Overburden and Quality of Life of Caregivers of Patients with Cancer during Palliative Care

Research Article

Open access

Check for updates

Sobrecarga y calidad de vida de cuidadores de personas con cáncer en cuidados paliativos

Sobrecarga e qualidade de vida de cuidadores de pessoas com câncer em cuidados paliativos

How to cite this article:
Arias-Rojas Mauricio, Carreño Moreno Sonia, Sepúlveda García Aura, Romero Ballesteros Ingrith. Sobrecarga y calidad de vida de cuidadores de personas con cáncer en cuidados paliativos. Revista Cuidarte. 2021;12(2):e1248.
http://dx.doi.org/10.15649/cuidarte.1248

Revista Cuidarte
Rev Cuid. May - Ago 2021; 12(2): e1248
http://dx.doi.org/10.15649/cuidarte.1248

E-ISSN: 2346-3414

Mauricio Arias-Rojas[1]
Sonia Carreño Moreno[2]
Aura Sepúlveda García[3]
Ingrith Romero Ballesteros[4]

1 Profesor asistente, Facultad de Enfermería, Universidad de Antioquia. Grupo de investigación práctica de enfermería en el contexto social GIPECS. Medellín, Colombia.
E-mail: emauricio.arias@udea.edu.co
Autor de correspondencia
2 Profesora asociada, Facultad de Enfermería, Universidad Nacional de Colombia, Bogotá, Colombia.
E-mail: spcarrenom@unal.edu.co
3 Enfermera, Auxiliar de investigación, Facultad de Enfermería, Universidad de Antioquia.
E-mail: aurasepulveda08@gmail.com
4 Enfermera, Auxiliar de investigación, Facultad de Enfermería, Universidad de Antioquia.
E-mail: iyromerob@unal.edu.co

Abstract

Introduction: Family caregivers often experience caregiving overburden, which in turn may have implications for their quality of life. This study is aimed at describing the associations between the level of caregiving overburden and the quality of life of caregivers of patients with cancer during palliative care attending a quaternary healthcare institution in Medellin, Colombia. **Materials and Methods:** A cross-sectional descriptive correlational study was conducted with 62 family caregivers. Participants' characterization, Zarit Caregiver Burden Scale and Caregiver Quality of Life questionnaires were administered. Correlation tests were performed using Pearson's correlation coefficient and simple linear regression model. **Results:** A Pearson's correlation coefficient of $r = -0.54$ at $p < 0.0001$ was found between caregiver overburden and quality of life. Negative correlations were also identified across all dimensions of overburden and quality of life in caregivers. A regression model was established in which caregiver overburden (β = -0.556 CI 95% = -3.114 - -1.237) and being a married or common-law partnered caregiver (β = 0.258 IC 95%= 0.907-52.99) are predicting variables of quality of life. **Conclusions:** A strong inverse correlation was found between overburden and quality of life of family caregivers of patients with cancer during palliative care.

Key words: Cost of Illness; Quality of Life; Caregivers; Palliative Care; Cancer.

Received: 13th May 2020
Accepted: 17th December 2020
Published: 30th April 2021

*Correspondence
Mauricio Arias-Rojas
E-mail: emauricio.arias@udea.edu.co

Sobrecarga y calidad de vida de cuidadores de personas con cáncer en cuidados paliativos

Resumen

Introducción. El cuidador familiar experimenta en muchos casos sobrecarga relacionada con asumir el cuidado de una persona, esto a su vez puede tener implicaciones para su calidad de vida. El objetivo de este estudio fue describir las asociaciones entre el nivel de sobrecarga del cuidado y la calidad de vida de cuidadores de pacientes con cáncer en cuidados paliativos que asistían a una institución de IV nivel de la ciudad de Medellín, Colombia. **Materiales y métodos**. Estudio descriptivo correlacional de corte transversal desarrollado con 62 cuidadores familiares. Se aplicaron los cuestionarios de caracterización del participante, escala de sobrecarga del cuidador Zarit y calidad de vida del cuidador. Se realizaron pruebas de correlación por coeficiente de Pearson y modelo de regresión simple. **Resultados**. Se encontró un coeficiente de Pearson de $r = -0.54$ con una $p < 0.0001$ entre la sobrecarga y la calidad de vida; surgieron además correlaciones negativas entre todas dimensiones de calidad de vida y la sobrecarga del cuidado. Se estableció un modelo de regresión en el que la sobrecarga del cuidador ($\beta = -0.556$ IC 95% = -3.114 - -1.237) y el ser cuidador casado o en unión libre ($\beta = 0.258$ IC 95%= 0.907-52.99) son variables predictoras de la calidad de vida. **Conclusiones.** Existe una correlación inversa y fuerte entre la sobrecarga y la calidad de vida del cuidador familiar de la persona con cáncer en cuidados paliativos.

Palabras clave : Costo de Enfermedad; Calidad de Vida; Cuidadores; Cuidados Paliativos; Cáncer.

Sobrecarga e qualidade de vida de cuidadores de pessoas com câncer em cuidados paliativos

Resumo

Introdução. O cuidador familiar vivencia, em muitos casos, uma sobrecarga relacionada ao cuidado de uma pessoa, isso por sua vez pode ter implicações na sua qualidade de vida. O objetivo deste estudo foi descrever as associações entre o nível de sobrecarga assistencial e a qualidade de vida de cuidadores de pacientes com câncer em cuidados paliativos atendidos em uma instituição de IV nível na cidade de Medellín, Colômbia. **Materiais e métodos**. Estudo descritivo correlacionado com a seção transversal desenvolvida com 62 cuidadores familiares. Foram aplicados questionários de caracterização dos participantes, escala de sobrecarga do cuidador Zarit e qualidade de vida do cuidador. Os testes de correlação foram realizados por meio do coeficiente de Pearson e modelo de regressão simples. **Resultados**. Encontrou-se coeficiente de Pearson de $r = -0.54$ com uma $p < 0.0001$ entre sobrecarga e qualidade de vida; surgiram também correlações negativas entre todas as dimensões da qualidade de vida e a sobrecarga de cuidados. Um modelo de regressão foi estabelecido no qual a sobrecarga do cuidador ($\beta = -0.556$ IC 95% = -3.114 - -1.237) e o ser cuidador casado ou em união estável ($\beta = 0.258$ IC 95%= 0.907-52.99) são variáveis preditivas de qualidade de vida. **Conclusões.** Existe uma correlação inversa e forte entre a sobrecarga e a qualidade de vida do cuidador familiar da pessoa com câncer em cuidados paliativos.**Conclusões**. Existe uma correlação forte e inversa entre a carga e a qualidade de vida do cuidador familiar da pessoa com câncer em cuidados paliativos.

Palavras chave: Efeitos Psicossociais da Doença; Qualidade de Vida; Cuidadores; Cuidados Paliativos; Câncer.

Introduction

In middle-income countries such as Colombia, cancer represents the second leading cause of mortality in the population even though advances in treatment have made it be considered a chronic disease[1]. This creates the need to implement palliative care for advanced stages of disease or treatment failures[2]. However, the study by Pastrana et al.[3] indicates that Colombia has 15.5 fewer palliative care services than Sweden and 7.5 fewer than Chile, and its population consumes 6.4 milligrams of morphine per capita per year less than the Argentine population. Together with the lack of training of personnel and the lack of regulations on palliative care, these indications place the country at a disadvantage with countries of similar income and far behind countries with higher income.

Palliative care is an experience in which there are two main actors: The patient with advanced cancer and his or her family caregiver[4] who assumes responsibility for the patient's care. In general, this experience is complex and demanding from a physical, emotional, and spiritual point of view. In many cases, caregivers must assume the role without adequate preparation, continuous health professionals' assistance, or appropriate support networks. This situation causes caregivers to perceive a low quality of life due to the multiple changes they must go through[5].

Different studies[6,7] on the quality of life of family caregivers of people receiving palliative care have identified lower quality of life in this population than in other populations. The caregivers of patients undergoing active treatment for cancer are an example. Their psychological dimension shows the worst levels of quality of life, which is related to the ways of coping with the situation, the low satisfaction with the social support received, and the knowledge about the progression of the disease and the end of life. This situation, in turn, causes sadness, pain, exhaustion, anxiety, and sleeping problems in caregivers who also develop psychosocial distress that leads to depression in almost 74% of caregivers, according to a study[8].

Different studies[6,7] on the quality of life of family caregivers of people receiving palliative care have identified lower quality of life in this population than in other populations.

Regarding the perception of caregiving overburden, some research has shown that from these caregivers' experience there is a burden of physical exhaustion; a mental burden related to feelings of loss of self-esteem, hopelessness, discouragement, sadness, and loneliness, and a social burden related to the female role in caregiving and the alteration of family dynamics[9]. In this same sense, caregivers report that their most frequent burdens are the feelings that they are the only people on whom their sick family member depends, making them feel more dissatisfied with their role in palliative care[10].

The relationship between caregiving overburden and the quality of life of caregivers has been studied in other contexts. In the study by Perpiña et al[11], they found that 48.1% of caregivers of people in palliative care were anxious and 18.2% depressed; they also reported low quality of life in the physical dimension. Sixty-three point seven percent showed moderate burden, and 41.6% reported intense burden. In the end, they found associations between anxiety, depression, and fatigue with caregiver overburden ($r = 0.65$ $p < 0.001$; $r = 0.70$ $p < 0.001$, and $r = 0.56$ $p < 0.001$ respectively); however, quality of life and its dimensions did not correlate significantly with caregiver overburden or the other study's variables.

Similarly, another study on the quality of life of the caregiver of people in palliative care and its association with sociodemographic variables showed that caregiver's age was related to quality-of-life variables called physical role ($r = 0.56$ $p < 0.001$) and vitality ($r = 0.47$ $p < 0.001$)[12]. It was concluded that, regardless of the type of pathology and the time spent on the caregiving role, the age of the caregivers is an important factor affecting their quality of life. Hence, a lower perception of quality of life of caregivers over 60 years of age persists, which determines the development of the so-called caregiver syndrome in which both physical and psychological symptoms appear[12]. Although it was not a measured variable, overburden is also considered one of the causes of caregiver role strain[13].

According to what has been argued, investigating this phenomenon is important for nurses because they are in charge of extending patient's care to the patient's proximal network, in this case, their family caregivers. Nurses also have to identify caregivers' care needs derived from performing their role. Besides, research on factors related to caregivers' quality of life will help produce evidence for developing therapeutics aimed at modifying or controlling such factors. Thus, this study aimed to describe the associations between caregivers' characteristics and profile, the level of caregiving overburden, and the quality of life of caregivers of cancer patients who received palliative care and attended a quaternary healthcare facility in Medellin, Colombia.

Materials and Methods

A quantitative study following a cross-sectional, descriptive-correlational design was conducted[14]. The sample comprised all the caregivers of people with cancer receiving palliative care hospitalized at the time of data collection, between May and December 2019. Eighty-three caregivers were invited to participate in the study, and 62 agreed to participate. The sample size was adequate for the purposes of the study considering that a sample size of 56 participants was obtained using the sample size calculator of the G*Power software with the following input parameters: F test, linear regression, effect size .3, Type I error .05, power level ($1 - \beta$) .95, and the number of predictors 10.

The sample was obtained by purposive sampling, including primary family caregivers of hospitalized advanced cancer patients in palliative care, older than 18 years old, who got in the SPMSQ mental questionary less than two wrong answers. The caregivers hired to take care of patients were excluded.

Three instruments were used to measure the study variables:

- *Caregivers' characteristics*: The survey for the characterization of the caring dyad (GCPC-UN-D), designed by the Chronic Patient Nursing Care Research Group of the School of Nursing at the Universidad Nacional de Colombia, was used. This survey has 23 items that identify sociodemographic characteristics of the caregiver and the patient, time as a caregiver, hours per day spent in patient care, whether the caregiver is the only patient caregiver, and satisfaction with the support received. This scale was 95% comprehensible and obtained face validity of 100% in a study in Colombia[15].
- *Caregiving overload*: The Zarit Burden Interview was conducted. It measures in a multidimensional way the role overload perceived by caregivers. The instrument has three dimensions: impact of care (12 items), interpersonal burden (6 items), and skills and

expectations about care (4 items). It has 22 items on a 5-point Likert scale. The score ranges from 22 to 110 points; if it is ≤46, it indicates no burden, between 47 and 55 indicates mild burden and ≥56 severe burden. This instrument underwent psychometric testing in Colombia, with a construct validity by varimax rotation that explained 68% of the variance and reliability with a Cronbach's alpha of 0.88[16,17].

- *Caregiver's quality of life*: The scale Quality of Life Version Family Caregivers of Cancer Patients designed by Betty Ferrell was used. This scale has 37 items scoring from 0 to 10, where 0 is the worst outcome, and 10 is the best. The scale has four dimensions: physical well-being (5 items), psychological well-being (16 items), social concerns (9 items), and spiritual well-being (7 items). The scale validation in Colombia was adjusted to a four-factor structure that agreed with the dimensions proposed in the original version of the scale, and it had a Cronbach's alpha reliability of 0.86[18].

Two trained research assistants administered the questionnaires and obtained written informed consent from the family caregivers before administering the instruments. The data collected was entered into a database in Microsoft Excel and the statistical analyses were performed using SPSS version 24, licensed by the Universidad de Antioquia.

Descriptive and inferential statistics were used for data analysis. Sample proportions, means, standard deviations, and 95% confidence intervals were calculated for participants' characteristics, caregiving overburden, and quality of life. The variables were normally distributed according to the Kolgomorov Smirnov test; therefore, Pearson's coefficient (*r*) and Pearson's Chi-square for dichotomous variables were used to explore correlations. P-values less than 0.05 were reported as statistically significant. For interpreting correlation coefficients obtained, values lower than 0.3 indicated a weak relationship, between 0.3 and 0.6 indicated moderate relationship, and higher than 0.6 indicated strong relationship[19]. Additionally, multiple regression was performed with the variables that showed a correlation in the previous analysis and those reported in the studies as influencing the quality of life.

This research was approved by the Institutional Review Board of the health facility where the study was conducted (minute no. 08/2018). In addition, the provisions of Resolution 008430 (1993), which establishes the scientific, technical, and administrative standards for health research, were taken into account, as well as Ezekiel Emanuel's seven requirements for research ethics. All participants signed the informed consent.

Results

Population characteristics

Table 1 shows that, of the 62 participating caregivers, 82.30% were female, and 75.80% were not sole caregivers. In 38.70% of the cases the caregivers were children of the person with cancer in palliative care, and, in the case of secondary caregivers, 54.83% were other blood relatives such as nieces, nephews, cousins, or grandchildren. As for people with cancer in palliative care, their average age was 63 years and all of them had a baseline cancer with metastasis to other organs; the most prevalent cancers were those related to the gastrointestinal system in 45.16% of the cases.

Table 1. Sociodemographic characteristics of the caregiver-patient dyad

Characteristic	% (n= 62)
Data on the person with cancer in palliative care	
Oncologic diagnosis	
Myeloma/Leukemia/Lymphomas	12.90 (8)
Stomach/colon/rectal cancer	25.81 (16)
Liver/pancreatic/gallbladder cancer	19.35 (12)
Breast cancer	11.29 (7)
Lung cancer	11.29 (7)
Cervical/uterine/cancer	4.84 (3)
Prostate cancer	6.45 (4)
Others	8.06 (5)
Sex	
Male	58.10 (26)
Female	41.90 (36)
Relationship to caregiver	
Child	38.70 (24)
Spouse	32.30 (20)
Grandchild	6.50 (4)
Sibling	9.70 (6)
Another relative	12.80 (8)
Family caregiver data Education	
Elementary school	35.50 (22)
High School	40.30 (25)
Technical and/orprofessional education	24.20 (15)
Marital status	
Married	53.20 (33)
Single	29.00 (18)
Non-marital cohabitation	17.70 (11)
Occupation	
Homemaker	45.20 (28)
Self-employed	27.40 (17)
Employee	14.50 (9)
Retired	12.90 (8)
Religion	
Catholic	82.30 (51)
Evangelical	8.10 (5)
No religion	9.70 (6)
Level of religious commitment	
High	77.40 (48)
Middle	14.50 (9)
Low	8.10 (5)
Cares for the person from the disease's onset	93.50 (58)

Source: Study data analyzed with SPSS 2020

Levels of caregiving overburden and family caregiver quality of life.

Table 2 describes the participants' characteristics with ratio variables and the scores for caregiver's burden and quality of life. Regarding caregivers' age, the average age was 57; they had been performing their role for an average of 19 months and cared for the patient for an average of

18 hours a day. The Karnofsky scale scored an average of 71.45, indicating a medium level of patient functionality. Regarding caregiving overburden, caregivers reported from mild to severe burden (no burden 56.50%; mild burden 19.40%, and severe burden 24.10%), with a mean of 27.44 on the dimension "impact," 8.61 on the dimension "interpersonal," and 11.82 on the dimension "skills and expectations." For the quality of life, caregivers presented average levels in the totality of the scale and all its dimensions.

Regarding caregiving overburden, caregivers reported from mild to severe burden (no burden 56.50%; mild burden 19.40%, and severe burden 24.10%)

Table 2. Descriptive values of the variables measured in family caregivers

Variables	Minimum	Maximum	Mean	Standard Deviation
Caregiver's characteristics*				
Caregiver's age (years)	20	77	57.40	15.10
Patient's age(years)	24	91	63.63	14.71
Time as a caregiver (months)	1	144	19.87	33.36
Number of hours spent on care	5	24	18.94	5.64
Patient's Karnofsky scale	40	90	71.45	15.56
Caregiving overburden				
Impact	13	47	27.44	8.18
Interpersonal	6	16	8.61	2.90
Skills and expectations	4	19	11.82	3.98
Over burden total score	23	79	57.87	12.21
Caregiver's quality of life				
Physical well-being	9	48	26.50	9.64
Psychological well-being	30	141	73.24	21.77
Social concerns	12	80	49.81	18.32
Spiritual well-being	5	70	45.52	12.73
Quality of life total score	62	292	195.06	47.79

* Normal distribution of variables

Source: Study data analyzed with SPSS 2020

Correlations between family caregiver profile, caregiving overburden, and quality of life

The Chi-square test showed a significant association ($p = 0.038$) between dichotomous variables "sole caregiver" and "overburdened," which is interpreted that when participants are not sole caregivers, they mostly do not present caregiving overburden. On the other hand, Pearson's correlation coefficient showed a moderate relationship between caregiving overburden and caregiver's quality of life ($r = -0.54$) with a p-value < 0.01.

Regarding the dimensions of the variables "caregiving overburden" and "caregiver's quality of life," correlations were found between the total score of caregiving overburden and the dimensions of physical well-being, psychological well-being, spiritual well-being, and social concerns. The caregiving overburden dimension "impact" was also correlated with all the dimensions of quality of life. Likewise, the dimension "interpersonal" of caregiving overburden and the quality-of-life dimensions of physical

Regarding the dimensions of the variables "caregiving overburden" and "caregiver's quality of life," correlations were found between the total score of caregiving overburden and the dimensions of physical well-being, psychological well-being, spiritual well-being, and social concerns.

well-being, psychological well-being, and social concerns showed a moderate association. Table 3 details in a matrix the correlations found.

Table 3. Correlation matrix

		Impact	Interpersonal	Skills and expectations	OVER BURDEN TOTAL SCORE	Physical well-being	Psychological well-being	Social concerns	Spiritual well-being	QUALITY OF LIFE TOTAL SCORE
Dimensions of caregiving overload	Impact	1								
	Interpersonal	.624**	1							
	Skills and expectations	.397**	0.109	1						
	OVER BURDEN TOTAL SCORE	.947**	.691**	.618**	1					
Dimensions of Quality of Life	Physical well-being	**-.304***	**-.343****	-0.209	**-.353****	1				
	Psychological well-being	**-.336****	**-.264***	-0.150	**-.337****	.354**	1			
	Social concerns	**-.654****	**-.518****	-0.231	**-.636****	.490**	.492**	1		
	Spiritual well-being	**-.283***	-0.231	-0.165	**-.298***	.308*	.396**	.449**	1	
	QUALITY OF LIFE TOTAL SCORE	**-.541****	**-.450****	-0.243	**-.548****	.633**	.821**	.826**	.681**	1

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).
Source: Study data analyzed with SPSS 2020

Table 4 details the multiple regression model, which was created including the variables “caregiver characteristics and profile,” “caregiving overburden,” and “caregiver quality of life,” the latter as the dependent variable. Two of the eleven predictors were found to account for 38% of the variance in the prediction model. Family caregiver’s marital status, whether married or cohabiting, predicts the quality of life (*t* = 2.07 p < 0.04); likewise, caregiving overburden also predicts the quality of life (*t* = -4.65 p < 0.001).

Family caregiver’s marital status, whether married or cohabiting, predicts the quality of life (t = 2.07 p < 0.04); likewise, caregiving overburden also predicts the quality of life (t = -4.65 p < 0.001).

Table 4. Multiple regression model

Variables	β (95% CI)	p
Karnofsky scale	0.086 (-0.510; 1.036)	0.498
Patient's age	-0.025 (-0.970; 0.805)	0.853
Caregiver's age	0.166 (-0.344; 1.410)	0.228
Time as caregiver	-0.094 (-0.496; 0.227)	0.458
Number of hours spent on care	-0.055 (-2.625; 1.689)	0.665
Total overburden level	**-0.556** (-3.114; -1.237)	**0.000**
Caregiver's sex	-0.023 (-32.661; 26.951)	0.848
Caregiver's marital status (married-cohabitating)	**0.258** (0.907; 52.997)	**0.043**
Cares for the person from the disease's onset	-0.043 (-55.648, 38.897)	0.723
Religious commitment	0.035 (-24.205; 32.118)	0.779
Sole caregiver	-0.035 (-31.744, 23.942)	0.780
R^2= 0.38, F = 2.90, p <0.05		

β = beta; t = Student's t-statistic; p = level of statistical significance
Source: Study data analyzed with SPSS 2020

Discussion

In this study, the caregivers of people with cancer receiving palliative care were mostly women, patients' children or spouses, had been in the role for approximately one and a half years, and had the support of secondary caregivers as they stated they were not sole caregivers. When comparing these characteristics with other studies, we found that they are similar to those of the study by Rizo et al.[20], where 70% of the caregivers of people with advanced cancer stages were women, 34% were spouses, and 49% had been caring for the sick person for 1 to 3 years. Likewise, the results of Flores et al.[21] show that caregivers of older adults are on average 36 to 55 years old, female (79.7%), married (64.4%), and homemakers (50.8%), showing that the profile of study participants is similar in populations with chronic diseases.

Another important result is related to not being a sole caregiver as 75.8% of the participants had support from other people for caregiving activities; that is, there were secondary caregivers. This fact might indicate that their perception of care burden is not the same if they were a sole caregiver. This hypothesis is supported by Lara et al.[22], who found that 83.3% of primary caregivers had secondary caregivers, most of them relatives of the same patient, who allowed them to better cope with their new caregiving role. In contrast, other studies have shown that family can be a burden rather than a support for the caregiver; this is described by Naoki et al.[10] in their study where the caregiver burden was found to be negatively correlated with family satisfaction in end-of-life care (r = -0.56 p < 0.005).

In this same sense, more than half of the participating caregivers reported no overburden, which may be related not only to the presence of secondary caregivers but also to the patients' functionality. In this regard, from Karnofsky's scale results, it is likely that these people in palliative care were not yet near the end of life and are still independent to perform some activities of daily living, decreasing the caregiver's perception of overburden[23,24].

In this regard, from Karnofsky's scale results, it is likely that these people in palliative care were not yet near the end of life and are still independent to perform some activities of daily living, decreasing the caregiver's perception of overburden[23,24].

It should not be forgotten that several of the participants reported some degree of burden, and a good percentage reported severe burden. This result can be explained by the dimension of "impact of care," since becoming a caregiver brings major changes in personal life, family, and work dynamics that lead caregivers to fell that the situation is beyond them, as reported in some studies[6,23,25].

On the other hand, low levels of quality of life have been observed in caregivers of terminally ill persons, the most affected dimensions being the mental and emotional health of the caregiver; an increase in anxiety and depression has also been reported as a consequence of the lack of control over the situation[12,26,27]. These findings are important when contrasted with the results of our study; the caregivers reported average levels of quality of life and quality-of-life dimensions, results that patient-specific aspects can explain, such as functionality levels, and caregiver's characteristics, such as having family support and a specific secondary caregiver. However, the spiritual well-being dimension showed the lowest score, which could indicate the spiritual impact and need for self-transcendence and finding meaning from the experience documented in other studies[28]; this is supported by the high religious commitment reported by the participants. Other studies have documented the need for connection with a supreme being to enhance spirituality[28].

Regarding the correlations found by the statistical analysis, moderate-to-strong relationships between the variables were interesting. It was found that caregiving overburden has a significant moderate negative correlation with caregivers' quality of life. This result is consistent with other studies[7,11,28] in which caregivers reported lower levels of quality of life when their burden perception was higher, especially affecting the dimension of psychological well-being. Several correlations were obtained that can be explained by examining the caregiver's behavior, the patient's condition, and the social support available.

Moderate-to-strong relationships between the variables were interesting. It was found that caregiving overburden has a significant moderate negative correlation with caregivers' quality of life. This result is consistent with other studies[7,11,28].

In the quality-of-life dimension of physical well-being, there were significant weak negative correlations between the impact of care, the interpersonal dimension, and the total score of caregiving overburden. When it is analyzed that the functionality of people in palliative care plays a primary role in the caregiver burden, these results are consistent. Thus, the disease progression and the proximity to death imply that caregivers must perform more of the patient's basic activities of daily living and manage the patient's symptoms, which causes them fatigue and has a physical impact on them[7,23,24]. In addition, there is a constant dedication to caregiving that impacts the performance of other roles and drives caregivers to exhaustion[29].

The psychological dimension of the quality of life also showed significant weak negative correlations with the impact of care, the interpersonal dimension, and the total score of caregiving overburden. As described above, from the psychological aspect, the impact of caring for a person whose illness trajectory has constant and unforeseen changes; likewise, fluctuations of symptoms in people with cancer receiving palliative care leads to a lack of control of the situation and alters the caregivers' emotional stability and mental health[20,26]. It

The psychological dimension of the quality of life also showed significant weak negative correlations with the impact of care, the interpersonal dimension, and the total score of caregiving overburden. As described above, from the psychological aspect, the impact of caring for a person whose illness trajectory has constant and unforeseen changes; likewise, fluctuations of symptoms in people with cancer receiving palliative care leads to a lack of control of the situation and alters the caregivers' emotional stability and mental health[20,26].

has also been documented that there are multiple changes that family caregivers face, including complex interactions with other significant individuals within their caregiving role such as the care recipient, the family, and the health care team. This situation can create an overload of tasks to be performed daily that ultimately impacts outcomes such as deterioration of the quality of life[30], caregiving overburden[31], stress, anxiety, loneliness, and depression[32]. Although the study by Gómez et al.[33] focuses on family caregivers of people with disabilities, the results described on the effects on psychological well-being produced by caregiving overburden can be extrapolated to caregivers of patients in palliative care. That study showed an influence of the caregivers' sex, the fragility of support networks and interpersonal relationships, and the multiplicity of caregiving roles on the caregivers' levels of anxiety and depression. These results also showed that 80% of the sample presented signs of anxiety and 82% of depression; besides, 69% of the caregivers experienced task overload. Consequently, the literature seems to indicate that assuming the role of family caregiver implies changes not only in personal and family dynamics but also in the emotional and psychological stability of the caregivers.

In relation to social concerns, this quality-of-life dimension was strongly and negatively associated with the impact of care, the interpersonal dimension, and the total score of caregiving overburden. These results show the need to strengthen support networks and favor the development of interpersonal relationships other than those with the sick person and even with the family itself, to use part of their time in other activities oriented to self-care and consequently improve their quality of life. These statements are supported by Vargas and Pinto[34], who described the quality of life of caregivers of people with Alzheimer's disease and reported that 66.2% of them presented alterations in their personal relationships, and 65% considered that they had problems of social isolation. Likewise, some research has documented that social support increases the well-being of caregivers and favors a positive change in the negative emotions and feelings that are present in the caregiving task; that is, it allows them to give back meaning[36] to the experience and help manage the stress, anxiety, and depression caused by the caregiving role performance[27].

The results of this study describe the impact of caregiving overburden and interpersonal relationships on the caregivers' social life. Although participants reported having family support and, for the most part, a secondary caregiver, spending many hours a day caring for the person in palliative care leaves little time to establish friendships or have moments of respite. Therefore, if caregivers do not have respite from their role, they have a worse perception of their quality of life because they are overwhelmed with the care of their family member[13,30].

On the other hand, the spiritual dimension of quality of life presented negative correlations with the impact of care and total caregiving overburden. This result can be justified by the experience of caring for a person who is close to death because this situation raises personal questions for caregivers, leading them to rethink even their own religious beliefs[37]. However, from another point of view, understanding the suffering of others and the meanings of this experience allows caregivers to strengthen their spiritual dimension[38].

Finally, the regression model resulting from the analysis shows that the caregiver overburden is a negative predictor of caregivers' quality-of-life levels, which is consistent with other similar studies in caregivers of people with chronic diseases. For caregiving overburden, Perpiña et al.[11] found using their regression model that aspects such as anxiety and depression, which could be related to caregiver's psychological well-being, were variables that predicted the perception of caregiving overburden ($r^2 = 0.52$). Thus, the results of this research together with those of

Achury et al.[39] indicate that the greater the overburden, the worse the perception of quality of life, where the emotional and mental spheres of the caregiver are mainly affected, especially by providing care to a family member who is approaching death, a time the caregiver begins to close cycles with the person being cared for and an anticipated mourning. The findings of Ferraz dos Anjos et al.[40] confirm the results of this study. Using their regression model, these researchers found that the level of dependence of patients and the caregiver's activity overload were significant variables that explained a lower caregivers' perception of the quality of life.

The model in our research also shows that caregivers with a spousal relationship have a better perception of quality of life, which can be explained by the interpersonal aspects of caregiving overburden. When caregivers have a stable partner, the partner can function as part of the social and emotional support required to perform the caregiving role, which allows caregivers to better tolerate the stress, anxiety, and distress of caregiving[20]. In addition, caregivers spend part of their time with their partner, which takes the caregiver out of the routine of caregiving and makes them perceive an improvement in the quality of life.

The implications of these study results for nursing professionals are related to the importance of detecting caregiver role strain. As it has been proven, overburden influences the caregiver's quality of life; for this reason, providing adequate social support by strengthening the role of the secondary caregiver and supporting the development of coping strategies is an ideal position to improve caregiver care. First of all, caregiver education allows caregivers to manage and control the situation better, as well as help them prepare for the death of their family member. Secondly, social support is fundamental to improving the perception of quality of life; therefore, nursing professionals should help caregivers strengthen their family networks and role definition within the family dynamics to reduce care burden. Finally, caregivers should receive interdisciplinary guidance and support in coping with the end of life of their family members to reduce the psychological and emotional impact on their quality of life.

Some limitations are identified in this research. First, the sample size was relatively small, which may reduce the generalizability of the results despite the strong correlations found. Secondly, purposive sampling did not allow for the random inclusion of participants in the study, which contributes to the inclusion of confounding variables. Third, due to the type of population, it was not easy to access because of the stage of care the participants were in and the health status of their family members.

Conclusion

Quality of life is multidimensional and is associated with the caregiving overburden of caregivers of people with cancer receiving palliative care, which indicates that the greater the burden, the lower the quality of life. Within this line, this study found that psychological well-being and social concerns are the most affected dimensions among these caregivers. Despite the variables' multidimensionality, moderate to strong correlations were found, demonstrating that when interpersonal relationships and the management of caregiving situations improve, psychological and social aspects of quality of life can improve as well. This study identified that marital status (married or cohabiting) and caregiving overburden are predictors of family caregivers' quality of life.

Finally, we hope that the results of this research will lead to conduct further longitudinal studies on quality of life, including other variables such as coping and social support of caregivers of people with cancer in palliative care. In addition, progress towards proposals for nursing and interdisciplinary interventions to reduce disease burden and improve the quality of life of caregivers is a priority.

Conflict of interest: The authors declare no conflict of interest

Funding: Research funded by Minciencias, Funding Opportunity Announcement 752-2018.

Referencias

1. **World Health Organization.** Noncommunicable Diseases Country Profiles 2018. World Health Organization. Geneva; 2018.
2. **Worl Health Organization.** Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/#. 2015
3. **Pastrana T, De Lima L, Pons JC.** Atlas de Cuidados Paliativos de Latinoamérica. Houston; 2013.
4. **Garcia-Rueda N, Carvajal Valcarcel A, Saracibar-Razquin M, Arantzamendi Solabarrieta M**. The experience of living with advanced-stage cancer: a thematic synthesis of the literature. *Eur J Cancer Care.* 2016;25(4):551–69. DOI: https://doi.org/10.1111/ecc.12523
5. **Arias-Rojas M, Carreño–Moreno S, Chaparro L**. Incertidumbre ante la enfermedad crónica. Revisión integrativa. *Rev Latinoam Bioética.* 2019;36(1):91-104. DOI: https://doi.org/10.18359/rlbi.3575
6. **Butow PN, Price MA, Bell ML, Webb PM, deFazio A, Friedlander M.** Caring for women with ovarian cancer in the last year of life: a longitudinal study of caregiver quality of life, distress and unmet needs. *Gynecol Oncol.* 2014;132(3):690–7. DOI: https://doi.org/10.1016/j.ygyno.2014.01.002
7. **Ullrich A, Ascherfeld L, Marx G, Bokemeyer C, Bergelt C, Oechsle K.** Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC Palliat Care.* 2017;16(1):31. DOI: https://doi.org/10.1186/s12904-017-0206-z
8. **Oechsle K, Ullrich A, Marx G, Benze G, Heine J, Dickel LM, et al.** Psychological burden in family caregivers of patients with advanced cancer at initiation of specialist inpatient palliative care. *BMC Palliat Care.* 2019;18(1):1–14. DOI: https://doi.org/10.1186/s12904-019-0469-7
9. **Moreira de Souza R, Turrini RN.** Paciente oncológico terminal: sobrecarga del cuidador. *Enfermería Glob*. 2011;10(22):1–13. DOI: https://doi.org/10.6018/eglobal.10.2.122771
10. **Naoki Y, Matsuda Y, Maeda I, Kamino H, Kozaki Y, Tokoro A, et al.** Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home. *Palliat Support Care*. 2018;16(3):260–8. DOI: https://doi.org/10.1017/S1478951517000232.
11. **Perpiñá-Galvañ J, Orts-Beneito N, Fernández-Alcántara M, García-Sanjuán S, García-Caro MP, Cabañero-Martínez MJ**. Level of burden and health-related quality of life in caregivers of palliative care patients. *Int J Environ Res Public Health.* 2019;16(23). DOI: https://doi.org/10.3390/ijerph16234806
12. **Coca S, Ramos F, Fernández R.** Calidad de vida en los cuidadores familiares de pacientes con enfermedad terminal, bajo un programa de cuidados paliativos domiciliarios. *Rev salud pública.* 2017;XXI(3):22–34. DOI: https://doi.org/10.31052/1853.1180.v21.n3.17386
13. **Antón BS, Meneses MA.** Cansancio del rol de cuidador: análisis de sus factores relacionados. *REDUCA.* 2014;6(3):74–106. Disponible en: http://revistareduca.es/index.php/reduca-enfermeria/article/view/1708

14.**Grove S, Gray J.** Understanding Nursing Research. Building an Evidence-Based Practice. 7th editio. Missouri, EEUU.: Elsevier; 2019. p.652

15.**Chaparro-Diaz L, Sánchez B, Carrillo-Gonzalez GM.** Encuesta de caracterización del cuidado de la diada cuidadorfamiliar - persona con enfermedad crónica. *Rev Cienc y Cuid.* 2015;11(2):31–45. DOI: https://doi.org/10.22463/17949831.196

16.**Barreto-Osorio RV, Campos de Aldana MS, Carrillo-Gonázdlez GM, Coral-Ibarra R, Chaparro-Diaz L, Durádn-Parra M, et al.** Entrevista Percepción de Carga del Cuidado de Zarit: pruebas psicométricas para Colombia. *Aquichan.* 2015;15(3):368–80. DOI: https://doi.org/10.5294/aqui.2015.15.3.5

17.**Albarracín Á, Cerquera A, Pabón D.** Escala de sobrecarga del cuidador zarit: estructura factorial en cuidadores informales de Bucaramanga. *Rev Psicol Univ Antioquia.* 2016;8(2):87–99. DOI: https://doi.org/10.17533/udea.rpsua.v8n2a06

18.**Barrera OL, Carrillo GM, Chaparro DL, Sánchez HB, Vargas RE, Carreño SP.** Validez de constructo y confiabilidad del instrumento calidad de vida versión familiar en español. *Enfermería Glob*. 2015;14(37):227–38. DOI: https://doi.org/10.6018/eglobal.14.1.185111

19.**Gray JR, Grove SK, Sutherland S.** The practice of nursing research: appraisal, synthesis, and generation of evidence. 8th ed. St. Louis, Missouri: Elsevier; 2016.

20.**Rizo VA, Molina LM, Milián MN, Pagán MP, Machado GJ.** Caracterización del cuidador primario de enfermo oncológico en estado avanzado. *Rev Cuba Med Gen Integr.* 2016;32(3):1–13.

21.**Flores M, Fuentes H, González G, Meza I, Cervantes G, Valle M.** Características principales del cuidador primario informal de adultos mayores hospitalizados. *Nure Inv.* 2017;14(88):1–16.

22.**Lara PG, Pedraza AA, Blanco LL.** Perfil del cuidador: sobrecarga y apoyo familiar e institucional del cuidador primario en el primer nivel de atención. *Rev Espec Médico-Quirúrgicas.* 2008;13(4):159–66.

23.**Barragán BJ.** Necesidades de cuidado de la diada cuidador-persona: Expectativa de cambio en intervenciones de enfermería. *Rev Cuid.* 2014;5(2). DOI: http://dx.doi.org/10.15649/cuidarte.v5i2.87

24.**Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, et al**. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer.* 2015;121(9):1513–9. DOI: https://doi.org/10.1002/cncr.29223

25.**Vahidi M, Mahdavi N, Asghari E, Ebrahimi H, Eivazi Ziaei J, Hosseinzadeh M, et al.** Other side of breast cancer: factors associated with caregiver burden. *Asian Nurs Res.* 2016;10(3):201–6. DOI: https://doi.org/10.1016/j.anr.2016.06.002

26.**Götze H, Brähler E, Gansera L, Schnabel A, Gottschalk-Fleischer A, Köhler N.** Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *Eur J Cancer Care.* 2018;27(2):1–8. DOI: https://doi.org/10.1111/ecc.12606

27.**Domínguez JA, Ruíz M, Gómez I, Gallego E, Valero J, Izquierdo MT.** Ansiedad y depresión en cuidadores de pacientes dependientes. *Semergen.* 2012;38(1):16–23. DOI: https://doi.org/10.1016/j.semerg.2011.05.013

28.**Krug K, Miksch A, Peters-Klimm F, Engeser P, Szecsenyi J.** Correlation between patient quality of life in palliative care and burden of their family caregivers: A prospective observational cohort study. *BMC Palliat Care.* 2016;15(1):1–8. DOI: http://dx.doi.org/10.1186/s12904-016-0082-y

29.**Toribio-Díaz ME, Medrano-Martínez V, Moltó-Jordá JM, Beltrán-Blasco I.** Red de cuidadores informales de los pacientes con demencia en la provincia de Alicante, descripción de sus características. *Neurologia.* 2013;28(2):95–102. DOI: http://dx.doi.org/10.1016/j.nrl.2012.03.010

30. **Ávila-Toscano JH, Vergara Mercado M.** Calidad de vida en cuidadores informales de personas con enfermedades crónicas. *Aquichan.* 2014;14(3):417–29. DOI: https://doi.org/10.5294/aqui.2014.14.3.11
31. **Carreño S, Chaparro L.** Agrupaciones de cuidadores familiares en Colombia: perfil, habilidad de cuidado y sobrecarga. *Pensam Psicológico.* 2017;15(1):87–101. DOI: http://dx.doi.org/10.11144/Javerianacali.PPSI15-1.ACFC
32. **Klassen AF, Gulati S, Granek L, Rosenberg-Yunger ZRS, Watt L, Sung L, et al.** Understanding the health impact of caregiving: a qualitative study of immigrant parents and single parents of children with cancer. *Qual Life Res.* 2012;21(9):1595–605. DOI: https://doi.org/10.1007/s11136-011-0072-8
33. **Gómez-Galindo AM, Peñas-Felizzola OLL, Parra-Esquivel EI.** Caracterización y condiciones de los cuidadores de personas con discapacidad severa en Bogotá. *Rev Salud Pública.* 2016;18(3):367. DOI: http://dx.doi.org/10.15446/rsap.v18n3.53048
34. **Vargas L, Pinto N.** Calidad de vida del cuidador familiar y dependencia del paciente con Alzheimer. *Av Enferm.* 2010;28(1):116-128.
35. **Colin Reid R, Stajduhar KI, Chappell NL.** The impact of work interferences on family caregiver outcomes. *J Appl Gerontol.* 2010;29(3):267–89. DOI: https://doi.org/10.1177/0733464809339591
36. **Domínguez Guedea MT, García AO, Rivera Sander MA.** Bienestar, Apoyo social y contexto familiar de cuidadores de adultos mayores. *Acta Investig Psicológica.* 2013;3(1):1018–30. DOI: https://doi.org/10.1016/S2007-4719(13)70949-9
37. **Pérez-García E.** Enfermería y necesidades espirituales en el paciente con enfermedad en etapa terminal. *Enfermería Cuid Humaniz.* 2016;5(2):41-45. DOI: https://doi.org/10.22235/ech.v5i2.1286
38. **Rodrigues GA.** La espiritualidad ante la proximidad de la muerte... *Enfermería Glob.* 2011;10(22):1–10. DOI: https://doi.org/10.4321/S1695-61412011000200019
39. **Achury DM, Pinilla M**. La comunicación con la familia del paciente que se encuentra al final de la vida. *Enfermería Univ.* 2016;13(1):55–60. DOI: https://doi.org/10.1016/j.reu.2015.12.001
40. **Ferraz dos AK, Silva de OB, Cruz SV, Nagib BE, Kareny da SJ, de Oliveira SR.** Fatores associados à qualidade de vida de cuidadores familiares de idosos. *Cienc enferm.* 2018;24(17):1–15. DOI: http://dx.doi.org/10.4067/s0717-95532018000100217.