables		N (n = 172)	%
Stratum	1	6	3.5
	2	62	36.5
	3	102	60.0
Kinship with the patient	Father or mother	81	47.6
	Son/Daughter	23	13.5
	Spouse	27	15.9
	Other	39	23.0
		Mean	SD
Age in years		52.3	13.2
Time as a caregiver in months		103.7	103.2
Number of daily hours devoted to care		12.3	7.8

Source: The authors.

Description of the “burden” and “social support” variables

The description of the caregivers' burden variable as measured by the Zarit questionnaire and the perceived social support variable as established by the MOS questionnaire are shown in Table 3. Regarding the caregivers' burden variable, the prevalence of a mild burden was obtained, with a mean of 53.16 ($SD = 14.47$). Regarding the social support perceived by the caregivers, the mean was 67.21 ($SD = 17.77$), corresponding to a high level.

Table 3. Descriptive statistics of the study variables

Variable		Min.	Max.	Mean	Standard Deviation	95 % CI
Caregivers' burden	Impact dimension	12	54	31.05	9.18	29.66-32.44
	Interpersonal dimension	6	27	11.17	4.06	10.55-11.79
	Competencies and expectations dimension	2	20	10.94	3.56	10.40-11.48
	Total Zarit	22	101	53.16	14.47	50.97-55.35
Perceived social support	Emotional/ Informational social support	8	40	28.15	8.11	26.92-29.38
	Instrumental support	4	20	12.99	4.51	12.30-13.67
	Positive social interaction	4	20	14.46	4.02	13.86-15.07
	Effective support	3	15	11.61	3.35	11.10-12.11
	Total of all dimensions	24	95	67.21	17.77	64.52-69.90

Source: The authors.

Table 4 presents the statistically significant correlations found between the different variables measured in the study. A statistically significant and positive correlation was found between the caregivers' age and their time in the role and between the caregivers' age and the number of daily hours devoted to care. A correlation between the "time as a caregiver" and "number of daily hours devoted to care" variables, the impact and interpersonal dimensions, and the overall Zarit burden score was also identified. On the other hand, a negative and statistically significant correlation ($p < 0.001$) was established between the Zarit burden dimensions and the different support dimensions from the MOS questionnaire, indicating that a higher burden was significantly correlated with low support scores or vice versa.

Table 4. Correlations between variables

Variables	Caregiver's age	No. of daily hours devoted to care	Impact dimension	Interpersonal dimension	Competencies and expectations dimension	Total Zarit
Time as a caregiver	0.246**	0.151	0.159*	0.055	0.143	0.151*
No. of daily hours devoted to care	0.321**	-	0.331**	0.176*	0.076	0.278**
Emotional/ Informational social support	-0.005	-0.100	-0.161*	-0.236**	-0.339**	-0.252**
Instrumental support	-0.121	-0.165*	-0.264**	-0.261**	-0.236**	-0.299**
Positive social interaction	-0.039	-0.051	-0.226**	-0.230**	-0.244**	-0.268**
Effective support	-0.014	-0.040	-0.209**	-0.305**	-0.310**	-0.294**
Total of all dimensions (MOS)	-0.045	-0.106	-0.232**	-0.283**	-0.328**	-0.307**

(*) $p < 0.05$, (**) $p < 0.001$

Source: The authors.

Discussion

According to the results, this low-income population group probably assumes the caregiver role facing more significant difficulties. As they spend more time on care tasks, they miss job opportunities and find it hard to earn a livelihood to meet their everyday needs and care demands (19, 26). As seen in this study, 70.0 % of the caregivers are unemployed and devote around twelve hours daily to housework. The caregivers' low socioeconomic level impacts access to the health system and relevant information about their health status (27, 28).

For the current study, the burden was reported as mild, with a mean of 53.16 and a standard deviation of 14.47; in general, the reported trend regarding a nonexistent or low burden that predominates in similar studies about caregivers' burden in Colombia is maintained, where 59.68 % and 20.97 % reported a null and mild burden, respectively (12, 29). Although the burden levels were low, it is vital to prevent them from increasing by implementing a timely intervention to improve the quality of life for patients and their caregivers.

A direct relationship was also found between the burden levels and the time that family caregivers devote to care tasks (0.151; $p < 0.05$), as well as a correlation between burden and the number of daily hours devoted to care (0.278; $p < 0.01$). Carreño and Chaparro had already reported these variables in their study (12), with which we agree. Other research studies with similar results in terms of the daily hours devoted to care reveal that devoting much time to these tasks can cause physical and mental health problems in caregivers, as well as stress and a reduction in subjective well-being, which exerts a direct influence on the quality of life (30).

Regarding perceived social support, several authors agree that socioeconomic condition determines how this social support is perceived. In (20), low-income individuals enjoy less social support, a situation aggravated by a lack of knowledge about access to health services and social aids. The results obtained in this study about perceived social support are not far from what was found in others, as we got a high score with a mean of 67.21, whereas Barrera *et al.* obtained a score of 75.2; in addition, they identified that the caregivers, mainly those from the Amazonía and Orinoquía regions, were satisfied with their perceived social support, with scores of 70.1 and 67.6, respectively (31). Moreover, in (6), although perceived social support was measured with Hilbert's Social Support in Chronic Illness Inventory (SSCII), the results obtained were high, with an average of 110.7, which means that family caregivers of people with chronic diseases are somewhat satisfied with the social support they perceive (32).

This study found an association between social support and burden levels, understanding that greater perceived social support of any type is related to lower burden levels, with a correlation of -0.307 ($p < 0.001$). These findings are consistent with those obtained in (13) with low-income Afro-American caregivers living in the United States and (29) in Bucaramanga, Colombia, where the caregivers with intense burden levels reported having no psychological or social support.

Considering the results obtained, the practical implications of this study evidence the need to seek strategies from the Nursing area to strengthen social support, understanding this support as necessary for the caregivers to be able to face and adequately

take on their role with no undesirable consequences and prevent burden. It has been shown that developing laws, decrees, and grants, among others, contributes to reducing the impacts imposed by the role and improving the caregivers' socioeconomic conditions, as some countries already do with various programs, such as those granting a disability pension in India (19) or the economic aids funded by the government in Canada, Africa, and Spain (20, 33, 34).

A limitation identified in the current study is the possible selection bias due to intentional sampling to obtain the results; therefore, they will apply to the sample under investigation and may be extrapolated to population groups with similar characteristics. It is also worth noting that this study was conducted during the COVID-19 pandemic period experienced in Colombia, so the results obtained might be influenced by the caregivers' aggravating factors due to the restrictions, isolation measures, and rules imposed by the Colombian Ministry of Health and the direct socioeconomic consequences brought about by these restrictions. Thus, a higher than the forecast number of answers was allowed to increase the results' variability.

Lastly, these results represent a practical approach for Nursing in Colombia concerning perceived social support and burden among low-income caregivers, which allows working continuously on the design and validation of strategies to prioritize this population segment or improve the results herein obtained.

Conclusions

The burden was significantly correlated with the number of hours devoted to care and time as a caregiver. A significant negative correlation was statistically obtained between perceived social support and the burden dimensions, which shows that the burden imposed by the role can be reduced if the social support provided to these caregivers is improved. However, for earning lower incomes, this population group faces more significant difficulties in receiving social support.

Based on the results obtained in this study, an intervention from different disciplines, such as Nursing, is necessary to devise state interventions, programs, and aids directed to these caregivers to ease their role and improve health results, both in themselves and in their patients.

Conflict of interest: None declared.

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