# BURDEN AND QUALITY OF LIFE OF CAREGIVERS OF INDIVIDUALS WITH CHRONIC STROKE

***SOBRECARGA E QUALIDADE DE VIDA DE CUIDADORES DE INDIVÍDUOS COM ACIDENTE VASCULAR CEREBRAL CRÔNICO***

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## ABSTRACT

**Objective:** To analyze the burden and quality of life (QoL) perceived by caregivers, the correlation with the degree of disability in individuals with chronic stroke, and their impairment in activities of daily living. **Methods:** A cross-sectional analytical study was conducted at the Specialized Rehabilitation Center (CER IV-IMIP, Recife, Pernambuco, Brazil). Informal primary caregivers were evaluated for burden and QoL after the assessment of the functional capacity or disability of their respective individual with chronic stroke. Individuals were considered chronic at least six months after the stroke. The International Classification of Functioning (ICF), the Informal Caregiver Burden Assessment Questionnaire (QASCI), and the World Health Organization QoL-BREF (WHOQOL-BREF) were used to evaluate QoL. Statistical analyses were performed using the Shapiro-Wilk test with a significance level of $p < 0.05$ (SPSS). **Results:** Thirty-eight informal primary caregivers were assessed, and most reported a high burden (mean score, 102.92). Regarding QoL, individuals were rated between "needs improvement" and "fair." A significant positive correlation was observed between caregiver burden and the "body functions" domain. **Conclusion:** Caregivers of individuals with chronic stroke and disabilities reported a substantial workload burden and a negative impact on their QoL.

**Keywords:** Caregivers; Stroke; Quality of life.

## RESUMO

**Objetivo:** Analisar a sobrecarga e qualidade de vida percebida por cuidadores, correlacionando-as com o grau de deficiência dos indivíduos com acidente vascular cerebral crônico e seu comprometimento nas atividades de vida diária. **Métodos:** Um estudo transversal e analítico foi desenvolvido no Centro Especializado em Reabilitação CER IV-IMIP (Recife – PE). Foram avaliados trinta e oito cuidadores primários informais, quanto à sobrecarga e qualidade de vida após a avaliação de seus respectivos pacientes, quanto a sua capacidade ou incapacidade funcional. Foram considerados crônicospacientes pós acidente vascular cerebral (AVC) crônico, com mais de 6 meses de lesão. Foram utilizados a Classificação Internacional da Funcionalidade (CIF), Avaliação da Sobrecarga do Cuidador Informal (QASCI), e a Avaliação da Qualidade de Vida (WHOQOL-BREF). As análises estatísticas foram feitas com o teste Shapiro-Wilk com $p<0,05$ (SPSS). **Resultados**: Foram avaliados 38 cuidadores primários informais, os quais, em sua maioria, relataram "sobrecarga intensa" (média de 102,92). Em relação à qualidade de vida, a maioria encontra-se entre "necessita melhorar" e "regular". Houve correlação positiva significativa, expressando relação direta entre a sobrecarga do cuidador e o item "função do corpo". **Conclusão:** Cuidadores de indíviduos com AVC crônico que apresentam deficiências, relatam sobrecarga de trabalho e interferência na sua qualidade de vida.

**Palavras-chave:** Cuidador; Acidente vascular cerebral; Qualidade de vida

## INTRODUCTION

Considering the changes in the epidemiological profile in Brazil over the past decades, circulatory system diseases are among the leading causes of death, such as stroke, leading to an increase of individuals with neurological sequelae and dysfunctions[1-5].

Most individuals who survive a stroke experience motor, sensory, cognitive, or behavioral sequelae[1,4,5]. Functional deficits significantly interfere with daily life, with a loss or reduction in functional capacity (ability to make decisions and manage their life). This functional disability results in dependence on activities of daily living (ADL) due to difficulties in performing them without assistance[3-6].

Furthermore, due to limited financial resources to hire professional caregivers or family arrangements, the responsibility of providing permanent and ongoing care for the dependent individual often falls to a family member, referred to as the informal primary caregiver[2,4,7]. However, this family member often has limited knowledge of this role, which negatively affects their physical and mental health[2,8,9].

In this context, the functional dependency of these individuals ranges from the need for assistance or supervision in ADL to complete dependence[10,11], impacting the quality of life (QoL) of caregivers[12].

The International Classification of Functioning (ICF) is based on a biopsychosocial approach centered on the patient, encompassing the biological, individual, and social perspectives that influence health conditions, functionality, and human disability[13,14].

Moreover, the Informal Caregiver Burden Assessment Questionnaire (QASCI) was used to assess the burden of informal caregivers. The instrument includes information on health, social and personal life, financial situation, emotional status, and the type of relationship with the individual.

For QoL assessment, the World Health Organization QoL (WHOQOL-BREF) was used for the perception of individuals across various groups and situations[15].

Thus, investigating relevant aspects and events that may compromise the physical and mental health of caregivers is crucial, considering the need for appropriate support and optimization of the QoL.

Therefore, this study aimed to analyze the burden and perceived QoL of caregivers, correlating with the degree of disability in individuals with chronic stroke and their impairment in ADL.

## METHODS

A cross-sectional, analytical study was conducted at the Specialized Rehabilitation Center (CER IV-IMIP, Recife, Brazil) from October 2018 to August 2019. The study was approved by the ethics committee in human research of IMIP (CAAE: 01904618.8.0000.5201). Individuals were included after the presentation, reading, and signing of the informed consent form following the resolution 466/12.

Individuals with chronic stroke (i.e., at least six months post-event) were assessed regarding their functional capacity or disability. Subsequently, their respective caregivers were evaluated for burden and QoL. The inclusion criteria were being the primary informal caregiver of an individual with chronic stroke without financial compensation and being under follow-up at CER IV – IMIP. Caregivers who had difficulty understanding the questionnaire and those caring for individuals who had died, been discharged, or withdrawn from the service during data collection were excluded from the study.

To classify the functionality or disability of individuals and factors that may influence their ability to perform ADL, the standard tool for Interdisciplinary Neurological Assessment was used based on the ICF.

First, an active search was conducted with the therapists for individuals with chronic stroke being monitored in the service. The lesion duration was identified using the medical records. Caregivers who met the inclusion criteria responded to the QASCI and WHOQOL-BREF instruments.

Statistical analysis was performed with data expressed as absolute and percentage frequencies for categorical variables and as measures of central tendency (mean, standard deviation [mean ± SD], median, 25$^{th}$, and 75$^{th}$ percentiles) and range (minimum and maximum values) for numerical variables. To assess significant associations between two numerical variables, correlation coefficients were calculated, and Student's t-test was used to verify the null hypothesis of absence of correlation. Pearson correlation was used for normal data, and Spearman

correlation was used when normality was rejected in at least one of the variables. Normality was assessed using the Shapiro-Wilk test.

The significance level was $p < 0.05$ and the analysis was performed using IBM SPSS software (Version 23.0, SPSS Inc., Woking, Surrey, UK).

## RESULTS

Thirty-eight individuals with chronic stroke were assessed regarding their functional capacity or disability, and their respective caregivers were evaluated for burden and QoL. Table 1 presents the results for "body functions" and "activities and participation" (including "mobility" and "self-care") as related to the ICF. Items "body functions related to muscle tone" and "dressing" showed the highest percentages for "severe disability", 34.2% and 36.8%, respectively. Related to a "complete disability", 36.8% of individuals cited the item "walking".

The mean scores for the physical, psychological, and social domains shown in Table 2 demonstrated that caregivers identify their QoL as "fair"; only the environmental domain was rated as "needs improvement". Furthermore, 55.4% of the caregivers were classified with an "intense burden".

Table 3 shows that none of the caregivers rated their QoL as "very good" in the "physical", "psychological", and "environmental" domains; 78.9% and 81.6% reported physical and psychological domains as "needs improvement" or "fair", respectively. In the social domain, despite one caregiver rating their QoL as "very good," 81.6% considered it as "needs improvement" or "fair".

Table 4 showed a significant positive correlation between the caregiver burden score and "body functions," indicating a direct relationship between caregiver burden and the level of dependency of the patient.

**Table 1.** Assessment of questions related to "body functions" and "activities and participation" according to the level of disability.

| Variables | Level of disability | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | None | | Mild | | Moderate | | Severe | | Complete | |
| | n | %(1) | n | %(1) | n | %(1) | n | %(1) | n | %(1) |
| **Body functions** | | | | | | | | | | |
| Body functions related to muscle strength | 2 | 5.3 | 11 | 28.9 | 12 | 31.6 | 12 | 31.6 | 1 | 2.6 |
| Body functions related to muscle tone | 6 | 15.8 | 9 | 23.7 | 9 | 23.7 | 13 | 34.2 | 1 | 2.6 |
| **Activity and participation: mobility** | 11 | 28.9 | 12 | 31.6 | 7 | 18.4 | 5 | 13.2 | 3 | 7.9 |
| Transferring oneself while lying down | 7 | 18.4 | 11 | 28.9 | 9 | 23.7 | 6 | 15.8 | 5 | 13.2 |
| Transferring oneself from sitting to standing | 6 | 15.8 | 8 | 21.1 | 12 | 31.6 | 8 | 21.1 | 4 | 10.5 |
| Maintaining a sitting position | 27 | 71.1 | 7 | 18.4 | 1 | 2.6 | 1 | 2.6 | 2 | 5.3 |
| Transferring oneself while sitting | 12 | 31.6 | 14 | 36.8 | 4 | 10.5 | 4 | 10.5 | 4 | 10.5 |
| Maintaining a standing position | 2 | 5.3 | 18 | 47.4 | 6 | 15.8 | 5 | 13.2 | 7 | 18.4 |
| Walking | 6 | 15.8 | 3 | 7.9 | 10 | 26.3 | 5 | 13.2 | 14 | 36.8 |
| **Self-care** | | | | | | | | | | |
| Bathing | 11 | 28.9 | 4 | 10.5 | 13 | 34.2 | 4 | 10.5 | 6 | 15.8 |
| Dressing | 7 | 18.4 | 5 | 13.2 | 5 | 13.2 | 14 | 36.8 | 7 | 18.4 |
| Caring for body parts | 7 | 18.4 | 12 | 31.6 | 10 | 26.3 | 3 | 7.9 | 6 | 15.8 |
| Eating | 17 | 44.7 | 11 | 28.9 | 5 | 13.2 | 2 | 5.3 | 3 | 7.9 |
| Drinking | 26 | 68.4 | 6 | 15.8 | - | - | 4 | 10.5 | 2 | 5.3 |
| Managing toileting needs | 14 | 36.8 | 13 | 34.2 | 4 | 10.5 | 3 | 7.9 | 4 | 10.5 |

(1) The percentage values were calculated based on the total sample (n = 38).

**Table 2.** Domains of the WHOQOL-BREF and caregiver burden.

| Variable | Mean ± SD (CV) | Median (P25; P75) |
|---|---|---|
| Physical | 54.98 ± 18.20 (33.10) | 51.79 (41.96; 65.18) |
| Psychological | 57.46 ± 16.89 (29.39) | 58.33 (41.67; 70.83) |
| Social | 50.22 ± 21.70 (43.21) | 50.00 (33.33; 60.42) |
| Environmental | 47.29 ± 13.88 (29.35) | 46.88 (34.38; 56.25) |
| Caregiver burden (QASCI) | 102.92 ± 16.90 (16.42) | 107.50 (86.50; 115.50) |

WHOQOL-BREF: "needs improvement" (0 to 49.99%); "fair" (50% to 74.99%); "good" (75.0% to 99.99%); and "very good" (100%). QASCI: scores < 46 are considered "no burden"; between 46 and 56, "mild burden"; and "severe burden" if > 56.

**Table 3.** Classification of caregivers according to the domains of the WHOQOL-BREF.

| Domains | Needs improvement | | Fair | | Good | | Very good | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| Physical | 16 | 42.1 | 14 | 36.8 | 8 | 21.1 | - | - |
| Psychological | 12 | 31.6 | 19 | 50.0 | 7 | 18.4 | - | - |
| Social | 13 | 34.2 | 18 | 47.4 | 6 | 15.1 | 1 | 2.6 |
| Environmental | 20 | 52.6 | 17 | 44.7 | 1 | 2.6 | - | - |

**Table 4.** Spearman correlation between the total score of caregiver burden and the mean scores related to body function, activities, and participation.

| Variable | Total caregiver burden score |
|---|---|
| Body function | 0.360 (p =0.027*) |
| Mobility | 0.242 (0.143) |
| Self-care | 0.288 (0.080) |

## DISCUSSION

The inversion of the demographic pyramid, increased life expectancy, and the high incidence of individuals with stroke highlight the importance of studies on the QoL of caregivers[16]. Stroke results in a reduction or even a loss of functional capacity, directly influencing the ability to perform ADL independently. Most individuals experience motor impairments that affect their functional capacity, leading to deficits in occupational performance and dependency on basic and instrumental ADL.

From 38 individuals evaluated, only two did not have impairments in muscle strength or tone. Oliveira and Silveira observed that, following a stroke, individuals experience structural changes that limit their daily activities and social participation. Motor impairments (e.g., muscle weakness, spasticity, and abnormal movement patterns) may hinder or prevent transfers, ambulation, and the performance of basic and instrumental ADL, leading to physical dependence. These findings corroborate the profile of the individuals in our study and are consistent with Morais et al. (2012)[5] and Pereira et al.[5-7].

Regarding psychological burden, the present study supports a systematic review of interventions for caregivers of stroke survivors, in which mental health is the most negatively affected domain due to the demands of caregiving[5,6,10]. The psychological domain was the most impacted among caregivers in this study, with a mean score of 57.46 (± 16.89). Similar results were reported by Costa et al. (2015)[4], indicating a significant psychological and social impact on the QoL of caregivers, increasing the susceptibility to signs and symptoms of depression and anxiety[17].

In the present study, 78.9% of caregivers reported a QoL classified as "fair" or "needs improvement" in the physical domain. This finding is probably related to the highest mean levels of severe and complete impairments observed in functions of body

strength and muscle tone and activities such as walking and dressing. These tasks often require the presence of the caregiver and physical effort, particularly during transfers, which directly affects their QoL.

Moreover, individuals with functional failures from chronic pathologies frequently experience a slower disease progression, with episodes referred to as "crises of need". At each crisis, their functional capacity may deteriorate without recovery, leading to high dependency[4].

The QoL of the caregiver is affected by work overload, reduced family income, limited social and leisure activities, and the anticipation of future health problems, contributing to further deterioration in well-being.

Caregivers may be exposed to stress factors such as the lack of adequate guidance or support, reduced social and leisure activities, financial difficulties, and family dysfunction. Supporting this, 81.6% of caregivers scored "needs improvement" and "fair" in the social domain. Similarly, Morais et al. (2012)[5] reported that 80.3% of caregivers experienced disruptions in social and leisure activities, 49.2% stopped receiving or reduced visits at home, 47.5% did not maintain a good relationship with family members, and 31.1% had lost friendships[5].

A higher physical burden was reported, probably due to the degree of functionality and dependency of individuals[18]. This study reported an intense mean burden (mean > 56) according to the QASCI instrument. In addition, a positive and significant correlation was found between caregiver burden and body functions (muscle strength and tone), indicating that increased physical impairment in the individual leads to a higher caregiver burden due to the need for more assistance. Thus, caregivers are continuously required, considering the limited functional capacity of the individual[5]. Costa et al. (2015)[4] observed that the functional disability of individuals with chronic stroke, measured using the Barthel index, demonstrated increased caregiving requirements[17].

Furthermore, the treatment with regular and guided physical activities improved muscle fitness and functional capacity for daily activities. Additionally, it contributed to mental health, encouraging them to live with their limitations[18]. The increase in the mean functional capacity from 34.16 to 84.72 after six months of regular physical activity and the increase in the mean score from 45.55 to 94.00 in the "mental health" domain are evidence observed in a study that correlated QoL with physical exercise in individuals with chronic stroke[11]. This improvement may also benefit the health of caregivers, as a better overall health of the individual requires less of the caregiver, thereby reducing the care routine[19-23].

## CONCLUSION

The caregivers reported an intense burden and a significant impact on their QoL, being at risk for physical and mental health problems. The act of caregiving itself is stressful, as it demands time and effort and may be exacerbated according to the functional capacity of the individual. Therefore, the care provided to individuals with chronic stroke needs changes, including actions from healthcare professionals at different levels of care.

## AUTHOR CONTRIBUTIONS

**TMM**: Conceptualization, data acquisition, writing – original draft. **MROL and AMVCL**: Supervision, writing - review, and editing. All authors read and agreed with the final version of the manuscript.

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