Quality of life of family caregivers of bedridden older adults
Qualidade de vida de cuidadores familiares de pessoas idosas acamadas
Calidad de vida de cuidadores familiares de adultos mayores encamados

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Abstract

Objective: To assess the quality of life of family caregivers and their relationship with socioeconomic, health and care conditions.

Methods: a cross-sectional and analytical study carried out in the city of Palmas/TO, in the period of 2020-2022, with a sample of 49 family caregivers of bedridden older adults. Quality of life was assessed by the instrument "12-Item- Short- Form Health Survey" (SF-12). To verify the relationship between physical and mental components and independent variables, the t-test was used.

Results: Caregivers presented mean values of the physical component of 43.26 points (95% CI: 39.87 – 46.64) and the mental component of 50.98 points (95% CI: 47.96 – 54.00). Significant differences were found between the scores of the mental component for family dysfunction, alcohol consumption and overload, and between the physical component for multimorbidity, polypharmacy, body mass index and overload.

Conclusion: The findings of this study demonstrated a relationship between social conditions, health, care and quality of life, thus granting knowledge to health professionals to guide them in planning actions aimed at improving caregivers' quality of life.

Resumo

Objetivo: Avaliar a qualidade de vida dos cuidadores familiares e sua relação com as condições socioeconômicas, de saúde e de prestação de cuidado.

Métodos: Estudo transversal e analítico realizado na cidade de Palmas/TO, no período de 2020-2022, com amostra de 49 cuidadores familiares de idosos acamados. A qualidade de vida foi avaliada pelo instrumento "*12-Item- Short- Form Health Survey*" (SF-12). Para verificar a relação entre os componentes físico e mental e variáveis independentes, utilizou-se o Teste T.

Resultados: Os cuidadores apresentaram valores médios do componente físico de 43,26 pontos (IC 95%: 39,87 – 46,64) e no componente mental, de 50,98 pontos (IC 95%: 47,96 – 54,00). Encontraram-se diferenças significativas entre os escores do componente mental para disfunção familiar, consumo de bebida alcóolica e sobrecarga; e, entre o componente físico para multimorbidade, polifarmácia, índice de massa corpórea e sobrecarga.

Conclusão: Os achados deste estudo demonstraram relação entre condições sociais, de saúde, cuidado e qualidade de vida, concedendo assim conhecimento aos profissionais de saúde para orientá-los no planejamento de ações que visem a melhoria da qualidade de vida do cuidador.

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Conflicts of interest: nothing to declare.

Resumen

Objetivo: Evaluar la calidad de vida de los cuidadores familiares y su relación con las condiciones socioeconómicas, de salud y de prestación de cuidado.

Métodos: Estudio transversal y analítico realizado en la ciudad de Palmas, estado de Tocantins, en el período 2020-2022, con una muestra de 49 cuidadores familiares de adultos mayores encamados. La calidad de vida fue evaluada mediante el instrumento "*12-Item- Short- Form Health Survey*" (SF-12). Se utilizó el test-T para verificar la relación entre los componentes físicos y mentales y las variables independientes.

Resultados: Los cuidadores presentaron un valor promedio del componente físico de 43,26 puntos (IC 95 %: 39,87 – 46,64) y del componente mental de 50,98 puntos (IC 95 %: 47,96 – 54,00). Se observaron diferencias significativas en la puntuación del componente mental en disfunción familiar, consumo de bebida alcohólica y sobrecarga; y en el componente físico, en multimorbilidad, polifarmacia, índice de masa corporal y sobrecarga.

Conclusión: Los resultados de este estudio demostraron que existe relación entre las condiciones sociales, de salud, cuidado y calidad de vida, lo que permite que los profesionales de la salud tengan conocimientos para la planificación de acciones que busquen mejorar la calidad de vida de del cuidador.

Introduction

It is evident that at the end of the last century there were declines in mortality and fertility rates, this factor brought as a great challenge population aging. Associated with the demographic transition arise non-communicable diseases, characterized by prolonged time, which can cause functional disability.[1] This factor can lead older adults to a demand for long-term care and assistance in the development of their daily activities, thus requiring a caregiver.

Caregivers can be classified as informal or formal. Informal caregivers are the ones who dedicate care without remuneration and are usually a family member. On the other hand, formal caregivers are those paid to perform this activity.[2] The family is usually the main source of support for older adults, providing care and assistance to them.[3]

The process of caring for someone requires a series of adaptations for both caregivers and dependent individuals. Family caregivers are those who take on the task of caring most of the time suddenly, because they are the closest member and have a more intimate affective relationship or even because they are the only family member and have no option. Generally, caregivers initiate the performance of activities without mastery of techniques and knowledge related to care.[4]

This factor makes the activity more arduous, as it generates wear and tear resulting from the change in lifestyle, with restrictions on their personal lives and most of the time dedicated to care. This limits social life, thus generating an overload and directly impacting caregivers' health and quality of life.[4-6]

Quality of life is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".[7] The literature points out several factors associated with caregivers' quality of life, such as sex, age, education, recreation and leisure, lack of family support, living with older adults, sleep disorders, anxiety, psychological distress, overload, older adults' dependence level, job tenure as a caregiver, being a primary caregiver, number of hours dedicated to care, presence of sequel and diseases in older adults.[3,6, 8- 14]

Taking into account the aging population and the increasing number of caregivers, it was decided to assess family caregivers as they are the main social actors involved in the care process. The study is relevant due to the need to recognize this public in a more singular way regarding the implications caused in the quality of life and also due to the low visibility that it has in the health context, especially in Primary Health Care.

These social actors need better health promotion, with more individualized care, so that targeted interventions can be designed in which the health staff can assist in the development of knowledge, contributing to well-being, self-care and thus promoting a better quality of life.

Thus, this study aimed to assess family caregivers' quality of life and their relationship with socioeconomic, health and care conditions.

Methods

This is a cross-sectional and analytical study carried out in the municipality of Palmas, Tocantins, Brazil, from the research "*Caregivers of dependents*

older adult's in the city of Palmas". The sample was calculated based on the following criteria: sample power of 0.95, mean effect size f=0.50, significance level of 5% and addition of 10% to the initial value for predicted losses, thus estimating the minimum number of 49 caregivers.

Caregivers who were family members, aged 18 years or over and caring for an older adult (≥ 60 years old) who was bedridden and registered in Family Health Strategy in the urban area of the city of Palmas were included. Caregivers who could not be contacted three consecutive times were excluded. The caregivers were contacted by telephone to schedule the home visit, which was carried out together with a community health worker. Trained interviewers applied a semi-structured questionnaire, previously tested, containing sociodemographic and health information. The interview was conducted between January 2020 and January 2022 and lasted an average of 90 minutes. Due to the pandemic, collections were suspended in March 2020 and resumed in October 2021.

For this study, the dependent variable was quality of life, which was measured by the 12-Item Short-Form Health Survey or SF-12. This scale assesses eight different dimensions, taking into account a period of the last four weeks. Their scores allow the calculation of two components separately: physical component score (PCS) and mental component score (MCS). The scale score ranges from 0 to 100, the lower the score, the worse the quality of life. The highest scores are associated with improved quality of life.[15,16]

The following conditions were considered independent variables:

- **Sociodemographic and economic**: sex (male; female), age (continuous), education (years of education - continuous), marital status (with partner; without partner – single, divorced/separated, widowed), family income (≤ 1 minimum wage; > 1 minimum wage), cohabits with older adults (no; yes), kinship with older adults (spouse; children; daughter-in-law/son-in-law; grandchildren ; formal caregiver) and family functionality (APGAR of families). The Family APGAR consists of five dimensions:

Adaptation, Partnership, Growth, Affection and Resolve. The items are scored from 0 to 2, being: always (2), sometimes (1), never (0). Its score varies from 0 to 10 and for analysis criteria, the older adults who had a sum of ≤6 points were considered as family dysfunctional.[17]

- **Health:** multimorbidity (having two or more chronic diseases: arterial hypertension, asthma, bronchitis or emphysema, diabetes, cardiovascular diseases, osteoporosis, osteoarticular diseases, cancer and psychiatric disorders); polypharmacy (≥ use of 4 continuous medications), body mass index (≤ 18.5 kg/m²: low weight; 18.5 to 24.9 kg/m²: eutrophic; and ≥ 25 kg/m²: overweight), smoking (smoker and non-smoker), physical activity (practice of at least 150 minutes per week) and alcohol consumption (low consumption: < one day a week; moderate/high intake (one or more days per week).

- **Care provision:** daily dedication to care (≤ 12 hours; > 12 hours), receiving training or training to provide care (no; yes), time of care (≤ 4 years; > 4 years); receiving assistance in providing care (no; yes); and care burden.

Caregiver burden was assessed by the Zarit Scale, which is composed of 22 statements regarding how people feel about taking care of another person. The scale ranges from 0 to 88 points, the higher the score, the higher the level of caregiver burden.[18] In this study, overload was considered when the score was equal to or greater than 21 points.[19]

The Stata® version 17 was used for data analysis. For all statistical tests adopted, p-value ≤ 0.05 was considered. PCS and MCS were tested for normality using the Shapiro-Wilk test. To compare the means of quality of life components and qualitative independent variables, the t-test was used. The correlation between quality of life and quantitative independent variables was assessed using Pearson's correlation test.

The research was approved by the Research Ethics Committee of *the Universidade Federal de Tocantins*, under Opinion 3.138.324/2019 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 00688118.0.0000.5519. All par-

Results

A total of 49 family caregivers answered questions related to quality of life, of which 73.08% were children, 13.46% spouses, 5.77% grandchildren, 3.85% children-in-law and 3.85% siblings. Most family caregivers were women (83.67%), with a mean age of 51.02 years and with 10.74 years of study, had a partner (69.39%), reported family income ≤ 1 minimum wage (58.62%), cohabited with older adults (91.84%) and reported good family functionality (70.83%) (Table 1). Regarding quality of life, caregivers presented mean values of 43.26 points for the physical component and 50.98 points for the mental component. As for socioeconomic aspects, a significant difference was observed between family dysfunction and mental component, as shown in table 1.

In table 2, the results are described according to quality of life and health condition components. There was a predominance of non-smoking caregivers (77.55%), physically inactive (91.84%), who had low alcohol consumption (81.63%), did not have multimorbidity (69.39%), did not use polypharmacy (87.76%) and were overweight (68.29%). Significant differences were found between the mean PCS for multimorbidity (p=0.003), polypharmacy (p= 0.003) and body mass index (p=0.012), while for MCS, alcohol consumption (p=0.038).

Regarding care provision, 82.63% of caregivers dedicated more than 12 hours a day, 69.39% received help from someone to perform the care, 51.02% reported a caregiver time of ≤ 4 years and 77.78% mentioned care overload. There was a significant relationship between overload and quality of life components. Caregivers with burden had lower PCS and MCS when compared to those without burden (Table 3).

Discussion

The assessed family caregivers are mostly women, daughters and middle-aged adults, similar characteristics were identified in other studies.[2,4-6,8,9,20,21]

Table 1. Characterization of family caregivers of bedridden older adults according to quality of life components, demographic and socioeconomic aspects (n=49)

Characteristics	Total n(%)	Quality of life			
		PCS Mean (95% CI)	p-value	MCS Mean (95% CI)	p-value
Sex			0.112		0.274
Male	8(16.33)	47.91(41.23 − 54.59)		53.05(44.49 − 61.62)	
Female	41(83.67)	42.34(38.47 − 46.21)		50.47(45.41 − 55.52)	
Age, years (Mean; SD)	51.02(11.51)	-0.26*	0.073	0.25*	0.081
Years of study (Mean; SD)	10.74(5.03)	0.187*	0.199	-0.22*	0.126
Marital status			0.324		0.342
With a partner	34(69.39)	42.73(37.55 − 51.32)		50.57(46.92 − 54.22)	
Without a partner	15(30.61)	44.43(38.67 − 46.80)		51.92(45.87 − 57.96)	
Family income (n=29)			0.468		0.077
≤ 1 minimum wage	17(58.62)	43.99(37.19 − 50.79)		52.64(47.87 − 57.41)	
> 1 minimum wage	12(42.38)	44.33(39.90 − 48.75)		47.18(40.38 - 53.98)	
Living with older adults			0.308		0.412
No	4(8.16)	46.12(33.04 − 59.19)		52.11(37.24 − 66.98)	
Yes	49(91.84)	43.00(39.37 − 46.63)		50.88(47.67 − 54.09)	
Family dysfunction (n=48)			0.217		0.013
No	34(70.83)	44.22(40.33 − 48.13)		52.88(49.84 − 55.91)	
Yes	14(29.17)	41.24(33.33 − 49.15)		45.57(39.15 − 52.99)	
Total	49(100.00)	43.26(39.87 − 46.64)		50.98(47.96 − 54.00)	

PCS - physical component score; MCS - mental component score; SD – standard deviation; CI – confidence interval. *Pearson's correlation test for age and years of study. For the other variables, the t-test was used

Table 2. Description of family caregivers of bedridden older adults according to quality of life and health condition components (n=49)

Characteristics	Total n(%)	PCS Mean (95% CI)	p-value	MCS Mean (95% CI)	p-value
Smoking			0.398		0.455
No	38(77.55)	43.02(38.96 – 47.07)		50.89(47.33 – 54.45)	
Yes	11(22.45)	44.08(37.29 – 50.86)		51.30(44.69 – 57.90)	
Physical exercise			0.27/9		0.210
No	45(91.84)	43.55(40.06 – 47.05)		50.62(47.53 – 53.70)	
Yes	4(8.16)	39.90(16.43 – 63.37)		55.08(32.88 – 77.28)	
Alcohol consumption			0.419		0.038
Low consumption	40(81.63)	43.09(39.23 – 46.95)		52.24(48.97 – 55.50)	
Moderate consumption	9(18.37)	43.99(35.50 – 52.47)		45.39(37.24 – 53.54)	
Multimorbidity			0.003		0.287
No	34(69.39)	46.29(42.61 – 49.97)		51.55(48.31 – 54.79)	
Yes	15(30.61)	36.38(29.79 – 42.95)		49.69(42.42 – 56.97)	
Polypharmacy			0.001		0.579
No	43(87.76)	44.53(41.09 – 47.97)		51.09(48.04 – 54.15)	
Yes	6(12.24)	34.09(20.49 – 47.70)		50.17(34.26 – 66.08)	
Body mass index (n=41)			0.012		0.214
Eutrophy	13(31.71)	49.75(44.03 – 55.47)		49.43(43.04 – 55.82)	
Overweight	28(68.29)	40.32(35.30 – 45.35)		52.24(48.19 – 56.29)	
Total	49(100.00)	43.26(39.87 – 46.64)		50.98(47.96 – 54.00)	

PCS - physical component score; MCS - mental component score; SD – standard deviation; CI – confidence interval. P-value was obtained by the t-test

Table 3. Characterization of family caregivers of bedridden older adults according to quality of life and care provision components (n=49)

Characteristics	Total n(%)	PCS Mean (95% CI)	p-value	MCS Mean (95% CI)	p-value
Daily dedication to care			0.241		0.389
≤ 12 hours	9(18.37)	45.78(36.66 – 54.91)		50.08(40.82 – 59.34)	
> 12 hours	40(81.63)	42.69(38.90 – 46.47)		51.18(47.89 – 54.47)	
Receive help from someone			0.282		0.467
No	15(30.61)	41.77(34.23 – 49.31)		51.17(45.32 – 57.03)	
Yes	34(69.39)	43.91(40.05 – 47.76)		50.89(47.19 – 54.61)	
Job tenure as a caregiver			0.339		0.358
≤4 years	24(48.98)	43.98(39.33 – 48.62)		50.42(45.85 – 54.98)	
> 4 years	25(51.02)	42.56(37.32 – 47.80)		51.52(47.23 – 55.82)	
Caregiver burden			0.034		0.012
No	16(22.22)	47.66(42.78 – 52.54)		55.76(52.07 – 59.45)	
Yes	33(77.78)	41.12(36.70 – 45.53)		48.66(44.68 – 52.64)	
Total	49(100.00)	43.26(39.87 – 46.64)		50.98(47.96 – 54.00)	

PCS - physical component score; MCS - mental component score; SD – standard deviation; CI – confidence interval. P-value was obtained by the t-test

As a result of the culture of care, children are the main sources of support as a form of retribution of care provided by parents to children as children. [20,22] Moreover, care is associated with women as a result of attention to the home, family, children and relatives, or it can be due to the proximity of the affective relationship and degree of kinship between caregivers and dependent individuals.[6]

The care activity added to the daily activities performed by caregivers requires a series of competencies that can make this work arduous, impacting physically, generating stress, compromising health and quality of life.[3, 12]

Regarding quality of life, it was noted that family caregivers had higher mean MCS when compared to PCS. MCS involves mental health, emotional aspects, social aspects and vitality,[15] and signals the balance in the relationship between caregivers and older adults as well as the cognitive and behavioral efforts to deal with care demands.

The findings showed that caregivers with good family functionality had better scores on MCS. Family functionality refers to interpersonal relationships that characterize the identity of the family, relating to the ability to solve problems and form of demonstration of affection.[22] It is noteworthy that family functionality was the only socioeconomic condition related to quality of life in this study. Caregivers' quality of life is intrinsically related to good family functionality, since, in caring for dependent people, a good family relationship, social support provided by the family to caregivers and family maturity are key characteristics that facilitate the division and assistance of each family member in carrying out care.[23]

However, if only one family member is involved in the performance of multiple activities, it can cause emotional and biomechanical dysfunctions, thus providing a situation of vulnerability for caregivers, triggering stress.[14,23-25]

Authors suggest that care-derived stress can lead caregivers to alcohol consumption.[26] In the present study, it was noted that caregivers moderate/high alcohol consumers had worse MCS means. Given this behavior, it is necessary to understand the problematic use of alcohol during caregiver assistance in order to propose ways to help prevent risks to caregivers' health regarding care receivers, as they are more vulnerable to situations of violence and neglect of care.

PCS involves aspects such as pain and discomfort, sleep and rest, physical mobility, activities of daily living, dependence on medications, among others.[16] Considering that caregivers were in the process of aging, they are more susceptible to chronic conditions and diseases, which impact on caregivers' physical health.

A study conducted in Vitória da Conquista, Bahia, with informal caregivers of older adults, showed that there is a statistically significant association between the physical domain and the presence of health problems.[27] This result is similar to that found in this study, since caregivers with multimorbidity had lower PCS. Chronic diseases require daily self-management activities and caregivers may be less likely to comply with therapeutic control.

PCS was related to polypharmacy, sedentary lifestyle and overweight, in which caregivers with such conditions had lower scores when compared to those who did not. Care provision diverts attention and self-care tends not to be a priority. And as a burden of self-care deficit, caregivers are more likely to present worsening in physical health, such as insomnia, body weight gain and tend to postpone the search for necessary medical care, and in emotional health, such as anxiety, depressive symptoms, overload, triggering changes in caregivers' quality of life. [8,9,23,25-29]

Burden reflects the tension levels associated with care and is explained by the combination of conditions related to the caregiver's profile, context of care, coping and support, and manifestations of stress.[29] Several authors have demonstrated the negative relationship between burden and quality of life, i.e., the higher the level of burden, the lower the caregivers' quality of life.[9,24,30] The findings of this study showed this relationship to both PCS and MCS, in which caregivers with burden presented lower mean values for quality of life scores.

Among the limitations of the study, it is pointed out that the sample consisted of family caregivers of bedridden older adults and cannot be generalized to those from different contexts. The findings cannot be interpreted as causal. The results reported here suggest the need for research that better understands the risk factors that compromise family caregivers' quality of life.

Conclusion

The findings of this research showed a relationship between quality of life and social, health and care conditions. Mental component scores were related to family dysfunction and alcohol consumption. Physical component scores were related to multimorbidity, polypharmacy and body mass index. Caregivers with care overload had worse MCS and PCS for quality of life. It is noteworthy that factors related to quality of life are guiding health professionals in identifying indicators, planning and implementing strategies for prevention and promotion of self-care to family caregivers, in order to provide beneficial effects on quality of life.

Acknowledgments

Collaborations

Batista IB, Marinho JS, Brito TRP, Guimarães MSA, Silva Neto LS, Pagotto V and Nunes DP contributed to the study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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