



The Open Nursing Journal

Content list available at: <https://opennursingjournal.com>



RESEARCH ARTICLE

Relationship Between Adoption of the Caregiver Role and Quality of Life in Caregivers of Cancer Patients Under Active Treatment

Carolina Posada^{1,*}, Laura Correa¹, Manuela Castañeda¹, Mauricio Arias-Rojas¹ and Bertha Tellez²

¹Faculty of Nursing, University of Antioquia, Medellin, Cl. 64 #53-09, Colombia

²Instituto de Cancerología de las Américas, Medellin, Colombia

Abstract:

Background:

Becoming a family caregiver for a patient with cancer implies the adoption of a new role that can affect multiple aspects of the person's life. Little is known about the relationships between the adoption of the role and the quality of life of these family caregivers.

Aim:

To describe the level of adoption of the role of Colombian family caregivers of cancer patients in active treatment and their quality of life, and to examine the relationship of the adoption of the role and other variables related to care in the quality of life.

Methods:

A descriptive-correlational study was conducted with 100 family caregivers of cancer patients. The scales of sociodemographic characteristics, Adopting the Caregiver Role and Quality of Life Family Version were used.

Results:

Findings indicate that educational level, religious commitment, gender of the caregiver, patient's age and one of the dimensions of the Adopting the Caregiver Role scale are predictors of the quality of life of caregivers. In summary, the adoption of the role of the caregiver is a predictor of the quality of life of caregivers.

Conclusion:

Becoming a caregiver requires support from nurses. Strategies to favor the recognition of this new role and make sense of this experience are important in caring for the caregiver. Likewise, it is important to pay attention to the demographic and profile characteristics that can also affect the quality of life.

Keywords: Caregivers, Quality of life, Psychological adaptation, Cancer patients, Sociodemographic, Demographic.

Article History

Received: September 1, 2022

Revised: December 12, 2022

Accepted: December 16, 2022

1. INTRODUCTION

Cancer is a chronic disease that has been increasing over the years and has begun to be recognized as a public health problem throughout the world [1]. According to WHO data of 2020, 19.3 million people worldwide had cancer, of which 10 million died, becoming the second cause of death worldwide. The Pan American Health Organization (PAHO) reports that by 2030, the number of people newly diagnosed with cancer

will increase by 32% and will increase to more than 5 million people per year in Latin American countries. Increased cancer rates result from population aging, lifestyles and continuous exposure to risk factors (Perfiles de País Sobre Cáncer, 2020). For Colombia, GLOBOCAN reported a prevalence of 293,524 cases in 2020, with an incidence of 113,221 cases and mortality of 54,987 cases (Colombia Source: Globocan 2020, 2020) [2, 3].

Chronic diseases such as cancer represent greater health challenges as they have high rates of appearance in developing countries such as Colombia. The precariousness of the health

* Address correspondence to this author at the Faculty of Nursing, University of Antioquia, Medellin, Cl. 64 #53-09, Medellin, Colombia;
E-mail: acarolina.posada@udea.edu.co

system to provide services, in which the possibility to have support, active monitoring and timely treatment access is more of an opportunity than a right [4]. A recent report by the Lancet Commission shows that the delivery of health services in cancer and the prescription of drugs for treatment represent a reason for inequality and a failure in the health system. As well it represents the best way to talk about factors in cancer that increase inequality or inequitable treatment and injustice that remains in developing countries (Knaul *et al.*, 2018). Consequently, having cancer and living in a developing country entails not only the adaptation to new conditions surrounding the disease, but also receiving little support from the healthcare system.

The experience of illness does not involve only the patient suffering from cancer but also his family caregiver and relatives [5, 6]. In this sense, the family caregiver assumes the role of supporting the patient in direct care, accompaniment during treatment administration, management of emotions, decision-making [7] in all disease phases, beginning with the diagnostic phase, and the establishment of treatment and subsequent survival. In role theory, all new roles require the acquisition of skills and can result in changes to other roles and life goals of the caregiver [8]. It has been documented that the adoption of this new role, without adequate support, can lead to a decrease in the caregiver's quality of life and consequently in the cancer patient [6].

The family caregivers must seek to maintain adequate living conditions and stability in physical, psychological, social and spiritual aspects in accordance with established habits while assuming this new role [6]. The adequate adoption of the role can contribute significantly to the process of personal growth and transformation, since in this experience can be found the opportunity to strengthen interpersonal relationships and feel that life has a new purpose [7]. Despite this, the family caregiver is invisible in many cases for health professionals, especially during diagnosis and active treatment (Úbeda Inmaculada, 2009). This lack of care and support during the adoption of the caregiver role can affect some of the dimensions of quality of life, such as physical, in which high levels of exhaustion [9, 10], headaches, back pain, lack of sleep and self-care have been evidenced. Consequently this impact leads to a caregiver burden (Úbeda Inmaculada, 2009). In the psychological dimension, anger, loneliness, uncertainty and stress are common [11].

In this sense, Afaf Meleis mentions that the adoption of a new role is a situational transition that implies changes in relationships with others, personal expectations and abilities (Meleis, 2010). When the transition is not developed adequately, an insufficiency of the role is experienced which refers to a failure of any of the processes that imply an adoption of the role, which hinders a healthy transition (Meleis, 2010). For healthcare professionals, understanding the level of adoption of the role of caregivers is essential since it serves as a basis for generating strategies that support the transition conditions and facilitate the process, consequently improving the caregiver's quality of life (Meleis, 2010).

Currently, studies have addressed the physical and emotional symptoms of caregivers of cancer patients under

active treatment and their relationship with burden [10, 11], as well as the impact of demographic and care variables on the caregiver's quality of life [1, 7, 12, 13], and the relationship of quality of life with variables such as depression, anxiety and burden [14]. However, to date, no studies have been found evaluating the adoption of the role of caregivers of cancer patients in active treatment, nor its relationship with quality of life. Understanding this level of adoption of the role will allow nurses to identify its impact on the quality of life, and design nursing care for a better adaptation to the role of the caregiver. Consequently, the objective of this study was to describe the adoption of the role of Colombian family caregivers of cancer patients in active treatment and their quality of life, and to examine the relationship between the adoption of the role and other variables related to care in the quality of life.

2. MATERIALS AND METHODS

2.1. Study Design and Participants

A descriptive correlational cross-sectional study was conducted. The study was carried out from October 2020 to May 2021 in the city of Medellín-Colombia. This study obtained approval from the institution's ethics committee (Office no. 0250-20). All participants signed written informed consent.

The study was carried out in an outpatient clinic with a focus on the care of cancer patients. To calculate the sample size, the G*Power software was used to calculate a sample size for a multiple linear regression based on a mean effect size of 0.1 and a power of 0.90, with an alpha value of 0.05, which gave a total sample size of 99 participants. The selection of the participants was made intentionally. The inclusion criteria were: being a caregiver of a cancer patient who was receiving chemotherapy as the primary treatment for their disease, being the patient's main responder, being a caregiver for more than a month, and being able to answer the surveys. Exclusion criteria were: being hired caregivers, and having previously cared for another person with cancer.

2.2. Data Collection

Participants were invited to the study by a nurse while they were waiting in the waiting rooms of the clinic's outpatient chemotherapy service. The caregivers received complete information about the study objectives and their role in the study, as well as the anonymity of the information. The nurse reviewed the inclusion criteria of the possible participants, and the caregivers who agreed to participate signed an informed consent form. An appointment was made for a telephone call during that week to fill out the study instruments. A call manual and an instruction manual were made for the completion of the three instruments, in addition, simulations were carried out among the researchers to guarantee the correct completion of the forms. After this, the researchers made telephone calls to the participants and collected the information through this medium, always at the most convenient time for the caregiver. The calls had an average duration of 20 minutes. The data collection by telephone was due to the biosecurity restrictions established in the institution where the information was collected due to the COVID-19 pandemic.

2.3. Data Collection Tools

2.3.1. Adoption of the Role of the Family Caregiver

For the measurement of this construct, the Adopting the Caregiver Role scale was used. This instrument was designed by Carreño *et al.* [7, 8], its foundation is based on the fact that the transition to a new role is made up of three main attributes (dimensions of the instrument) 1) responses to the role (7 items), 2) organization of the role (8 items) and 3) role execution (7 items). This instrument has 22 items with responses on a Likert-type scale from 1) never to 5) always. The total score on the scale ranges from 22 to 110. Levels of 22 to 60 indicate insufficient role adoption, 61 to 77 basic adoption, and 78 to 110 satisfactory adoption. This instrument has psychometric properties in the Spanish language, including content validity with an inter-observer agreement index of 0.93, a factor analysis that confirms the three dimensions of the instrument and a Cronbach's alpha score of 0.816 for the entire scale, and between 0.767 to 0.835 for each dimension [7, 8]. The Cronbach's alpha in this study was 0.65 for all items.

2.3.2. Quality of Life of the Family caregiver

Quality of life was measured with the Quality of Life Scale-Family version developed by Ferrell and Grant for caregivers of cancer patients under active treatment [15, 16]. In this study, the scale was used in its version adapted to Spanish and the Colombian context, which presents tests of construct validity that fit the proposed dimensions in the original version. It has test-retest reliability ($r = 0.86$) and internal consistency ($\alpha = 0.86$) [16]. The quality of life scale has 4 dimensions: 1) physical well-being: physical problems of the caregiver (5 items); 2) psychological well-being: the emotional state of the caregiver and satisfaction with life (16 items); 3) social concerns: social support, employment and social relationships of the caregiver (9 items); 4) spiritual well-being: religious activities and the hope of the caregiver (7 items). The scale has 37 items that are scored on a scale of 0 to 10, with 0 being the worst quality of life and 10 being the best possible quality of life. Likewise, each of the subdimensions can be interpreted through its specific score. For discussion purposes, a standardization of scores by dimensions was performed on a total score of 100 points. In this study, the internal consistency of the scale showed an alpha value of 0.91.

2.3.3. Sociodemographic Profile of the Family Caregiver

For the sociodemographic characterization, a caregiver-patient dyad form developed in Colombia for caregivers of

patients with chronic illness was used [17]. This form collects information about sociodemographic aspects of both the person with cancer and their caregiver, aspects related to sociodemographic characteristics and information related to the disease, as well as the caregiver profile in aspects such as time as a caregiver if they have the support of another relative and the number of hours dedicated to caring.

2.4. Data Analysis

The information was analyzed using SPSS, version 25.0, licensed from the University of Antioquia. There were no missing data in this study. We performed a descriptive analysis with measures of central tendency and frequencies to describe the characteristics of the participants and the variables measured. The association between the adoption of the role, demographic variables and caregiver profile, and quality of life was measured by Pearson's correlation test. Finally, to meet the basic requirements of multiple regression, the data were evaluated to check the presence of multicollinearity, normality, homoscedasticity, and independence of the residuals in all the models tested. In relation to multicollinearity, it was found that the correlation between the variables identified as independent had values below .6, and the tolerance and variance inflation factor (VIF) values were greater than .1, and less than 10, respectively. None of the eigenvalues for each dimension corresponded to a larger condition index, thus indicating that there was no multicollinearity in the independent variables.

All predictor variables were entered into the regression model at the same time. Three models were manually tested by entering the sociodemographic characteristics, the care profile, and the adoption of the caregiver role as independent variables until the model with the best-explained variance was found. The statistical significance of the model was determined with P values $<.05$.

3. RESULTS

A total of 100 family caregivers participated in the study, of which 83% were women, the average age was 50.41 years. Participants had a primarily husband-and-wife relationship with cancer patients (32%). The marital status was mainly married (52%). The educational level was high school in most of the participants (37%). Regarding the occupation of the caregiver, it was found that most of the caregivers were at home, representing 44% and the Catholic religion was predominant in 91%, with a high level of commitment in 49% of them (Table 1).

Table 1. Distribution of the sociodemographic characteristics of the caregivers.

Characteristic	Category	n (%)
Caregiver's age	mean \pm standard deviation	50.51 \pm 14.74
Sex	Female	83 (83)
	Male	17 (17)

(Table 1) contd....

Characteristic	Category	n (%)
Relationship with the patient	Husbands	32 (32)
	Children	32 (32)
	Other relatives	16 (16)
	Siblings	14 (14)
	Parents	6 (6)
Marital status	Married	52 (52)
	Single	37 (37)
	Free Union	11 (11)
	Widower	0 (0)
Educational level	Illiterate	3 (3)
	Primary school	15 (15)
	High school	37 (37)
	Technical	21 (21)
	Undergraduate	17 (17)
Employment status	Postgraduate	7 (7)
	Home	44 (44)
	Employee	24 (24)
	Self-employed	17 (17)
	Student	4 (4)
Socioeconomic status	Other	11 (11)
	Income in poverty range	43 (43)
	Income above poverty range	47 (47)
	Income in middle-class range	10 (10)
Level of religious commitment	High	49 (49)
	Low	51 (51)

Regarding the care profile, 83% of the participants mentioned caring for the patient from the moment of diagnosis. 16% of the participants mentioned having the support of another relative, composed mainly of siblings. The caregivers had spent an average of 1.01 years caring for the patient and an average of time dedicated to caring per day of 14.16 hours (Table 2). The participants of this research mainly cared for people with breast (29%) and gastrointestinal cancer (25%),

with a mean age of 63.24 years (Standard deviation (SD) = 13.91). Likewise, all patients were on active chemotherapy treatment, and they had an average of 2.17 years since the diagnosis of the disease.

The total mean score of the adoption of the caregiver role scale was 91.42 (SD = 8.57), this mean indicates a satisfactory adoption of caregiver role. Regarding the quality of life scale the total mean was 209.95 (SD = 55.02) (Table 3).

Table 2. Distribution of the characteristics of the care profile of the caregivers.

Characteristic	Category	n (%)
Time as a caregiver in years	mean ± standard deviation	1.01 ± 2.14
Hours dedicated to patient's care	mean ± standard deviation	14,16 ± 7,34
Single primary caregiver	Yes	49 (49)
	No	51 (51)
Care from the time of diagnosis	Yes	83 (83)
	No	17 (17)
Who supports the caregiver	Siblings	16 (16)
	Parents	9 (9)
	Husbands	7 (7)
	Children	7 (7)
	Other family	12 (12)
	Nobody	49 (49)
Previous experience as a caregiver	Yes	34 (34)
	No	66 (66)

Table 3. Description of the levels of adoption of the role and quality of life of the caregivers.

Scale	Number of Items	Values Min – Max	Mean ± Standard Deviation	Confidence Interval 95%
Adoption of the role				
Total	22	22 – 110	91.42 ± 8.57	[89.72, 93.12]
Responses to the role	7	7 - 35	29.14 ± 3.66	[28.41, 29.87]
Organization of the role	8	8 – 40	31.27 ± 4.84	[30.31, 32.23]
Role execution	7	7 - 35	31.01 ± 3.39	[30.34, 31.68]
Quality of life				
Total	37	0 – 370	209.95 ± 55.02	[199.03, 220.87]
Physical	5	0 – 50	33.12 ± 10.81	[30.97, 35.27]
Psychological	16	0 – 160	78.15 ± 25.87	[73.02, 83.28]
Social concerns	9	0 – 90	50.17 ± 19.10	[46.38, 53.96]
Spiritual	7	0 – 70	48.51 ± 12.71	[45.99, 51.03]

Table 4. Relationships between the caregiver's sociodemographic characteristics, care profile, adoption of the role, and quality of life of the caregivers.

Variables	-	Quality of life				
		Dimensions	Physical	Psychological	Social concerns	Spiritual
Adoption of the role	Responses to the role	0.373**	0.579**	0.508**	0.348**	0.585**
	Organization of the role	0.096	0.079	0.245*	0.204*	0.198*
	Role execution	0.033	0.200*	0.229*	0.307**	0.246*
	Total	0.232*	0.362**	0.428**	0.367**	0.447**

Note: * $P < .05$, ** $P < .01$.

Significant positive correlations were found between the total scores of quality of life and adoption of the role ($r = 0.447, P < 0.01$). Correlations were also found between the dimension responses to the role with the total score of quality of life ($r = 0.585, P < 0.01$) and all its dimensions (physical $r = 0.373, P < 0.01$; psychological $r = 0.579, P < 0.01$; social $r = 0.508, P < 0.01$; spiritual $r = 0.348, P < 0.01$). Between the dimension organization of the role and the dimension the spiritual dimension of quality of life ($r = 0.204, P < 0.05$) and the dimensions organization and execution of the role with the spiritual dimension of quality of life respectively ($r = 0.204, P < 0.05$; $r = 0.307, P < 0.01$) (Table 4).

A multiple linear regression was used to evaluate the influence of the sociodemographic characteristics, the care profile and the adoption of the role in the caregivers' quality of life. Nominal demographic and care profile variables were transformed into nominal dichotomous level variables. This was done to meet the requirements of linear regression and to be able to test the model with these variables as predictors. Because the educational level was categorized into six levels, three of basic studies and three of advanced studies, this variable became a dichotomous nominal variable: basic education and higher education (technical, university and

postgraduate). Marital status became a dichotomous nominal variable: with a partner and without a partner (single). The employment status was recoded into the dichotomous variable with active workers and unemployed workers (student or household), the income level was classified as low and middle income. The relationship with the patient was reclassified as a partner (husband / wife) and other relatives (parents, children, friends).

Initially, 20 independent variables were entered together as a block. The results showed 3 models that explained between 35 and 42% of the variance in quality of life. In a subsequent analysis, the authors chose the 5 most significant variables in the 3 models until reaching a maximum value of the explained variance of 42% ($R^2 = 0.449$; $R^2 \text{ adj} = 0.449$), $F(15.34), P < .001$. The significant variables that contributed to the model were the age of the patient, the gender of the caregiver, the educational level of the caregiver, the level of religious commitment, and the Responses to the role dimension of the adoption of the role scale. Table 5 presents the summary of multiple regression of all the variables and their influence on the quality of life of the caregiver. In the final model, the five variables studied were statistically significant.

Table 5. Significant variables of quality of life using multiple linear regression.

-	B	SE	Standard B	t	P	Tolerance	VIF
(Constant)	-56.602	39.627	-	-1.428	.156	-	-
Patient's age (lower age)	.647	.320	0.164	2.020	.046	.892	1.121
Caregiver's gender (female)	-28.310	11.532	-.194	-2.455	.016	.936	1.069

(Table 5) contd.....

	<i>B</i>	<i>SE</i>	<i>Standard B</i>	<i>t</i>	<i>P</i>	<i>Tolerance</i>	<i>VIF</i>
-							
Educational level (higher education)	24.762	10.347	.190	2.393	.019	.926	1.080
Level of religious commitment (High)	17.597	8.607	.161	2.045	.044	.949	1.054
Responses to the role (Adoption of the role)	8.057	1.177	.537	6.843	.000	.951	1.052

4. DISCUSSION

According to the literature review carried out by the authors, this is one of the first studies to evaluate the impact of the adoption of the role, the sociodemographic characteristics, and the care profile on the quality of life of the family caregiver supporting the cancer patient under active treatment.

The findings of our study show that family caregivers have a mean quality of life of 209.95 points (SD, 55.02). These results are similar to those reported in a study in caregivers of cancer patients under active treatment in which a mean of 199.5 points (SD, 35.2) [18] of quality of life was described. Interestingly, when comparing the scores within each dimension in these two studies, it was found that the most affected dimension was psychological well-being (after performing a standardization of scores by dimensions), as it presented the lowest scores. In this regard, a study [19] identified that there was a decrease in psychological well-being in those caregivers who were spouses or children, as well as in those without the option to choose to become a caregiver [20]. Additionally, associated with the psychological dimension, it is common for these caregivers to present feelings such as loneliness, sadness, and exhaustion associated with worry and uncertainty about treatment during active treatment, feelings that can impact their psychological quality of life [21].

In this study, the mean role adoption score was 91.42 (SD, 8.57), which is interpreted as a satisfactory adoption of the role. Because the adoption of the role construct is novel and began with the first publication in 2018 [7], there are still no published studies to compare the information in this study. Nevertheless, when reviewing the scores by dimensions, it was found that the best-evaluated dimension was role execution, while the organization of the role presented the lowest score. The organization dimension of the role refers to the distribution of care tasks, seeking social support and having time for one's own needs [7]. Studies [22] have reported that caregivers of cancer patients must attend up to 7 instrumental activities of daily life, such as managing finances or transfers; in addition, they assist the patient in medical or nursing tasks by 44.6%. This reflects the high number of activities that a caregiver must develop. A caregiver with an adequate adoption of their role must be able to make the decision to seek support and strengthen relationships with the people who support them, which will allow them to have more time to organize their care and self-care spaces [23]. Strengthening relationships as caregivers is important, over time family caregivers tend to lose support because they are caring and don't have time to return support offered by others [24].

According to the quality of life scores and adoption of the caregiver role, our research did not correlate any of these scores to the sociodemographic characteristics of the participants or their care profile (age, time as a caregiver, educational level, marital status, type caregiver, etc.). However, other studies have found correlations between

characteristics (gender, employment status, income status) [1] and the care profile (hours dedicated to care, relationship with the patient, time as a caregiver, patient treatment time) [1, 25] related to the quality of life levels. However, these studies were conducted on caregivers who dedicated more hours to daily care (20 to 24 hours) [1], with lower educational levels [25] and younger age [1]. Although no such correlations were found in the bivariate analyzes of our study, the regression model did find the influence of 4 of these variables on the caregiver's quality of life.

The significant predictors of the caregiver's quality of life were only the patient's age, caregiver's gender, educational level, level of religious commitment, and responses to the role. The age of the patient has been reported as a variable associated with the impact on the quality of life of caregivers. For example, a study [26] showed that older adults with cancer had more needs for care assistance, higher levels of dependence and other comorbidities in addition to cancer. These aspects can make the experience of caring more complex for the caregiver, which could consequently affect their quality of life. Regarding the sex of the caregiver, the evidence has shown that female caregivers must, apart from caring for the cancer patient, continue with their other roles as mothers, wives, and workers [27], in addition to this, culturally, the man tends to receive more support from their support networks than women [26], this generates caregiver burden on women and significantly affects their quality of life [28, 29].

This study found that the educational level of the caregiver was a significant predictor of quality of life. In contrast, other studies with caregivers with similar characteristics did not find this result [18]. Nevertheless; other studies indicate that a high educational level can facilitate in the caregiver the understanding of the information provided by healthcare professionals about the disease, the treatment and the care of the patient in complex tasks such as the evaluation of symptoms or the administration of medications [23]. It can eventually decrease the psychological stress associated with understanding the disease and its treatment.

The level of religious commitment was one of the predictors of the quality of life in our sample. Interestingly, the practice of religion has been found as a predictor variable of higher quality of life in other studies of caregivers of patients with cancer in early ($P < 0.001$) [18] and advanced stages of the disease ($B = 0.55$, $P < 0.001$) [30, 31].

Finally, this study found that one of the dimensions of adoption of the role was a predictor variable of the quality of life in caregivers. Specifically, the score for the role responses dimension showed not only a moderate to strong correlation with all dimensions of quality of life, but it also showed to be a predictor variable. The response to the role refers to aspects related to the recognition of the work as a caregiver and making sense of the experience [7]. In this regard, other studies in caregivers of cancer patients have found how supporting

them through the course of the disease generates feelings of uncertainty and ignorance of the situation at the beginning; however, over time and with adequate social support networks, the caregiver manages to re-signify the care experience and makes sense of the situation, despite its complexity [32]. Once the caregiver finds meaning in their experience, they are empowered to care for the patient, thus increasing their knowledge of instrumental tasks, which reduces the feeling of fear and distress generated by the assistance of the patient in activities of daily life and symptom management, thus improving quality of life [33]. In this way, the results of this study are consistent with the studies reported, and even, in addition to this, it could be thought that, since most caregivers are the spouses or children of the patient (64%), assuming their new role can be interpreted to strengthen the bond with the loved one. This finding may help to understand the mechanisms through which caregiver preparation influences his/her quality of life.

5. LIMITATIONS

The study authors recognized several limitations. First, the lack of randomization in the selection of participants may increase the risk of bias in the selection of the sample. Second, the lack of published studies on adoption of the role did not allow for greater contrast of the results with other reported findings, which made it difficult to recognize whether the levels of role adoption were adequate compared to other populations. Given the nature of the cross-sectional study, it is not possible to identify the changes that the variables studied have over time, therefore, future studies should study the longitudinal trajectory of these variables, preferably from the moment of diagnosis and until advanced treatment.

6. IMPLICATIONS FOR NURSING

This is one of the first studies that seeks to know the predictive variables of quality of life in a sample of caregivers of cancer patients under active treatment in Colombia. In this study and other studies, the influence of the characteristics of the caregiver, the patient and variables such as caregiver burden on the perception of quality of life has been identified [34, 35]. But an important finding has been the identification of the adoption of the caregiver role as an important predictor of quality of life. In this connection, to favor the adoption of this new role and facilitate a healthy transition for the caregiver, educational support and continuous follow-up should be given in instrumental activities, as well as connecting these caregivers with the network of institutional and community resources available. Additionally, it has been documented that the role of the caregiver can be learned with strategies for role modeling with healthcare professionals and peers, through role play, with educational sessions and with the development of hypothetical situations to solve [36]. Even from the findings of this research, spiritual care interventions for the caregiver could be favored, as has been documented in other studies [37].

On the other hand, more personalized attention should be given to those caregivers who are women with a low educational level, or who care for patients with an older age since there may be a lower quality of life. Finally, assessing the caregiver's quality of life should be a recurring activity in

professionals to detect the impact that care has on the physical dimension of the person.

CONCLUSION

This study identified that family caregivers of cancer patients in the active treatment had a satisfactory level of adoption of the role. In relation to the quality of life, caregivers in this study had a mean of 209 points. The psychological dimension was the one that presented the lowest scores. No relationships were found between the caregiver's sociodemographic characteristics or his care profile with the adoption of the caregiver's role or quality of life. This study revealed that the gender of the caregiver, educational level, religious commitment, and patient's age, as well as the dimension responses to the role of the adoption of the role variable are predictors of the quality of life of family caregivers. In this connection, nursing has an important responsibility in the accompaniment during the adoption of the new role as family caregivers of a patient with cancer and in the assessment and implementation of strategies to improve the quality of life of these people.

LIST OF ABBREVIATIONS

VIF	=	Variance Inflation Factor
SD	=	Standard Deviation

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The ethical approval was obtained from the Ethics Committee of the University of Antioquia. The approval number for this study was Ref. No. 0250-20.

HUMAN AND ANIMAL RIGHTS

No animals were used for studies that are the basis of this research. All the humans used were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national) and with the Helsinki Declaration.

CONSENT FOR PUBLICATION

The written informed consent form was taken from the patients and volunteers.

STANDARD OF REPORTING

STROBE guidelines were followed for this study.

AVAILABILITY OF DATA AND MATERIALS

The data supporting the findings of this study is available at <https://zenodo.org/record/7600221#.Y9vk23bMLIU>.

FUNDING

The study received funding from the research center of the University of Antioquia.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

The authors of this study would acknowledge the study participants.

REFERENCES

- [1] Kilic ST, Oz F. Family caregivers' involvement in caring with cancer and their quality of life. *Asian Pac J Cancer Prev* 2019; 20(6): 1735-41. [http://dx.doi.org/10.31557/APJCP.2019.20.6.1735] [PMID: 31244294]
- [2] Cancer country profiles. In: WHO. World Health Organization, Pan American Health Organization 2020. Available from: https://www3.paho.org/hq/index.php?option=com_content&view=article&id=15716:country-cancer-profiles-2020&Itemid=72576&lang=es [cited: 15 august 2021].
- [3] World Health Organization. Colombia Source: GLOBOCAN 2018. WHO 2019. Available from: <https://gco.iarc.fr/today/data/factsheets/populations/170-colombia-fact-sheets.pdf> [cited: 15 august 2021].
- [4] Pereira A. The paths of pain. Access to palliative care and treatment for heroin use in Colombia. Bogotá, DC: Centro de Estudios de Derechos, Justicia y Sociedad 2019.
- [5] Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018; 391(10128): 1391-454. [http://dx.doi.org/10.1016/S0140-6736(17)32513-8] [PMID: 29032993]
- [6] Williams A. Family caregivers to adults with cancer: The consequences of caring. *Recent Results Cancer Res* 2018; 210: 87-103. [http://dx.doi.org/10.1007/978-3-319-64310-6_6] [PMID: 28924681]
- [7] Carreño Moreno S, Chaparro Diaz L. Adopción del rol del cuidador familiar del paciente crónico: Una herramienta para valorar la transición. *Revista Investigaciones Andina* 2018; 20(36): 39-54. [http://dx.doi.org/10.33132/01248146.968]
- [8] Arias M, Carreño S, Chaparro L. Validity and reliability of the scale, role taking in caregivers of people with chronic disease, ROL. *Int Arch Med* 2018; 11: 1-10. [http://dx.doi.org/10.3823/2575]
- [9] Úbeda BI. Quality of life of family caregivers: assessment using a questionnaire. : PhD dissertation. Barcelona: Universidad de Barcelona 2009.
- [10] Johansen S, Cvancarova M, Ruland C. The effect of cancer patients' and their family caregivers' physical and emotional symptoms on caregiver burden. *Cancer Nurs* 2018; 41(2): 91-9. [http://dx.doi.org/10.1097/NCC.0000000000000493] [PMID: 28426539]
- [11] Stenberg U, Cvancarova M, Ekstedt M, Olsson M, Ruland C. Family caregivers of cancer patients: perceived burden and symptoms during the early phases of cancer treatment. *Soc Work Health Care* 2014; 53(3): 289-309. [http://dx.doi.org/10.1080/00981389.2013.873518] [PMID: 24628120]
- [12] Meleis A. Transitions theory middle-range and situation specific theories in nursing research and practice. New York: Springer Publishing Company 2010.
- [13] Alptekin S, Gönüllü G, Yücel İ, Yarış F. Characteristics and quality of life analysis of caregivers of cancer patients. *Med Oncol* 2010; 27(3): 607-17. [http://dx.doi.org/10.1007/s12032-009-9256-2] [PMID: 19590990]
- [14] Shin JY, Lim JW, Shin DW, et al. Underestimated caregiver burden by cancer patients and its association with quality of life, depression and anxiety among caregivers. *Eur J Cancer Care* 2018; 27(2): e12814. [http://dx.doi.org/10.1111/ecc.12814] [PMID: 29333736]
- [15] Ferrell BR, Grant M. Quality of life family version. National Medical Center and Beckman Research Institute 1995. Available from: <https://prc.coh.org/QOL-Family.pdf> [cited 06 december 2021].
- [16] Ferrell BR, Grant M, Chan J, Ahn C, Ferrell BA. The impact of cancer pain education on family caregivers of elderly patients. *Oncol Nurs Forum* 1995; 22(8): 1211-8. [PMID: 8532545]
- [17] Chaparro-Diaz L, Sánchez B, Carrillo-Gonzalez GM. Encuesta de caracterización del cuidado de la diada cuidador/familiar - persona con enfermedad crónica. *Rev Cienc y Cuid* 2015; 11(2): 31-45. [https://doi.org/10.22463/17949831.196]
- [18] Soleimani MA, Lehto RH, Negarandeh R, Bahrami N, Chan YH. Death anxiety and quality of life in Iranian caregivers of patients with cancer. *Cancer Nurs* 2017; 40(1): E1-E10. [http://dx.doi.org/10.1097/NCC.0000000000000355] [PMID: 26925995]
- [19] Li L, Lee Y. Caregiving choice and caregiver-receiver relation: Effects on psychological well-being of family caregivers in Canada. *Can J Aging / La Rev Can Du Vieil* 2020; 39(4): 634-46. [http://dx.doi.org/10.1017/S0714980819000825]
- [20] Morgan T, Duschinsky R, Gott M, Barclay S. Problematising carer identification: A narrative study with older partner's providing end-of-life care. *SSM - Qual Res Heal* 2021; 1: 100015. [http://dx.doi.org/10.1016/j.ssmqr.2021.100015]
- [21] 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): 31-41. [http://dx.doi.org/10.1186/s12904-017-0206-z] [PMID: 28486962]
- [22] Mollica MA, Smith AW, Kent EE. Caregiving tasks and unmet supportive care needs of family caregivers: A U.S. population-based study. *Patient Educ Couns* 2020; 103(3): 626-34. [http://dx.doi.org/10.1016/j.pec.2019.10.015] [PMID: 31704030]
- [23] Ribé JM, Salameo M, Pérez-Testor C, Mercadal J, Aguilera C, Cleris M. Quality of life in family caregivers of schizophrenia patients in Spain: Caregiver characteristics, caregiving burden, family functioning, and social and professional support. *Int J Psychiatry Clin Pract* 2018; 22(1): 25-33. [http://dx.doi.org/10.1080/13651501.2017.1360500] [PMID: 28799427]
- [24] Jung J. The role of reciprocity in social support. *Basic Appl Soc Psych* 1990; 11(3): 243-53. [http://dx.doi.org/10.1207/s15324834bas1103_2]
- [25] Cubukcu M. Evaluation of quality of life in caregivers who are providing home care to cancer patients. *Support Care Cancer* 2018; 26(5): 1457-63. [https://doi.org/10.1007/S00520-017-3968-1/TABLES/3]. [PMID: 29164376]
- [26] del Río Lozano M, García-Calvente MM, Calle-Romero J, Machón-Sobrado M, Larrañaga-Padilla I. Health-related quality of life in Spanish informal caregivers: Gender differences and support received. *Qual Life Res* 2017; 26(12): 3227-38. [http://dx.doi.org/10.1007/s11136-017-1678-2] [PMID: 28780713]
- [27] Cascella Carbó GF, García-Orellán R. Burden and gender inequalities around informal care. *Invest Educ Enferm* 2020; 38(1): 2216-0280. [http://dx.doi.org/10.17533/udea.iee.v38n1e10]
- [28] Connors MH, Seeher K, Teixeira-Pinto A, Woodward M, Ames D, Brodaty H. Dementia and caregiver burden: A three-year longitudinal study. *Int J Geriatr Psychiatry* 2020; 35(2): 250-8. [http://dx.doi.org/10.1002/gps.5244] [PMID: 31821606]
- [29] Xiong C, Biscardi M, Astell A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PLoS One* 2020; 15(4): e0231848. [http://dx.doi.org/10.1371/journal.pone.0231848] [PMID: 32310969]
- [30] Leow MQH, Chan MF, Chan SWC. Predictors of change in quality of life of family caregivers of patients near the end of life with advanced cancer. *Cancer Nurs* 2014; 37(5): 391-400. [http://dx.doi.org/10.1097/NCC.0000000000000101] [PMID: 24172755]
- [31] Córdoba AM, Poches DK. Resilience and associated variables in informal caregivers of Alzheimer's patients. *Rev Colomb Psicol* 2016; 25(1): 33-46. [http://dx.doi.org/10.15446/rcp.v25n1.44558]
- [32] Given BA, Sherwood P, Given CW. Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiol Biomarkers Prev* 2011; 20(10): 2015-21. [http://dx.doi.org/10.1158/1055-9965.EPI-11-0611] [PMID: 21980009]
- [33] Fujinami R, Sun V, Zachariah F, Uman G, Grant M, Ferrell B. Family caregivers' distress levels related to quality of life, burden, and preparedness. *Psychooncology* 2015; 24(1): 54-62. [http://dx.doi.org/10.1002/pon.3562] [PMID: 24789500]
- [34] Anjos KF, Boery RNSO, Pereira R, et al. Association between social support and quality of life of relative caregivers of elderly dependents. *Cien Saude Colet* 2015; 20(5): 1321-30. [http://dx.doi.org/10.1590/1413-81232015205.14192014] [PMID: 26017935]
- [35] Alves Costa MS, Pereira MG. Predictors and moderators of quality of

- life in caregivers of amputee patients by type 2 diabetes. *Scand J Caring Sci* 2018; 32(2): 933-42. [<http://dx.doi.org/10.1111/scs.12528>] [PMID: 28940618]
- [36] Carreño-Moreno S. Transitional nursing care enhances competency in the role of the caregiver of the child with cancer. *Psicooncología* 2016; 13(2-3): 321-32. [<http://dx.doi.org/10.5209/PSIC.54439>]
- [37] Gabriel I, Creedy D, Coyne E. Feasibility of a socio-spiritual intervention to improve quality of life of adult Nigerians with cancer and their family caregivers: Protocol for a randomised controlled trial. *Contemp Clin Trials Commun* 2021; 22: 100802. [<http://dx.doi.org/10.1016/j.conctc.2021.100802>] [PMID: 34195469]

© 2023 Posada

This is an open access article distributed under the terms of the Creative Commons Attribution 4.0 International Public License (CC-BY 4.0), a copy of which is available at: <https://creativecommons.org/licenses/by/4.0/legalcode>. This license permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.