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Quality of life of caregivers of individuals with acquired neurological disorders

Qualidade de vida dos cuidadores de pessoas com transtornos neurológicos adquiridos

Calidad de vida de los cuidadores de personas con trastornos neurológicos adquiridos

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Abstract

Introduction: Acquired neurological changes are stressful events for both the patient and their family caregivers. In many cases, patients are attended to by informal caregivers - non-specialists - thus, these caregivers require support to learn how to care for the patient and balance caregiving with their personal lives. **Objective:** To identify predictive factors of the quality of life among informal caregivers of individuals with acquired neurological disorders. **Methods:** Observational, cross-sectional study with quantitative analysis. Data collection was conducted via an online survey, which included questions on sociodemographic and health data of the caregivers. The WHOQOL-Bref and Zarit Burden Interview scales were employed. Participants were informal caregivers of individuals with acquired neurological

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conditions, of any gender, aged over 18 years, and who had been the primary caregiver for at least 6 months. Multiple linear regression was used for statistical analysis, with a significance level set at 5%. **Results:** The sample consisted of 144 informal caregivers, predominantly women with an average age of 43.7 years. Of these, 51.3% were children, with completed higher education and employed. The Caregiver burden was assessed as mild to moderate in 42.36% of caregivers. This study compiled predictors of quality of life among informal caregivers: burden level, sleep difficulties, presence of health problems, diagnosis of anxiety or depression, caregiving duration, family income, and patient use of a feeding tube. **Conclusions:** The level of burden, difficulty sleeping, the presence of health problems, the diagnosis of anxiety or depression, the time of care, family income and the use of a feeding tube by the patient were predictors for the quality of life of informal caregivers.

Keywords: Caregivers; Dementia; Stroke; Indicators of Quality of Life.

Resumo

Introdução: As mudanças neurológicas adquiridas são eventos estressantes tanto para o paciente quanto para seus cuidadores, familiares ou não. Em muitos casos, os pacientes são assistidos por cuidadores informais - não especializados - portanto, esses cuidadores necessitam de apoio para aprender a cuidar do paciente e equilibrar o cuidado com suas vidas pessoais. **Objetivo:** Identificar fatores preditivos da qualidade de vida entre cuidadores informais de indivíduos com transtornos neurológicos adquiridos. **Métodos:** Estudo observacional, transversal com análise quantitativa. A coleta de dados foi realizada por meio de uma pesquisa online, que incluiu questões sobre dados sociodemográficos e de saúde dos cuidadores. Foram empregadas as escalas WHOQOL-Bref e Zarit Burden Interview. Os participantes eram cuidadores informais de indivíduos com condições neurológicas adquiridas. Análise estatística realizada por meio de regressão linear múltipla, com nível de significância de 5%. **Resultados:** A amostra foi composta por 144 cuidadores informais, predominantemente mulheres, com idade média de 43,7 anos. Desses, 51,3% eram filhos, com ensino superior completo e empregados. A sobrecarga do cuidador foi avaliada como leve a moderada em 42,36% dos cuidadores. Este estudo reuniu preditores da qualidade de vida entre cuidadores informais: nível de sobrecarga, dificuldade para dormir, presença de problemas de saúde, diagnóstico de ansiedade ou depressão, duração do cuidado, renda familiar e uso de sonda de alimentação pelo paciente. **Conclusões:** O nível de sobrecarga, a dificuldade para dormir, a presença de problemas de saúde, o diagnóstico de ansiedade ou depressão, o tempo de atendimento, a renda familiar e o uso de sonda de alimentação pelo paciente foram preditores para a qualidade de vida dos cuidadores informais.

Palavras-chave: Cuidadores; Demência; Acidente Vascular Cerebral; Indicadores de Qualidade de Vida.

Resumen

Introducción: Los cambios neurológicos adquiridos son eventos estresantes tanto para el paciente como para sus cuidadores familiares. En muchos casos, los pacientes son atendidos por cuidadores informales - no especialistas - por lo que estos cuidadores requieren apoyo para aprender a cuidar del paciente y equilibrar el cuidado con sus vidas personales. **Objetivo:** Identificar los factores predictivos de la calidad de vida entre los cuidadores informales de individuos con trastornos neurológicos adquiridos. **Métodos:** Se trató de un estudio observacional, transversal con análisis cuantitativo. La recolección de datos se realizó a través de una encuesta en línea, que incluyó preguntas sobre datos sociodemográficos y de salud de los cuidadores. Se utilizaron las escalas WHOQOL-Bref y Zarit Burden Interview. Los participantes eran cuidadores informales de individuos con condiciones neurológicas adquiridas. Se empleó la regresión lineal múltiple para el análisis estadístico, con un nivel de significancia del 5%. **Resultados:** La muestra estuvo compuesta por 144 cuidadores informales, predominantemente mujeres con una edad media de 43,7 años. De estos, el 51,3% eran hijos, con educación superior completa y empleados. La carga del cuidador se evaluó como leve a moderada en el 42,36% de los cuidadores. Este estudio recopiló predictores de la calidad de vida entre cuidadores informales: nivel de sobrecarga, dificultades para dormir, presencia de problemas de salud, diagnóstico de ansiedad o depresión, duración del cuidado, ingreso familiar y uso de sonda de alimentación por parte del paciente. **Conclusiones:** El nivel de sobrecarga, la dificultad para dormir, la presencia de problemas de salud, el diagnóstico de ansiedad o depresión, la duración del cuidado, el ingreso familiar y el uso de sonda de alimentación por parte del paciente fueron predictores de la calidad de vida informal de los cuidadores.

Palabras clave: Cuidadores; Demencia; Accidente Cerebrovascular; Indicadores de Calidad de Vida.

Introduction

There have been numerous socioeconomic transformations in Brazil since 1960, which have altered the morbidity and mortality profiles of the population. Today, non-communicable chronic diseases (NCDs) are the leading causes of mortality in Brazil[1]. Globally, the World Health Organization (2020)[2] estimates that 70% of all deaths are attributable to NCDs. NCDs encompass chronic health conditions such as cerebrovascular diseases, cardiovascular diseases, diabetes mellitus (DM), chronic respiratory diseases, and neoplasms.

This shift is primarily attributed to population aging and cognitive impairments resulting from acquired neurological injuries, particularly from cardiovascular diseases (such as stroke), traumatic brain injuries, and the onset of dementia[3]. Although age is an important factor, recently, the discussion about premature stroke has aroused the interest of researchers, and its increase has presented an additional challenge for public health policies[4] (POTTER, 2022).

The impact of neurological changes can be either permanent or transient, necessitating the need for a caregiver to assist the patient with daily activities[5]. Family members often undertake these caregiving responsibilities, referred to as informal caregivers (ICs), who provide all necessary care without formal training and/or financial compensation for this caregiving work[6]. Caregiving is a challenging task, especially for informal caregivers who must balance it with other daily activities. This often results in symptoms such as physical fatigue, social isolation, accelerated aging (physical appearance), career abandonment, and even issues in social and emotional relationships[7].

The involvement of family members, assuming the role of caregiver promotes acceptance, security, and comfort (both physically and emotionally) for the care recipient. However, literature indicates that this role may lead to overburden. Despite their crucial role, there needs to be more public policies aimed at promoting caregiver health[8].

Caregivers must receive support not only to learn how to care for the patient but also to maintain a balance between caregiving tasks and personal life, thereby preserving the caregiver's quality of life. Studying the level of burden and quality of life of informal caregivers allows for the planning of public policies that prioritize not only patient care but also support for caregiver[9], encouraging health-promoting behaviors by informal caregivers.

Therefore, the present study aimed to investigate the predictive factors of quality of life among caregivers of individuals with acquired neurological disorders.

Method

This was an observational, cross-sectional study with quantitative analysis, approved by the Research Ethics Committee of Federal University of Sergipe (CAAE 55687222.3.0000.5546), conducted online via Google Forms from May to July 2022.

Participants were recruited using a Snowball Strategy. In this sampling method, researchers initially recruit the first participants and ask them to share the research with people who are in the same situation. The first participants were recruited through WhatsApp and social media platforms (Instagram, Facebook, and Twitter). Invitations were shared along with an informative brochure containing explanatory text, eligibility criteria, a link to access and respond to the instruments and download the informed consent form.

Inclusion criteria required participants to be informal caregivers of adult patients with acquired neurological disorders for more than 6 months, aged between 18 and 60 years, regardless of gender.

Three questionnaires were utilized:

1. Questionnaire on sociodemographic and health information of caregivers and patients with acquired neurological disorders.
2. WHOQOL-Bref quality of life questionnaire[10], consisting of 26 questions assessing global quality of life across four domains: physical, psychological, social relationships, and environmental. Responses were rated on a Likert scale ranging from 1 (very poor) to 5 (very good).
3. Zarit Burden Scale[11] used to assess caregiver burden. This questionnaire included 22 questions evaluating the caregiver's burden in terms of physical health, psychological well-being, and socio-economic aspects. Responses for questions 1 to 21 were scored as follows: 0 – never, 1 – rarely, 2 – sometimes, 3 – quite frequently, and 4 – nearly always. Question 22 had a different scoring system: 0 – not at all, 1 – a little bit, 2 – moderately, 3 – quite a bit, and 4 – extremely. The total score ranged from 0 to 88, with higher scores indicating greater caregiver burden, categorized as: 0 – 20 no burden, 21 – 40 mild to moderate burden, 41 – 60 moderate to severe burden, and 61 – 88 severe burden.

Data were analyzed descriptively and inferentially using SPSS 25.0 software. A significant level of 5% was adopted for inferential analyses. Descriptive analysis of quantitative variables included calculation of central tendency (mean and median), variability (standard deviation), and position (minimum, maximum, first, and third quartiles). For qualitative variables, absolute frequency and relative frequency in percentage were calculated. Multiple linear regression models were used to predict scores of dependent quantitative variables across quality-of-life domains. The stepwise selection was used for independent variables, and nominal categorical variables with multiple categories were converted into dummy variables. For each variable, unstandardized coefficients, standard errors, standardized coefficients (Beta), t-values, p-values, and 95% confidence intervals (CIs) are presented.

Results

This study involved 144 informal caregivers, with the following characteristics: average age of 43.7 years; 87.5% were women; 61.11% were married; 65.28% self-identified as White in terms of race/skin color; 65.28% had completed education up to higher education level; 51.3% reported caring for parents; 21.5% reported caring for children. Approximately 56.25% of caregivers reported engaging in some form of paid work, with a family income equal to or greater than five minimum wages and a reduction in income due to the COVID-19 pandemic (52.78%). Moreover, 96.53% of respondents stated they did not receive government assistance, and 75% of caregivers owned their homes. Regarding caregivers' health data, 53.39% reported no diagnosis of depression or anxiety, and 63.89% reported experiencing sleep difficulties.

Regarding caregivers' burden levels, the Zarit Scale indicated a prevalence of mild to moderate burden (42.36%), followed by moderate to severe burden (36.1%).

Concerning quality of life, similar average scores were observed across all domains studied (Table 1).

Regarding the cared-for patients, the average age was 63.24 years, 56.25% were female, and 25% had completed high school. The diagnosis of the patients included dementia (38.89%), followed by stroke (34.03%). Approximately 63.89% of the patients had mobility difficulties, although only 25.69% were bedridden. Regarding feeding, 85.42% of the patients did not have difficulty feeding themselves and did not require a feeding tube. In terms of communication, 77.08% of the patients were able to speak clearly, and 77.08% had good comprehension during conversations.

Table 1. Description of the quality-of-life domains according to the WHOQOL-Bref questionnaire.

Domain	Average	SD	Minimum	Maximum	1Q	Median	3Q
Physical	12.58	3.02	4.00	19.43	10.29	13.14	14.29
Psychological	11.77	3.07	5.33	19.33	9.33	12.00	14.00
Social Relationships	11.12	3.72	4.00	20.00	8.00	10.67	14.33
Environment	12.55	2.60	5.00	19.00	11.00	12.50	14.50
Self-assessment of QoL	11.78	3.56	4.00	20.00	10.00	12.00	14.00
TOTAL	12.15	2.55	5.54	18.31	10.31	12.23	14.15

Legend: SD=standard deviation; 1Q=first quartile; 3Q=third quartile.

Table 2 presents the results of the predictive analysis of the physical domain of quality of life in informal caregivers of people with acquired neurological disorders. The final multiple linear regression model identified five variables as statistically significant predictors with a negative impact on the physical domain of quality of life: having trouble sleeping, burden level (Zarit), having health issues, the patient's use of a feeding tube, and a diagnosis of depression or anxiety. All results reflect the associations adjusted in the final model.

Table 2. Predictive analysis of the physical domain of quality-of-life in informal caregivers of people with acquired neurological disorders.

	Unstandardized Coefficients		Standardized Coefficients	t	p-value	95.0% CI for B	
	B	Standard error	Beta			Lower limit	Upper limit
Do you have trouble sleeping?	-2,471	0,412	-0,395	-6,003	0,000	-3,284	-1,657
Burden Level – Zarit	-0,058	0,012	-0,306	-4,906	0,000	-0,081	-0,035
Do you have any health issues?	-1,114	0,367	-0,185	-3,032	0,003	-1,841	-0,388
Does the patient use a feeding tube?	-1,473	0,494	-0,173	-2,982	0,003	-2,449	-0,496
Do you have any diagnosis of depression or anxiety?	-0,914	0,388	-0,152	-2,357	0,020	-1,681	-0,147

Legend: Final statistically significant model of multiple linear regression; CI=confidence interval.

Table 3 presents the results of the predictive analysis of the psychological domain of quality of life in informal caregivers of people with acquired neurological disorders. The final multiple linear regression model identified six variables as statistically significant predictors: burden level (Zarit), having trouble sleeping, other diagnoses of the cared-for person, length of caregiving (years or months), a diagnosis of depression or anxiety, and the patient's use of a feeding tube.

Table 3. Predictive analysis of the psychological domain of quality-of-life in informal caregivers of people with acquired neurological disorders.

	Unstandardized Coefficients		**Standardized coefficients**	**t**	**p- value**	**95.0% CI for B**	
	B	**Standard error**	**Beta**			**Lower limit**	**Upper limit**
Burden Level - Zarit	-0.065	0.013	-0.338	-4.830	0.000	-0.092	-0.038
Do you have trouble sleeping?	-2.011	0.449	-0.316	-4.482	0.000	-2.899	-1.124
Other diagnoses of the cared-for person	-2.404	0.744	-0.209	-3.231	0.002	-3.876	-0.933
How many years or months has the person you are caring for been under your care?	0.104	0.041	0.168	2.549	0.012	0.023	0.184
Do you have any diagnosis of depression or anxiety?	-0.950	0.430	-0.155	-2.212	0.029	-1.800	-0.101
Does the patient use a feeding tube?	-1.210	0.552	-0.140	-2.195	0.030	-2.301	-0.120

Legend: Final statistically significant model of multiple linear regression; CI=confidence interval.

Table 4 presents the results of the predictive analysis of the social relationships domain of quality of life in informal caregivers of individuals with acquired neurological disorders. The final multiple linear regression model identified four variables as statistically significant predictors: burden level (Zarit), having trouble sleeping, length of caregiving (years or months), and other diagnoses of the cared-for person.

Table 4. Predictive analysis of the social relationships' domain in quality-of-life for informal caregivers of individuals with acquired neurological disorders.

	Unstandardized Coefficients		**Standardized Coefficients**	**t**	**p-value**	**95.0% CI for B**	
	B	**Standard error**	**Beta**			**Lower limit**	**Upper limit**
Burden Level - Zarit	-0.105	0.017	-0.451	-6.050	0.000	-0.140	-0.071
Do you have trouble sleeping?	-1.468	0.558	-0.190	-2.633	0.009	-2.571	-0.366
How many years or months has the person you are caring for been under your care?	0.144	0.053	0.192	2.724	0.007	0.040	0.249
Other diagnoses of the cared-for person	-2.518	0.976	-0.180	-2.580	0.011	-4.447	-0.588

Legend: Final statistically significant model of multiple linear regression; CI=confidence interval.

Table 5 presents the results of the predictive analysis of the environmental domain of quality of life in informal caregivers of people with acquired neurological disorders. The final multiple linear regression model identified four variables as statistically significant predictors: burden level (Zarit), family income greater than or equal to R$ 5000.00, having trouble sleeping, and completed higher education.

Table 5. Predictive analysis of the environmental domain of quality-of-life in informal caregivers of people with acquired neurological disorders.

	Unstandardized Coefficients		**Standardized Coefficients**	**t**	**p-value**	**95.0% CI for B**	
	B	**Standard error**	**Beta**			**Lower limit**	**Upper limit**
Burden Level - Zarit	-0.056	0.012	-0.343	-4.832	0.000	-0.079	-0.033
Family income greater than or equal to R$ 5000.00	1.501	0.363	0.290	4.140	0.000	0.784	2.218
Do you have trouble sleeping?	-1.204	0.384	-0.223	-3.138	0.002	-1.962	-0.445
Completed Higher Education	1.101	0.491	0.156	2.244	0.026	0.131	2.072

Legend: Final statistically significant model of multiple linear regression; CI=confidence interval.

Discussion

The literature asserts that the profile of informal caregivers is predominantly composed of middle-aged women (between 50 and 55 years old), married, and daughters of the cared-for patient[12]. These findings align with the results of this study – most participating caregivers are women, although the average age is slightly younger than reported. The age difference may be explained by the exclusion criteria of this study (caregivers over 60 years old), aimed at reducing biases related to functional losses that normal aging brings, such as decreased physical, functional, and cognitive abilities.

In this study, most participants self-identified as White, contradicting findings from the Brazilian Institute of Geography and Statistics[13], which indicates a larger population of mixed-race and Black individuals in Brazil, as well as other studies with similar demographics[14].

Regarding education level, there was a disparity compared to literature results, which show that most caregivers have low education levels ranging from illiteracy to incomplete elementary education, unlike this study where the majority had completed higher education[15].

The disparity in education levels and higher prevalence of White individuals may be attributed to the chosen data collection method for the research, which was online survey. This method involved disseminating the questionnaire online, either through email registration, website promotion, or social media. Post-COVID-19 pandemic, there has been an increase in the use of this data collection method. Thus, participants needed to be literate and have a minimum level of knowledge and access to information[16].

In the current study, the majority of caregivers reported having some form of paid work, while other studies found contrasting data[7,17]. The monthly income value aligns with national studies, showing most caregivers have no individual income or earn less than a minimum wage[16]. The absence of government assistance to these families is because family income exceeds the threshold to receive benefits. Informal caregivers with higher levels of education and income often outsource part of their care, but in this study, conducted during the pandemic, they were the largest group. Possibly the caregivers participating in this study no longer had institutional support for care due to fear of contagion or due to reduced income and consequent loss of access to private services.

Regarding family income and education level, this study presented a different result than what the literature shows[18]: it mainly describes a population with a medium financial income of up to two minimum wages and low education (elementary education). Both are related to the environmental quality of life domain, which concerns physical safety, financial resources, availability and quality of health and social services, opportunities to acquire new information and skills, and participation in recreational/leisure opportunities.

The literature links caregiver competence level to income and education, implying that informal caregivers with higher education and better purchasing power provide higher-quality care[18]. Financially disadvantaged families tend to be more vulnerable due to established expenses and additional medical costs for a sick family member, which differs from the population studied in this research. It also states that low education level can hinder understanding of the illness and proper caregiving practices, besides affecting access to information that could improve quality of life. Thus, it confirms that education acts as a protector, enabling caregivers to provide a higher standard of care through knowledge and available income

In terms of caregiver health, a higher prevalence of insomnia was observed. The presence of this alteration in the studied population can be attributed to work demands, as caregivers need to balance their work, leisure activities, health care, and caregiving responsibilities[19].

Regarding caregiver burden level, the presence of mild to moderate burden corroborates findings in Brazilian literature[1,7,20]. The presence of burden indicates a disturbance in managing the physical and cognitive dependencies of loved ones, along with physical, mental, and socioeconomic issues. This also includes managing social relationships and maintaining emotional balance[20].

Difficulty sleeping and burden level were common predictors for the physical, psychological, and environmental domains, self-assessment, and overall quality of life; these data align with the literature[21]. The literature states that caregivers often feel overwhelmed due to the time spent caring for and protecting patients, thereby neglecting their own needs, such as the need for sleep[22]. There is a strong link between nighttime care and caregiver burden, which consequently affects their quality of life[21].

The act of caregiving directly impacts the caregiver's life. This population often exhibits poor physical health, frequent medication use, high rates of depression and/or anxiety, lower life satisfaction, and feelings of burden, which align with the findings of this study. The presence of health problems was also a statistically significant predictor for assessing quality of life in the physical domain. The lack of self-care is associated with the presence of health problems. Caring for others requires commitment and time, and it is common for caregivers to neglect their own health[18].

The caregiver's quality of life in the physical domain may be related to the degree of dependence of the cared-for patient. There is an inverse relationship between the degree of dependence and caregiver burden, meaning that the more independent the patient, the less physical burden for the caregiver. Such a finding may explain why the use of feeding tubes is a predictive variable for the physical domain of quality of life[23].

In addition to burden level and difficulty sleeping, other variables influencing quality of life in the psychological domain include duration of caregiving, presence of depression and/or anxiety, and patient feeding tube use. The literature indicates that caregivers who have been in their role for a shorter period experience a higher burden. On the other hand, studies have shown how restrictions on social activities and coping with difficult situations keep caregivers' hostage to burden and dysfunctional symptoms. In other words, the longer time spent on consistently problematic activities, the higher the risk of developing physical and psychological illnesses. It is essential to understand their capabilities and limitations and to maintain self-care as a routine[24].

To illustrate the occurrence of these diseases, the data from this research point to caregivers diagnosed with depression and/or anxiety. The significant correlation of this diagnosis with quality of life may be related to the emotional and affective suffering experienced by this population. The exhausted caregiver tends to develop stress, feelings of guilt, impatience, and the accumulation of these problems directly impacts their psychological health[24].

The caregiver's social relationships are interconnected with sleep difficulties, level of overload, and time spent providing care. The literature highlights the difficulty in reconciling personal demands with daily care activities. Routine and time spent providing care reduce the space needed for personal activities. There is a need to promote ways of dividing and reorganizing care in search of a balance between the caregiver's well-being[25].

Social relationships are of utmost importance for a better quality of life for the population studied. Social interaction within and outside the family, religious activities, reading, watching TV and radio, moments of recreation, relaxation, and rest are necessary for this population[26] (Mattos et al, 2020).

Social support is extremely important for the development of a better quality of life, whether it be affective, instrumental, or in the form of support in coping with problems[27] (Ximenes et al, 2022).

There is also a need to organize daily activities so that the routine includes care activities with personal activities. Thus, there is an improvement in the physical and psychological well-being of the caregiver, which benefits not only them, but also those receiving care[22].

The prevalence of mobility difficulties among the cared-for patients aligns with studies in the field, showing that functional sequelae are common in the progression of dementia. However, the number of post-stroke patients was also significant in this study. The literature confirms this as one of the leading causes of hospitalizations and morbidity and mortality among the Brazilian population. Approximately 90% of survivors exhibit multiple cognitive, language, and motor sequelae[28].

The characterization of study participants does not allow for generalization of results, as it does not represent an entire population, given that the data collection method covered a population with access to information and a certain level of literacy. Thus, more studies are needed in this field to enable a specific initiative to promote a clear policy that protects informal caregivers, aiming to promote health aspects that predict a better quality of life for this population.

Public policies can play a key role in supporting overburdened caregivers by promoting measures aimed at improving their quality of life and reducing the negative impacts associated with their role. Some possible actions include: Financial support and social benefits: offering subsidies, financial aid or tax incentives to offset the costs associated with care; implementing social security protection programs for caregivers, guaranteeing labor rights, are examples of public measures.

Conclusion

The level of burden, difficulty sleeping, the presence of health problems, the diagnosis of anxiety or depression, the time of care, family income and the use of a feeding tube by the patient were predictors for the quality of life of informal caregivers.

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