

Perception of quality of life after stroke

Percepção de qualidade de vida após acidente vascular cerebral

Percepción de calidad de vida después de un ictus

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Abstract

Introduction: Stroke is considered one of the main public health problems in the world, becoming the second leading cause of mortality in several countries, causing temporary or permanent physical disability. **Objective:** To analyze the perception of quality of life of subjects after stroke. **Method:** This is a quantitative, descriptive, cross-sectional study. For the current study, literature searches were carried out in different databases. Data collection was performed via the institution's own electronic medical record, taking into account the inclusion and exclusion criteria. For the last stage of data collection, subjects eligible to participate in the study answered some questions through an adapted and semi-structured questionnaire, containing questions prepared by the author himself, and contact was made by telephone. **Results:** A total of 145 medical records were verified, 34.4% of the subjects were part of this sample. Using a five-point satisfaction scale, it was possible to measure the quality of life perception index, and using the modified Rankin scale (mRS), it was possible to analyze the level of disability encompassing the subjects' daily life activities after stroke. **Conclusion:** In this study, stroke affected the elderly population more frequently. Functional changes, mental and behavioral symptoms, and changes in these symptoms influence the perception of quality of life. It is essential to conduct more in-depth studies with new methodologies, which emphasize the performance of new research focused on the assessment of QoL in people affected by stroke.

Keywords: Stroke; Swallowing disorders; Dysphagia, Aphasia, Dysarthria; Quality of life.

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Authors' contributions:

DSN: Research design; data collection; article writing; translation.

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Resumo

Introdução: O Acidente Vascular Cerebral (AVC) é considerado um dos principais problemas de saúde pública no mundo, tornando-se a segunda maior causa de mortalidade em vários países, ocasionando incapacidade física temporária ou permanente. **Objetivo:** Analisar a percepção de qualidade de vida dos sujeitos após AVC. **Método:** Trata-se de um estudo quantitativo, descritivo, transversal. Para atualização deste estudo, foram realizadas buscas na literatura em diferentes bases de dados. As coletas de dados foram realizadas via prontuário eletrônico próprio da instituição, levando em consideração os critérios de inclusão e exclusão. Para a última etapa da coleta de dados, os sujeitos aptos a participarem do estudo responderam algumas perguntas por meio de um questionário adaptado e semiestruturado, contendo questões elaboradas pelo próprio autor, sendo o contato realizado via telefone. **Resultados:** Verificou-se 145 prontuários, 34,4% dos sujeitos fizeram parte desta amostra. Por meio de uma escala de satisfação de cinco pontos, foi possível mensurar o índice de percepção de qualidade de vida, e pela escala Rankin modificada (ERM), foi possível analisar o nível de incapacidade englobando as atividades de vida diária dos sujeitos após AVC. **Conclusão:** Neste estudo, o AVC acometeu de forma superior o público adulto-idoso. Alterações funcionais, sintomas mentais e comportamentais, sendo a alteração desses sintomas influenciadores na percepção de qualidade de vida. É imprescindível realizar estudos mais aprofundados com novas metodologias, que deem ênfase à realização de novas pesquisas focadas na avaliação da QV em pessoas afetadas por AVC.

Palavras-chave: Acidente Vascular Cerebral; Transtornos de deglutição; Disfagia, Afasia, Disartria; Qualidade de vida.

Resumen

Introducción: El accidente cerebrovascular es considerado uno de los principales problemas de salud pública en el mundo, convirtiéndose en la segunda causa de mortalidad en varios países, ocasionando discapacidad física temporal o permanente. **Objetivo:** Analizar la percepción de la calidad de vida de los sujetos tras un ictus. **Método:** Se trata de un estudio cuantitativo, descriptivo, transversal. Para actualizar este estudio se realizaron búsquedas bibliográficas en diferentes bases de datos. La recolección de datos se realizó a través de la historia clínica electrónica propia de la institución, teniendo en cuenta los criterios de inclusión y exclusión. Para la última etapa de recolección de datos, los sujetos elegibles para participar en el estudio respondieron algunas preguntas mediante un cuestionario adaptado y semiestructurado, conteniendo preguntas preparadas por el propio autor, realizándose el contacto vía telefónica. **Resultados:** Se verificaron 145 historias clínicas, el 34,4% de los sujetos formaron parte de esta muestra. Mediante una escala de satisfacción de cinco puntos, fue posible medir el índice de percepción de la calidad de vida, y mediante la escala de Rankin modificada (mRS), fue posible analizar el nivel de discapacidad que abarca las actividades de la vida diaria de los sujetos luego de un accidente cerebrovascular. **Conclusión:** En este estudio el accidente cerebrovascular afectó con mayor frecuencia a la población de edad avanzada. Cambios funcionales, síntomas mentales y conductuales, influyendo los cambios en estos síntomas en la percepción de la calidad de vida. Es fundamental realizar estudios más profundos con nuevas metodologías, que enfatizen el desempeño de nuevas investigaciones enfocadas a la evaluación de la CV en personas afectadas por accidente cerebrovascular.

Palabras clave: Ictus; Trastornos de la deglución; Disfagia, Afasia, Disartria; Calidad de vida.

Introduction

Stroke is considered one of the main public health problems worldwide, becoming the second leading cause of mortality in several countries, resulting in temporary or permanent physical disability and causing a large number of hospitalizations^{1,3}. Stroke is defined as the reduction or complete interruption of cerebral blood supply, being divided into two types: thrombotic (ischemic type) or caused by the rupture of a cerebral vessel, leading to hemorrhage within the brain tissue or on the surface between the brain and the meninges, classifying it as the hemorrhagic type².

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It is noteworthy that thrombolytic therapy is recognized in the treatment of ischemic stroke due to its ability to restore blood flow through the administration of recombinant tissue plasminogen activator (RT-PA), which must be administered within 4.5 hours of stroke symptom onset².

Stroke represents one of the leading causes of death in Brazil. Studies indicate that approximately 70% of individuals who have suffered a stroke are unable to return to work, and 50% of these patients face difficulties even in performing their Activities of Daily Living (ADLs)^{1,5}.

It is noted that the impact of stroke on individuals' lives poses a significant challenge to society. This unexpected event affects not only the person affected but also their family members, who are often unprepared to face the recovery process or the limitations arising from this situation⁴.

The quality of life (QoL) of individuals affected by stroke can be impacted by mental, physical, functional, and behavioral disorders, as well as psychological changes, cognitive alterations, and motor problems such as balance, strength, and coordination^{5,8}. Additionally, swallowing disorders,

muscle tone, gait, proprioception, and coordination are important aspects. Although communication problems differ, the most common cognitive deficits, such as apraxia and dysarthria, are frequently identified after a stroke^{5,6}.

Seen as one of the main sequelae after a stroke, neurogenic dysphagia can cause changes in the stages of the oral and pharyngeal phases of swallowing, leading to the use of alternative feeding methods and, consequently, a delayed return to oral intake^{6,7}. Dysphagia in stroke cases can be associated with pulmonary problems, in addition to causing malnutrition and dehydration, where this condition can be seen as a predictive factor of morbidity and mortality, especially in acute stroke episodes⁹.

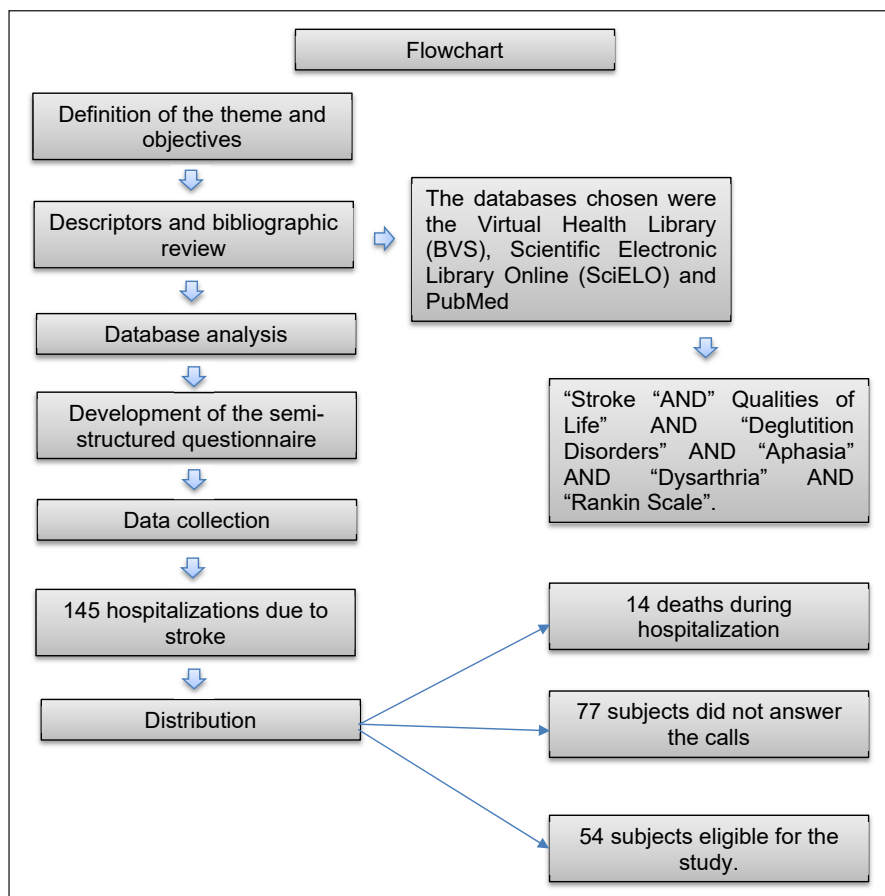
The speech-language pathologist is the professional qualified to assess and classify language disorders such as aphasias, dysarthrias, and swallowing disorders like dysphagia. They provide therapeutic interventions in hospital and post-hospital settings, aiming to promote rehabilitation, even during a short hospitalization period⁹. This strategy aims to provide more effective care and reduce the risks of complications that may worsen the patient's clinical condition, leading to an extended hospitalization period and, consequently, increased hospital costs¹⁰.

After a stroke, the degrees of disability can impact the levels of assistance required during and after hospital discharge. Many individuals return home with physical, cognitive, and behavioral sequelae that often impair their functional capacity, autonomy, and independence, making them vulnerable and dependent on others to manage their activities of daily living (ADLs)¹¹.

The aim of this study is to analyze the perception of quality of life (QoL) after a stroke among patients from different municipalities in the northern region of Rio Grande do Sul state. This will enable better guidance in the care provided to people living in the same region with similar conditions, as well as the identification of potential improvements or changes in intervention strategies, both for patients and their families.

Materials and methods

Diagram/flowchart



Casuistry

This study is part of a macro project entitled “Multiprofessional residency programs as generators of innovation and evidence-based services for users of the Unified Health System - SUS” and is characterized as quantitative, descriptive, and cross-sectional. It was approved by the Research Ethics Committee of the University of Passo Fundo - RS, CAAE 79356624.6.0000.5342, opinion 6.884.492. Data collection took place in three stages, described below.

In the first stage, to provide a foundation for this study, the theme of perception of quality of life after a stroke was defined. After selecting the theme and formulating the guiding question, a literature review was conducted to ensure the study’s relevance, carried out between June and October

2024. As databases selected were the Virtual Health Library (BVS), Scientific Electronic Library Online (SciELO), and PubMed. The search utilized the descriptors “Stroke” AND “Life Qualities” AND “Deglutition Disorders” AND “Aphasia” AND “Dysarthria” AND “Rankin Scale.”

Inclusion and exclusion criteria

The following data were analyzed in the institution’s own database, via medical records, and an Excel file was generated with information on patients hospitalized during the period from January to July 2024, who met the following criteria: 1) Patients hospitalized due to ischemic stroke, hemorrhagic stroke, or transient ischemic attack. 2) Individuals of both sexes; 3) Age between 18

and 100 years. Exclusion criteria included patients with a prior history of stroke.

Data collection

At this stage of the study, epidemiological data were collected from the selected patients, such as age, length of hospital stay, discharge date, gender, age, reason for hospitalization, type of health insurance, diagnostic hypothesis, and whether they presented conditions such as dysphagia, apraxia, dysarthria, and feeding method at hospital discharge.

For the final stage of data collection, subjects eligible to participate in the study answered some questions through a semi-structured adapted questionnaire, containing questions developed by the author, via telephone contact. At this stage, in order to obtain responses that aligned with the study's objective, patients or caregivers were asked about their perception of quality of life regarding their level of functionality and daily living activities Daily living activities (using the Rankin scale), family income, whether they sought speech therapy for patients who presented language and swallowing disorders at hospital discharge, time taken to access rehabilitation, type of health insurance, current feeding method, whether they still have speech and language disorders, whether they required rehospitalization, and a 5-point scale was used to analyze the perception of quality of life. Some difficulties were encountered at this stage, as the contacts were made via telephone, and many subjects had outdated records, were outside the coverage area, had their phones turned off, or did

not answer the calls. Contact attempts were made during different shifts: morning, afternoon, and evening. The evening shift showed greater adherence, being the time when most subjects answered the phone, but a large portion of them still did not respond to the calls.

Data analysis

The data were stored in a database using Microsoft Office Professional Plus 2016 - Excel, organized into simple spreadsheets with updated frequencies and separated into columns according to the questionnaire questions. For quantitative data analysis, the results were expressed as mean, standard deviation, and absolute frequency. Data processing was performed using the Statistical Package for the Social Sciences (SPSS) version 23.0. The adopted statistical significance value was ($p \leq 0.05$).

Results

During the established analysis period, data from 145 patient records of individuals hospitalized due to stroke were collected. Of these 145 records, only 54 subjects (patients and/or caregivers) answered the phone, enabling the third stage of the research, as described in Table 1, Referencing the clinical and demographic characteristics of the participants, this study reports that the average age of the patients was 70 years, with a minimum age of 39 years and a maximum age of 99 years.

Table 1. Clinical and demographic characteristics of participants during hospitalization.

Description	Average	±	SD
Age	70.46	±	13.67
Length of hospital stay in days	7.48	±	5.67
Descrição	N		%
Sex			
Male	27		50
Female	27		50
Hospitalization Agreement			
Public Health System	41		75.93
Supplementary Health System	11		20.37
Private	2		3.70
Stroke Typen (%)			
Non-thrombolized ischemic	31		57.41
Thrombolized ischemic	9		16.67
TIA	10		18.51
Hemorrhagic	4		7.41
Change in Speech Therapy			
Yes	23		42.60
No	31		57.40
Speech Therapy Diagnosis			
Dysphagia	6		11.11
Dysphagia + Aphasia	9		16.66
Dysphagia + dysarthria	4		7.40
Dysarthria	2		3.70
Aphasia + dysarthria	2		3.70
No speech therapy alterations	31		57.40
Degree of dysphagia			
Mild	4		7.41
Mild-Moderate	7		12.96
Moderate	2		3.70
Moderate-Severe	1		1.85
Severe	5		9.26
Feeding route at discharge n(%)			
Oral route	48		88.89
Alternative feeding route	5		9.26
Oral route + Alternative feeding route	1		1.85
Referred for speech therapy rehabilitation	23		42.60

Legend: TIA = transient ischemic attack, N = absolute value, % = percentage, SD = standard deviation.

In Table 2, after hospital discharge and family organization, it is possible to identify the outcomes of the patients. In this table, 4 patients who passed

away post-discharge were excluded, resulting in a sample of 50 participants.

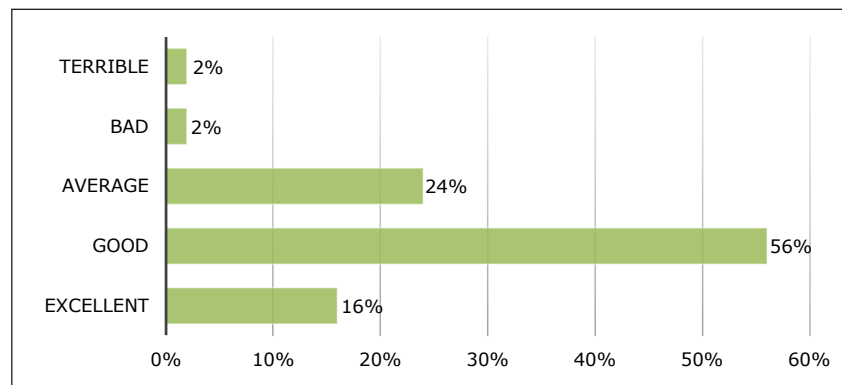
Table 2. Clinical conditions post-hospital discharge

Description	N	%
Survival after 3 months of discharge	50	92.59
Sought speech therapy rehabilitation	15	30
Current feeding route		
Oral route	46	92
Alternative feeding route	1	2
Oral route + Alternative feeding route	3	6
Current Oral Diet Consistencies		
Free	42	84
Adapted	7	14
Current clinical changes		
Dysphagia	8	16
Speech and language changes	14	28
Rehospitalization	7	14
Pneumonia	2	4
Mental and behavioral symptoms	12	24
Physical symptoms	9	18

Legend: N = absolute value, % = percentage, SD = standard deviation.

To analyze the perception of quality of life, a 5-point satisfaction scale was used. It was possible to identify the perception index related to the quality of life of individuals after a stroke. The individual, based on their perspective and perception, assigned a score from 1 to 5, as follows: 1: Very

poor perception of quality of life (QoL); 2: Poor perception of QoL; 3: Fair perception of QoL; 4: Good perception of QoL; 5: Excellent perception of QoL. This scale allowed for the identification of the perception index regarding quality of life from the individuals' own perspective.

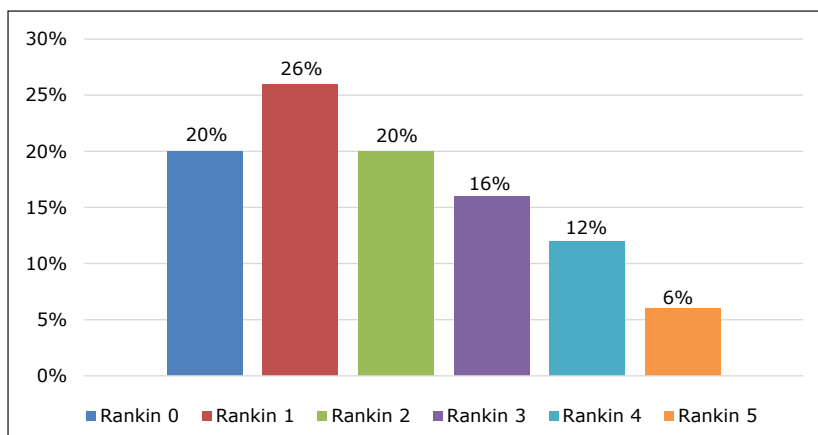
Graph 1. Quality of Life Perception Index.

Through the modified Rankin Scale (mRS), it was possible to identify the overall level of disability, encompassing the daily living activities of individuals after a stroke. The scale includes scores ranging from 0 to 6, based on the characteristics presented: 0: No symptoms; 1: No significant disability; 2: Mild disability; 3: Moderate disability; 4: Moderately severe disability; 5: Severe disability; 6: Death.

According to Graph 2, it is possible to identify the levels of functionality, which vary according to the score related to the patient's condition: Level 0: No symptoms, no sequelae or difficulties in moving, remembering, or communicating with others. Level 1: No significant disability, being

able to perform daily living activities as before the stroke, including working, driving, using public transportation, and engaging in leisure activities. Level 2: Mild disability, not requiring assistance from others to perform activities such as cooking, using the bathroom, eating, and dressing. Level 3: Moderate disability, as the patient needs help to move from one room to another in the house, possibly using a cane or walker. Level 4: Moderately severe disability, unable to walk without assistance and unable to meet their own physiological needs without help. Level 5: Severe disability, bedridden, incontinent, and requiring constant care and attention from the caregiver.

Graph 2. Modified Rankin Scale - Perception related to the level of disability of subjects after a stroke.



Discussion

Stroke, regardless of its etiology, is recognized for its multifactorial causes, which are related to the particularities of each individual, as well as the structure and environment in which they live. All subjects in this study were hospitalized due to the condition of stroke, With post-discharge telephone contact being a possibility to monitor their outcomes, related to the perception of quality of life and functionality parameters for activities of daily living.

Several aspects were discussed in this study, which help to understand patients' perceptions of

quality of life. The term "quality of life" is complex and has been studied by several researchers, as it varies according to the individual. Being considered interdisciplinary, factors such as lifestyle, physical health, mental health, and life expectancy are some of the elements that may influence this context¹². It is worth noting here that, regarding family income, 52% (n=26) earned up to 3 minimum wages, 32% (n=16) earned up to 5 minimum wages, and 16% (n=8) earned more than 5 minimum wages. This factor certainly impacts the perception of quality of life among the respondents.

In addition, through the Rankin scale, it is possible to assess a person's functional autonomy, which is linked to adequate motor and cognitive

conditions, the proper functioning of organs, systems, and body structures, depending on the level of sequelae caused by the stroke¹³. When age is the factor analyzed, this study is consistent with current research that highlights transient ischemic attack and stroke predominantly affect elderly individuals with an average age between 64 and 70 years^{3, 4}. Thrombolytic therapy has proven to be effective in the rapid and lasting recovery of patients who have suffered a stroke, reducing neurological severity and functional disability^{6, 15}. The predominance is still related to the delay in arrival for thrombolytic administration, as most subjects are unable to benefit from thrombolytic therapy, which is applied in the acute phase, due to difficulties in identifying the signs and symptoms of the disease¹⁵. Similar to the findings of this study, in which more than 57% of the subjects did not arrive within the 4.5-hour window for drug administration.

The social effects of stroke encompass and directly affect family relationships, financial aspects, health, and leisure¹⁴. In our study, 50% of the patients live with an income of up to three minimum wages, and the only means of healthcare assistance is seeking help through the Unified Health System, accounting for more than 75% of the respondents. Patients discharged from the hospital and their families are referred to healthcare services in their hometown, where they have a greater chance of receiving home care depending on the level of injury. This suggests that a well-planned discharge with appropriate referrals increases the likelihood of rehabilitation as quickly as possible¹⁶. In this study, 23 individuals were referred for speech therapy rehabilitation due to causes such as dysphagia, aphasia, and apraxia, which are common in patients who suffer from a stroke, with some patients presenting more than one condition simultaneously. Of those referred for rehabilitation ($n=15$), the process began within 15 days, positively influencing the perception of improved quality of life.

Regarding the functionality of individuals affected by a stroke in a study conducted in a municipality in the state of Paraíba, which aimed to evaluate the functionality of 50 subjects through the application of the Rankin scale, it was found that 32% of the subjects presented level 2 functionality with mild disability, followed by 26% who presented level 1 functionality—no significant disability¹⁷. In line with this study, the findings revealed that 20% of the 50 respondents reported a

perception of level 2 disability, while 26% reported level 1 functionality with no significant disability.

The study shows that elements related to physical fitness and functional performance can be understood as limitations in the need to dress, eat, bathe, and even walk short distances autonomously, potentially resulting in deficits and serving as a crucial factor in the perception of changes in quality of life^{18, 20}. Revisiting previous research conducted in Brazil (Northeast and Midwest) on the quality of life of individuals who suffered a stroke, several changes were identified in various aspects, such as mood, cognition, depression, and functional limitations, which negatively influenced quality of life¹⁹. In this study, factors influencing the subjects' perceptions of quality of life were also identified, with 24% ($n = 12$) reporting behavioral and mental changes such as depression, isolation, and anxiety, as well as 18% ($n = 9$) mentioning perceived changes in physical symptoms such as fatigue, loss of appetite, and dizziness. However, this study also revealed that 24% of the subjects reported a perception of regular quality of life, while 56% reported a perception of good quality of life, aligning with the results of the functional assessment scale and activities of daily living.

Conclusion

In this study, it was identified that 56% of the population surveyed referred to their post-stroke quality of life perception as good. This suggests that acute care processes, as well as access to rehabilitation, are interconnected and decisive aspects for better quality of life after a stroke.

It was identified that stroke predominantly affected the adult-elderly population. Functional changes, mental and behavioral symptoms, along with altered physical symptoms, can influence the perception of quality of life.

Therefore, it is recommended to continue neuroscientific studies aimed at deepening new methodologies related to the proposed topic, with the goal of identifying aspects that directly affect individuals' quality of life. This will enable the development of specific strategies to reduce the negative effects of this event, based on scientific advances that positively impact this social determinant of health.

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