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Quality of life of family caregivers of people with cancer in palliative care

Calidad de vida de cuidadores familiares de personas con cáncer que reciben atención de cuidados paliativos

Qualidade de vida dos cuidadores familiares de pessoas com câncer em cuidados paliativos

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ABSTRACT

Objective: To describe quality of life and related factors in a sample of Colombian caregivers of people with cancer in palliative care. **Method:** A correlational, descriptive and cross-sectional study conducted with 208 family caregivers of people with cancer in outpatient palliative care in Medellín, Colombia. The Quality of Life in Life-Threatening Illness - Family Caregiver Version (QOLLTI-F) instrument was used. **Results:** Quality of life obtained scores between 116.36 and 122.35 (95%CI). The dimensions with the lowest scores were Patient condition (2.4–3.2, 95%CI), Caregiver's own state (36.2–39.9, 95% CI) and Environment (14.4–15.7, 95%CI). The patient's and caregiver's ages and the Karnofsky index presented a positive correlation, from weak to moderate and significant with the caregiver's quality of life. The daily hours devoted to care presented a weak correlation, negative and significant, with the overall quality of life and with the Caregiver's own state dimension. **Conclusion:** It is necessary to develop interventions to improve quality of life in caregivers of people with advanced cancer in the palliative phase, considering the importance of relief actions and the management of the patient's functional dependence.

DESCRIPTORS

Quality of Life; Caregivers; Neoplasm; Palliative Care.

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INTRODUCTION

Chronic diseases are a growing reality in the world and cancer significantly adds to their global burden. According to the World Health Organization (WHO), by 2016, cancer had taken nine million lives, which represented 22% of the burden for mortality attributable to the chronic disease(1).

Added to the problem of mortality due to cancer is the fact that there is insufficient integration of palliative care in the systems for the provision of health services worldwide. According to PAL-LIFE(2), each year 35 million people live with chronic conditions susceptible of palliative care, of which 25 million die, many times without receiving the type of care they require. A clear example of such disintegration is the Colombian case, where there are structural, access, human resources training and cultural deficiencies around palliative care(3); for example, there are less than 0.5 palliative care services per million inhabitants and 17 care units for nearly 47 million inhabitants, the services are concentrated in large cities, a low amount of 6.7 mg of opioid is consumed by year/person, and there are only 3 documented palliative care programs.

The reality of the problem associated to palliative care is not only that of the individuals who need it, but also that of their family caregivers, who sometimes remain invisible with their needs unmet, a situation that affects their quality of life. Family caregivers of people in palliative care report lower quality of life levels than the general population and than the caregivers of people with cancer with a curative treatment intention. A study reported deep differences in the mental health and emotional role dimensions between the general population and the family caregivers after the patient's death; in addition to a significant deterioration in the general health status and in the physical dimension(4). Likewise, another study(5) reported worse results in the physical functioning, physical role, general health status, vitality, social functioning, emotional role and mental health dimensions than the general population, that is, with the exception of the physical pain dimension, in general the quality of life of the caregiver of a person with cancer in palliative care is significantly lower than that of the general population.

Lower quality of life levels have been reported in caregivers of people with gastric cancer in palliative care, in comparison to the mean of the general population; in addition, factors such as young age in caregivers and patients were related to better physical health; it is also found that aged caregivers, with better perceived health, who are not the patients' spouses, and whose patients had not undergone any surgery and were not hospitalized, reported better quality of life levels in the mental health area(6).

Regarding health-related quality of life, a study conducted in Germany showed that family caregivers of people with cancer in the palliative phase presented lower levels when compared to the general population; in addition, women reported worse quality of life levels than men in the emotional scope; low quality of life in women can be related to the high emotional burden they develop(7). In contrast, a study conducted in Norway reported low quality of life levels in family caregivers of people with cancer in the late palliative phase, with lower levels of the mental component in men than in women; although the literature reports greater emotional and mental impact in women than in men, this study did not confirm this hypothesis; and alternative explanation is cultural differences(8).

The research of quality of life in caregivers of people with cancer in palliative care has concentrated on describing and comparing the quality of life levels with those of the general population, in addition to explaining influencing factors, as previously described. Considering in the first place that situations of a cultural nature can mediate quality of life and not only those related to the care of a person with cancer in palliative care and, in the second place, that the health systems in many Latin American countries still do not integrate palliative care into the provision of health services, leads to the need to conduct descriptions in contexts like the Latin American one. In that respect, to the present day, the review only found one study conducted with caregivers of people with cancer in palliative care in Chile, where quality of life levels similar to those of studies conducted with caregivers of hospitalized individuals with cancer were reported; in addition, worse results were reported in mental health than in physical health, as well as significantly lower levels in vitality, emotional role, and mental health in women than in men(9).

Given the few existing studies in Latin America regarding the description of the quality of life of the caregiver of the patient with cancer in palliative care, this study set out as its objective to describe quality of life and related factors in a sample of Colombian family caregivers of people with cancer in palliative care.

METHOD

Study design

A correlational, descriptive and cross-sectional study with a quantitative design.

Population and Scenario

This study was developed in an outpatient service of a third-level care hospital, specialized in cancer and located in the city of Medellín, Colombia.

Selection criteria

For this study, within the inclusion criteria, it was considered that the participant was the main family caregiver of the patient with stage IV cancer who was under outpatient palliative care and over 18 years old. Hired caregivers were excluded. Convenience sampling was performed, with the participation of 208 family caregivers.

Data collection

To collect the study participants' data, the palliative care version of the dyad characterization survey

(GCPC-UN-D-CP) was applied, designed by the Nursing Care for the Chronic Patient Research Group of the Universidad Nacional de Colombia. The survey identifies the caregiver's and the patient's sociodemographic characteristics, variables related to the provision of care, such as time as a caregiver, if the participant is the only caregiver, and number of daily hours devoted to care. This survey has been used in several studies in Latin America and presents suitable face and content validity characteristics(10).

To assess quality of life, the Quality of Life in Life-Threatening Illness - Family Caregiver Version (QOLLTI-F)(11) (in Spanish) was used. The instrument was created based on a qualitative study that asked the caregivers about the aspects that they consider important for their quality of life. The instrument's validity was confirmed by factor analysis, with an explained variance of 53%; in addition, a test/re-test reliability value of 0.77 to 0.80 was reported. This instrument has been documented as unique, as it assesses quality of life, reported by the family caregiver, and includes the patient condition, which confirms the close relationship between both. It has also been documented that it is special, as it derives from a qualitative study that asked the caregivers on the aspects that they considered important for their quality of life, instead of focusing on the changes and burdens derived from the care duty. This scale presented adequate psychometric properties for the Colombian context. In a study not published by the authors, conducted with caregivers of people with cancer in palliative care, its 6-dimension factorial structure was confirmed, with a model that explained 70% of the variance. In addition, internal consistency with a Cronbach's alpha coefficient of 0.82 and test/re-test stability of 0.879 were documented. The Colombian version of the instrument has 16 items, with the following dimensions: Environment (2 items), Patient condition (1 item), Caregiver's own state (6 items), Caregiver's outlook (3 items), Quality of care (2 items), and Relationships (2 items). The scale has scoring options from 0 to 10, where the higher the score, the higher the quality of life level, except for items 3, 4, and 15, which are reversely scored.

Data collection took place during the second semester of 2019. The caregivers were contacted through the outpatient palliative care program of the institution. The researchers and two previously trained research assistants invited the caregivers to participate, verified that the inclusion and exclusion criteria were met, and explained the study objectives for the participants to later sign the written informed consent. The caregiver's participation was voluntary. Once consent was obtained, the sociodemographic characterization sheet was applied, as well as the quality of life scale. This procedure was conducted in a reserved and quiet place in the institution; the application of the instrument lasted an average of 10-15 minutes.

Data analysis and treatment

The analysis was performed with the SPSS statistical package, version 24, licensed to the Universidad de Antioquia, Colombia. For the description of the demographic variables and of those related to the participants' care, descriptive statistics was resorted to, with the use of relative frequency distributions, and measures of central tendency and dispersion. For the description of the continuous quantitative variables such as age, time as a caregiver, daily hours devoted to care, and quality of life, measures of central tendency and dispersion were used, as well as 95% confidence intervals. To explore the factors associated with the caregiver's quality of life, Pearson's correlation coefficients were used, with prior compliance of the normality requirements and inversion of the scores of the answers to items 3, 4 and 15.

Ethical aspects

This study was approved by the Ethics and Research Committee of the institution where it was conducted (Approval No. 11-2018). All the participants signed the written informed consent.

RESULTS

Characteristics of the participants

A total of 208 family caregivers were included, mainly female (79%), with a mean age of 49.72 years old, with complete high school (36%), and who cared for the person with cancer since diagnosis (90%). The sociodemographic characteristics and profile of the caregivers are presented in Table 1.

Table 1 – Characteristics of the participating family caregivers – Medellín, Colombia, 2019.

Variable		Number	Percentage
Gender	Female	164	79%
	Male	44	21%
Maximum schooling level	Post-graduate studies	19	9%
	Elementary school	33	16%
	High school	74	36%
	Technical	44	21%
	University	38	18%

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Variable		Number	Percentage
Marital status	Married	97	47%
	Separated	15	7%
	Single	57	27%
	Consensual union	32	15%
	Widowed	7	3%
Occupation	Employee	44	21%
	Student	2	1%
	Household chores	111	53%
	Other	13	6%
	Autonomous worker	38	18%
Socioeconomic strata	1	9	4%
	2	52	25%
	3	94	45%
	4	34	16%
	5	14	7%
	6	5	2%
Do you care for the person since diagnosis?	No	21	10%
	Yes	187	90%
Religion	Catholic	174	84%
	Christian	15	7%
	None	17	8%
	Jehovah's Witness	2	1%
Are you the only caregiver?	No	131	63%
	Yes	77	37%

	Mean	SD*	95%CI**
Age in years old	49.72	13.836	47.82–51.62
Time as a caregiver, in years	3.029	3.34	2.1–3.87
Number of hours a day devoted to care	17.606	8.186	16.48–18.72

*Standard Deviation; **Confidence Interval

Table 2 presents the characteristics of the patients in palliative care who were under the responsibility of the study participants.

DESCRIPTION OF QUALITY OF LIFE

Table 3 presents the description of quality of life in life-threatening diseases, reported by the caregivers who participated in the study.

Table 2 – Characteristics of the patients in palliative care – Medellín, Colombia, 2019.

Variable/Type of statistical data		Number/Descriptive	Percentage
Diagnosis	Bone cancer	3	1%
	Lung cancer	23	11%
	Ovarian cancer	44	21%
	Breast cancer	28	13%
	Gastrointestinal cancer	32	15%
	Kidney cancer	3	1%
	Head and neck cancer	38	18%
	Endocrine cancer	9	4%

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Variable/Type of statistical data		Number/Descriptive		Percentage
Diagnosis	Brain cancer	9		4%
	Prostate cancer	4		2%
	Uterine cancer	3		1%
	Lymphoma	8		4%
	Myeloma	4		2%
Gender	Female	137		66%
	Male	71		34%
		Mean	SD*	95%CI
Age in years old		62.55	16.21	60.33–64.76
Karnofsky scale		62.64	6.61	61.74–63.55

*Standard Deviation

Table 3 – Quality of life of the family caregivers – Medellín, Colombia, 2019.

Quality of life	Statistical data		
	Mean	Standard Deviation	95%CI
QOLLTI-F total	119.36	21.904	116.36–122.35
Environment	15.12	4.633	14.48–15.75
Patient condition	2.84	3.214	2.40–3.28
Caregiver's own state	38.08	13.601	36.22–39.94
Caregiver's outlook	27.29	3.795	26.77–27.81
Quality of care	18.63	2.630	18.28–18.99
Relationships	17.40	3.314	16.95–17.86

Factors associated to the caregiver's quality of life

The total quality of life score in life-threatening diseases was associated to the caregiver's age in years old ($r = .307$) and to the number of daily hours devoted to care ($r = -.155$). The Environment dimension was associated to the caregiver's age in years old ($r = .244$); the Caregiver's own state dimension was associated to the patient's age ($r = .162$), to the caregiver's age ($r = .240$), and to the daily hours devoted to care ($r = -.181$); the Caregiver's outlook dimension was associated to the score of the Karnofsky scale ($r = .143$) and to the caregiver's age ($r = .228$); finally, the Relationships dimension was associated to the caregiver's age ($r = .225$). All the associations were significant, with $p < 0.05$.

DISCUSSION

In view of the characteristics of the people with advanced cancer in palliative care, this study reports a mean value of 62.64 points in the Karnofsky scale, varied cancer diagnoses, and a mean age of 62.55 years old. These characteristics are similar to those reported in a meta-analysis of eight studies, conducted in outpatient and home settings, which comprised a total sample of 2,385 patients, where an ECOG score between zero and two was reported, as well as diverse types of advanced cancer and a mean age of 64.3 years old(12).

The characteristics of the main family caregivers express a profile with female predominance, mean age of 49.72 years old, with bachelor and technical degrees, in a stable union, housewives, with greater frequency distribution in low and medium socioeconomic levels, caring for the person since diagnosis, with care responsibilities shared with other family members, and with high dedication to care in months and daily hours. The characteristics described are similar to those reported in a Colombian study(13), with the exception of dedication as single caregivers, which was lower in this study. The reason why dedication to care is not exclusive of a single caregiver in this study can be due to the fact that the study was conducted in a medium-sized city with care cultural traditions that fall on several family members, where support to the main caregiver is greater. Likewise, the characteristics of the family caregivers reported in this study are similar to those reported in a sample of Italian caregivers(14).

The quality of life levels in the caregivers of people with advanced cancer in palliative care in this study were far from optimal; the total quality of life score was between 116.36 and 122.35 points out of 160. The results of this study differ to a large extent from those reported in other studies conducted in India(15), where a mean quality of life of 63.36 (SD: 15.73) was found; in an intervention study conducted in Germany(16) with caregivers of adult individuals with cancer in the palliative phase, where the quality of life baseline was 61 (SD: 12); and also in another study conducted in Jordan(17) with family caregivers of patients with advanced cancer, which reported a mean quality of life of 82.80 points. The three aforementioned studies found show a much lower mean value than the one reported in this study.

On the other hand, the dimensions that presented lower scores in this study were Patient condition, Caregiver's own state and Environment, findings which are similar to those reported by a study conducted in the Czech Republic, where the dimensions with the worst results were Caregiver's own state and Patient condition(18). It is interesting that, although in this study the caregiver was not the only person caring for the patient, low values were presented regarding the caregiver's own state; in view of this, the evidence has documented that caring for long periods of time generates wear in the caregivers' physical and psychological health, affecting their quality of life(19).

In relation to the factors associated to quality of life, most of the studies have indicated gender as an associated factor; in particular, it has been documented that women who care for people with advanced cancer in the palliative phase obtain lower quality of life scores than men(7), a finding that was not ratified in this study. A plausible explanation is related to the gender distribution of the sample of this study, which consisted mostly of women.

The patient's and caregiver's ages and the Karnofsky index presented a positive correlation, from weak to moderate and statistically significant, with the caregiver's quality of life or some of its dimensions; in other words, the older the patient and the caregiver and the better the functional status, the better the quality of life scores. In that regard, a study reported that young family caregivers reported better quality of life levels and that caregivers of patients with a deficient functional status presented lower quality of life levels(18). On the other hand, the findings of another study conducted with Brazilian caregivers(9) are in opposition to what was found in this study regarding age as a factor related to quality of life since, in ten regression models, they did not identify age as a predictive factor for the caregiver's quality of life, nor for its dimensions. In this sense, it is herein ratified that the patient's good functional status exerts a positive influence on quality of life; however, regarding the finding about the patient's and the caregiver's ages, further research is needed that explains the nature of the relationship. An alternative explanation is the aged individuals' coping style, which has been documented with a tendency towards resignation(20), in addition to the development of resilience factors inherent to the present generation of older adults in Medellín, Colombia, who have been exposed to decades of armed conflicts(21).

The daily hours devoted to care presented a weak, negative and statistically significant correlation with the overall quality of life and with the caregiver's own state dimension. In that respect, a study(9) reported the time of daily care as a predictor of the quality of life of the caregiver of the person with cancer in palliative care, in the physical role domain, just as other authors(19) who reported lower levels of mental health and emotional well-being in caregivers who devoted more time each day providing care.

This study acknowledges several limitations. In the first place, the selection of the participants was not random, so it is up to future studies to determine if the distribution of the caregivers and the results of this study are the same in a sample selected at random. In the second place, the participants of this study were recruited from a palliative care outpatient program, where the patients' health status and their needs can be mostly stable in view of the context of patients who are hospitalized and its impact on the caregiver.

Regarding the study strengths, it is acknowledged that the sample size of 208 caregivers is larger than what is reported in other studies in the area. Likewise, the detailed description of the sample of this study will be useful to establish comparisons with future studies that assess the caregivers' quality of life.

CONCLUSION

The quality of life levels reported in this study varied from 116.36 to 122.35 (95%CI). The dimensions with the lowest scores were Patient condition (2.4–3.2, 95%CI), Caregiver's own state (36.2–39.9, 95%CI) and Environment (14.4–15.7, 95%CI). The patient's and caregiver's ages and the Karnofsky index presented a positive correlation, from weak to moderate and statistically significant, with the caregiver's quality of life or some of its dimensions. The daily hours devoted to care presented a weak, negative and statistically significant correlation with the overall quality of life and with the caregiver's own state dimension.

It is necessary to develop interventions to improve quality of life in caregivers of people with advanced cancer in the palliative phase, considering the importance of relief actions and for the management of the patient's functional dependence. It is necessary to explore the role of age as an influencing factor on the caregiver's quality of life.

RESUMEN

Objetivo: Describir la calidad de vida y factores relacionados, en una muestra de cuidadores colombianos de personas con cáncer en cuidados paliativos. **Método:** Estudio descriptivo correlacional de corte transversal, con 208 cuidadores familiares de personas con cáncer en cuidados paliativos ambulatorios en Medellín-Colombia. Se usó el instrumento de calidad de vida en enfermedades que amenazan la vida - versión cuidador familiar (QOLLTI-F). **Resultados:** La calidad de vida puntuó entre 116,36 y 122,35 (IC95%). Las dimensiones con las puntuaciones más bajas fueron del estado del paciente (2,4–3,2, IC95%), estado del cuidador (36,2–39,9, IC 95%)

y medio ambiente (14,4–15,7, IC95%). La edad del paciente, edad del cuidador e índice Karnofsky, presentaron una correlación positiva, de débil a moderada y significativa con la calidad de vida del cuidador. Las horas diarias dedicadas a cuidar, presentaron una correlación débil, negativa y significativa con la calidad de vida total y la dimensión estado del cuidador. **Conclusión:** Se requiere desarrollar intervenciones para mejorar la calidad de vida de los cuidadores de personas con cáncer avanzado en fase paliativa, considerando la importancia de acciones de relevo y manejo de la dependencia funcional del paciente.

DESCRIPTORES

Calidad de Vida; Cuidadores; Neoplasias; Cuidados Paliativos.

RESUMO

Objetivo: Descrever a qualidade de vida e fatores relacionados em uma amostra de cuidadores colombianos de pessoas com câncer em cuidados paliativos. **Método:** Estudo descritivo transversal correlacional com 208 cuidadores familiares de pessoas com câncer em cuidados paliativos ambulatoriais em Medellín-Colômbia. Foi utilizado o instrumento de qualidade de vida para doenças com risco de vida - versão cuidador familiar (QOLLTI-F). **Resultados:** A qualidade de vida foi pontuada entre 116,36 e 122,35 (IC95%). As dimensões com as pontuações mais baixas foram *status* do paciente (2,4–3,2; IC95%), *status* do cuidador (36,2–39,9; IC95%) e ambiente (14,4–15,7; IC95%). A idade do paciente, a idade do cuidador e o índice de Karnofsky apresentaram correlação positiva, fraca a moderada, e significativa com a qualidade de vida do cuidador. As horas diárias dedicadas ao cuidado apresentaram correlação fraca, negativa e significativa com a qualidade de vida total e a dimensão estado do cuidador. **Conclusão:** É necessário desenvolver intervenções para melhorar a qualidade de vida dos cuidadores de pessoas com câncer avançado na fase paliativa, considerando a importância das ações de alternância entre cuidadores e o manejo da dependência funcional do paciente.

DESCRITORES

Qualidade de Vida; Cuidadores; Neoplasias; Cuidados Paliativos.

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