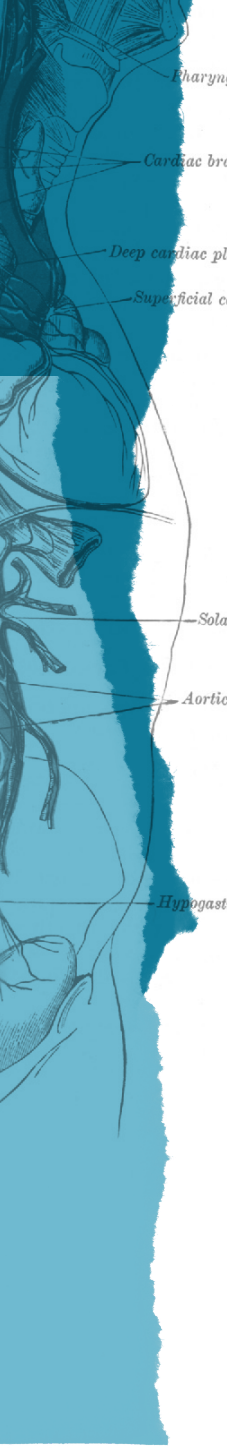

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The Patient with COPD and the Burden of the Primary Caregiver: A Descriptive Analysis Study

El paciente con EPOC y la sobrecarga del cuidador principal: un estudio de análisis descriptivo

Lina Vergara-Jiménez[1], Keidis Ruidiaz-Gómez[2]

[1] Nurse. Master in Sexual and Reproductive Health. Professor, Corporación Universitaria Rafael Núñez, Universidad del Sinú, Nursing Program, Cartagena (Colombia). limaveji@gmail.com. https://orcid.org/0000-0002-9611-9334

[2] Nurse. PhD in Nursing. Research professor, Universidad de Sinú EBZ, School of Nursing, Cartagena (Colombia). keydiruidiazg@gmail.com. https://orcid.org/0000-0001-9335-8930

Correspondence: Keidis Ruidiaz Gómez. keydis.ruydiaz@unisinu.edu.co

ABSTRACT

Objective: To determine the level of caregiver burden among the main caregivers of patients with chronic obstructive pulmonary disease.

Methodology: A quantitative, descriptive study was conducted with a sample consisting of 74 main caregivers of patients with COPD. The Spanish version of the Zarit Test was applied. The analysis used descriptive statistics with frequencies and percentages.

Results: Specifically, 58% of respondents reported being afraid of the future of their relatives, while 56% think that their relative depends on them. Furthermore, 52% think that they do not have enough financial resources to cover the expenses of caring for their relative. Notably, 63.3% think that they should do more for their relative, and 58% think that they could take better care of their relative. Overall, 11.3% of caregivers presented caregiver burden.

Conclusions: Caregivers are individuals with rights who require targeted attention within risk prevention programs associated with caregiving responsibilities. Consequently, it is essential to provide them with education and ongoing support to empower them in maintaining and promoting their own health.

Keywords: overload, caregivers, caregiver burnout, Zarit test.

RESUMEN

Objetivo: Determinar nivel de sobrecarga del cuidador principal de pacientes con enfermedad crónica.

Metodología: Estudio cuantitativo, descriptivo. La muestra la constituyeron 74 cuidadores principales de pacientes con EPOC. Se aplicó Test de Zarit versión español. El análisis empleó una estadística descriptiva con frecuencias y porcentajes.

Resultados: El 58 % de encuestados tienen miedo por el futuro de su familiar; 56 % piensan que su familiar depende de ellos; 52 % opinan que no tienen suficientes ingresos económicos para los gastos de cuidar a su familiar, además de sus otros gastos; 63,3 % piensan que deberían hacer más por su familiar; 58 % piensan que podrían cuidar mejor a su familiar y 11,3 % de cuidadores presentaron sobrecarga.

Conclusiones: Los cuidadores son individuos con derechos que requieren atención específica dentro de programas de prevención de riesgos asociados con las responsabilidades del cuidado. Es esencial proporcionarles educación y apoyo continuo para empoderarlos en el mantenimiento y la promoción de su propia salud.

Palabras clave: sobrecarga, cuidadores, cuidador quemado, Test Zarit.

INTRODUCTION

The prevalence of chronic obstructive pulmonary disease (COPD) in the world population is estimated to be approximately 1%, but it rises sharply to more than 10% in the population over 40 years of age, rising significantly with increasing age. Furthermore, in adults, it seems to be between 4% and 10% in countries where it has been rigorously measured (1). This situation leads to a considerable percentage of primary caregivers who are forced to carry out care actions in this population.

Understanding the personal impact and social context experienced by primary caregivers enables the development of effective intervention strategies from both primary and specialized healthcare settings. These strategies aim to improve caregivers' quality of life and overall well-being, which, in turn, positively affects the well-being of patients with COPD.

Informal caregivers play a fundamental and often irreplaceable role; therefore, it is essential to identify their needs and implement preventive interventions and support measures to minimize the risk of "caregiver syndrome" (2). Given their close relationship with both patients and caregivers, nursing professionals must remain attentive to the needs and challenges of these individuals in order to detect issues early.

To this end, it is crucial to conduct research projects grounded in the realities faced by nursing professionals—projects that not only reflect their working environments but also serve as foundations for future research (3).

A deep understanding of this phenomenon is vital to grasp the circumstances contributing to the sense of burden experienced by individuals and families caring for patients with COPD (4). These caregivers, drawing from their lived experience, are uniquely positioned to identify the most significant aspects of caregiving. By recognizing the specific realities of caregiver burden, the nursing discipline can develop strategies aimed at improving the quality of life for both caregivers and patients with COPD, thereby strengthening the overall healthcare process (5).

When reviewing the literature, it is evident that there is a gap in the existence of studies carried out in Colombia that specifically address the burden of the main caregiver in patients with COPD. Moreover, few studies provide relevant or sufficient information that glimpses the specific reality

of individuals and families. In contrast, in the international arena, there are related studies in countries such as Spain, Mexico, and Brazil (6). In Colombia and Peru, there is a considerable population of people with COPD (5), but aspects related to the caregiver burden are unknown, including whether individuals in these circumstances would be willing to participate in a process that represents short- and long-term benefits. Hence, this study emphasizes the relevance of determining the level of burden of the main caregiver of patients with chronic obstructive pulmonary disease in a private institution.

MATERIALS AND METHODS

Type of Study

A quantitative, descriptive, and cross-sectional study was conducted.

Study Area and Population

The study was conducted at a private health institution in Cartagena de Indias, with the participation of 133 primary caregivers of patients with COPD. Participants were selected based on the following inclusion criteria: they were women and men aged between 18 and 60 years, resided in Cartagena, performed care activities regularly at least three times a week, and had a minimum care dedication of six months. The information was collected during April 2023.

Participants

The sample was selected through non-probabilistic consecutive sampling by convenience. The final sample was made up of 74 people identified in the databases from 2020 to 2023 of a private health institution in Cartagena, with permanent residence in the study area and of legal age.

Instruments

The Zarit Test (7) was applied, which is an instrument that quantifies the degree of burden suffered by caregivers of dependent people. This tool has validated versions in English, French, German, Swedish, Danish, Portuguese, Spanish, Chinese, and Japanese. The original English version dates from 1983 and consists of a list of 22 statements that describe how caregivers sometimes feel; for each of them, the caregiver must indicate how often they feel this way, using a

Likert scale. The scores obtained in each item are added together, and the final score represents the degree of caregiver burden. Therefore, the overall score ranges from 0 to 88 points (7).

Procedure and Collection of Information

Surveys were administered through visits to the healthcare institution and direct contact with primary family caregivers. In some cases, caregivers were contacted by telephone using the institutional database. Furthermore, data collection took place between March and April 2023.

Participants completed a data collection instrument composed of two sections: 1) A sociodemographic questionnaire consisting of 10 items, which included variables such as country/city of residence, area of origin, ethnic background, socioeconomic status, sex, age, marital status, educational level, religious beliefs, and occupation. 2) The Zarit Burden Interview (ZBI), a widely validated instrument—including its Spanish version—used to assess caregiver burden. Specifically, it explores the negative effects on the caregiver, considering physical and mental health, social activities, and economic resources. The caregiver must indicate the frequency with which he or she feels identified with each statement. Each response is classified as: never=0, rarely=1, sometimes=2, many times=3, and almost always=4. This allows for identifying how often the caregiver feels affected by each item; moreover, item 22 gives us an overall assessment of the burden perceived by the caregiver, rating it as: not at all=0, little=1, moderate=2, much=3 and extreme=4. All points must be added for the final result. Different degrees of caregiver burden are established, depending on the score obtained. From 22 to 46, no burden; from 47 to 55, mild burden and from 56 to 110, intense burden (7).

Statistical Analysis

The information obtained was systematized and classified using Microsoft Excel and exported to SPSS Version 25.0. The descriptive analysis included the calculation of percentages, summations, and the preparation of tables and graphs.

Ethical Statement

Compliance with the ethical principles and standards of the Declaration of Helsinki of 1975 and its subsequent revisions, as well as Resolution 8430 of 1993 of the Ministry of Health of Colombia for research with human beings, was ensured (8). The collection of information and

the handling of data were performed while maintaining the anonymity of the participants, from whom informed consent was obtained. The Ethics and Bioethics Committee of the University of Sinú endorsed the procedures in the act of March 7, 2023. Additionally, Law 266 of 1996 (9), which regulates the nursing profession in Colombia, Judgment T-096 of 2016(10), in which the Constitutional Court establishes the differences between caregiving and home nursing, and Law 39/2006, on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency, were considered.

RESULTS

Characterization of the Population

Among the caregivers surveyed, the majority were women (77.2%, n = 61). Regarding age, the most represented age group was 26–35 years (31.6%), followed by those aged 36–45 years (25.3%). Most caregivers were in a productive life stage, often balancing work, academic, and professional responsibilities.

Regarding socioeconomic status, 46.8% belonged to socioeconomic stratum 2, while strata 1 and 3 each accounted for 25.3%, indicating that most caregivers lived in low to middle-income households. Additionally, 41.8% were single. In terms of religion, 65% identified as Catholic and 21.5% as Protestant.

With respect to education, 50.6% of caregivers had completed university studies, 27.8% had a high school diploma, and 10.1% had completed only primary education.

Factors that Affect the Overload of the Main Caregiver

A total of 46 participants (58%) reported feeling fear about the future of their family members. Of these, 29.1% indicated they sometimes experience this fear, 21.1% said they feel it almost always, and 7.6% reported thinking about it frequently.

Also, half of the caregivers (50%, n = 40) stated that their family members see them as the only person capable of providing care. Additionally, 20.3% selected “almost always,” 16.5% “sometimes,” and 12.7% “quite often,” reflecting varying degrees of perceived exclusivity in caregiving responsibilities (Table 1).

Table 1. Perception of caregiver burden by specific items 1-3

Item	Category	Number (n)	Percentage (%)
Fear for the future of their family members	Never	21	26.6
	Seldom	12	15.2
	Sometimes	23	29.1
	Quite a few times	6	7.6
	Almost always	17	21.5
	Never	20	25.3
Do you think your family members depend on you?	Seldom	15	19.0
	Sometimes	20	25.3
	Quite a few times	7	8.9
	Almost always	17	21.5
You think that your family members consider you the only person who can take care of them.	Never	22	27.8
	Seldom	18	22.8
	Sometimes	13	16.5
	Quite a few times	10	12.7
	Almost always	16	20.3

Source: own elaboration.

Furthermore, when asked whether they believe their income is insufficient to cover caregiving expenses in addition to other personal costs, 52% (n = 41) responded affirmatively. In addition, 10.1% reported this concern "almost always," 19% "quite often," and 22.8% "sometimes," as detailed in Table 2.

In this context, findings from an exploratory systematic review—including 20 studies on caregiver burden in Colombia—revealed a direct association between socioeconomic conditions and the level of perceived burden. Specifically, cultural context and financial limitations were identified as key contributing factors, particularly among homemakers with scarce resources and caregiving experience exceeding three years. These factors, therefore, play a significant role in shaping the caregiver's perception of overload. A total of 50 people (63.3%) think that they should do more for their family members, 29.1% consider this option sometimes, 20.3% the option quite a few times, and 13.9% say that they think about it almost all the time. When asked if they think they

could take better care of their family, 46 caregivers (58.2%) responded affirmatively; of these, 29.1% consider this option sometimes, 11.4% the option quite a few times, and 17.7% say that they think about it almost always (Table 2).

Table 2. Perception of caregiver burden by specific items 4-6

Item	Category	Number (N)	Percentage (%)
You think you do not have enough income for caregiving expenses	Never	23	29.1
	Seldom	15	19.0
	Sometimes	18	22.8
	Quite a few times	15	19.0
	Almost always	8	10.1
You think you should do more for your family members	Never	16	20.3
	Seldom	13	16.5
	Sometimes	23	29.1
	Quite a few times	16	20.3
	Almost always	11	13.9
	Never	17	21.5
He thinks he could take better care of his family members	Seldom	16	20.3
	Sometimes	23	29.1
	Quite a few times	9	11.4
	Almost always	14	17.7

Source: own elaboration.

Caregiver Overload Level

This study aimed to determine the level of burden experienced by primary caregivers of patients with COPD in a private healthcare institution in Cartagena. For this purpose, the Zarit Caregiver Burden Interview was applied. This instrument yields a maximum score of 88 points, where scores below 46 indicate no burden and scores above 56 suggest intense burden.

Based on the results, the majority of participants (89%) did not report caregiver burden and stated that they received support from others in caregiving tasks. Nevertheless, 6.3% (n = 5) were

classified as experiencing caregiver burden, and 5% (n = 4) presented intense burden—resulting in a total of 9 primary caregivers identified with some level of burden (Table 3).

These findings are consistent with a previous study conducted in the Tierra Firme neighborhood of Ibagué, Colombia, which reported that 61% of caregivers felt "capable of continuing to care for their family member for a long time." Similarly, results from the Zarit scale in that study indicated that 92.7% of participants were not experiencing caregiver burden.

Tabla 3. Caregiver burden level

Category	Number	Percentage
No overload	70	89%
Overload	5	6,3%
Intense overload	4	5%
Total	100%	79

Source: own elaboration.

DISCUSSION

In a private healthcare institution in Cartagena, Colombia, the majority of primary caregivers for patients with COPD did not experience overload (89%), while 11% reported some level of burden. The highest proportion of participants were female (77.2%, corresponding to 61 women). The primary factors contributing to caregiver burden in this population were: fear for the family member's future (58%), believing their family member is dependent on them (56%), the family member considering them the sole caregiver (50%), insufficient economic income to cover both caregiving and personal expenses (52%), feeling they should do more for their family member (63.3%), and believing they could provide better care (58%).

This finding holds significant value for disciplines such as nursing, as it facilitates the early identification of factors influencing caregiver overload, enabling timely intervention and support for primary caregivers. Such proactive measures can prevent caregivers from reaching intense levels of burden that could significantly impact their physical and emotional health. Furthermore,

recognizing the multidimensional nature of caregiver overload underscores the need for multidisciplinary interventions.

The observed interaction among social, economic, and emotional factors in the caregiver's burden experience can be better understood through the Caregiver Adaptive Resilience Model (CARM). This model posits that burden is not merely a consequence of care demands but rather the dynamic result of a complex interaction between (a) primary stressors derived from the patient's needs (e.g., dependency), (b) secondary stressors related to the social and economic repercussions of caregiving (e.g., social isolation, financial limitations), and (c) the caregiver's resilience capacity, which includes their personal resources (e.g., self-efficacy, coping strategies), their social capital (e.g., family and community support networks), and access to external resources (e.g., health services, economic support). Thus, high emotional burden (fear for the future, feeling dependency) is exacerbated when economic insufficiency or lack of social support exist, these interactions directly define the level of overload, influencing the caregiver's physical and mental well-being (11).

In addition, the level of burden and associated factors in the primary caregiver are comparable to findings from a relevant study conducted in Medellín (12), which identified the main sociodemographic and care-related factors linked to caregiver burden in 340 caregivers. Those results indicated a prevalence of overload at 39.7%, with 92.6% of caregivers being women and an average age of 57 years. Additionally, 53.8% perceived their health as fair or poor, and associated characteristics included poor health perception, abandonment of personal activities, and lack of prior caregiving training (13-14).

In another report on caregiver burden among primary caregivers of patients with permanent dependency, which aimed to identify the degree of burden of 50 primary caregivers in an outpatient setting, the Zarit Caregiver Burden Scale was applied. The results showed that 75% of caregivers were women, 36% of whom were the patients' children, 34% had primary schooling, and 52% were unemployed. The median age was 46 years, 54% were married, and 50% were from socioeconomic stratum three. Furthermore, 54% had spent over 24 months caring for the patient, 70% dedicated 10 or more hours daily, and 66% received support from others. Notably, 56% reported no overload, 34% experienced slight overload, and 10% had intense overload. In terms of impact, 36% reported their health was sometimes affected, social relationships were frequently affected

in 40%, and 52% sometimes lacked sufficient funds. This information is similar to the findings in the present study (15-16).

Concerning self-care for both the caregiver and their family member, the findings highlight the imperative to offer education and support to caregivers, empowering them to take charge of their own health (17). Consequently, a crucial initial step involves implementing educational campaigns that provide comprehensive information on caregiver well-being and leverage various techno-pedagogical tools to address potential questions. This approach ensures the delivery of reliable knowledge grounded in available literature (18).

Finally, it is paramount to recognize that caregivers are individuals with rights who require proactive attention through risk prevention programs. Such programs should encompass multidisciplinary care and continuous support to ensure the maintenance of their health and, subsequently, their quality of life (19-20).

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