

# CUIDADO É FUNDAMENTAL

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RESEARCH

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## IMPACT AND QUALITY OF LIFE ON PATIENTS AFFECTED BY CEREBRAL VASCULAR ACCIDENT

*Impacto e qualidade de vida no paciente acometido por Acidente Vascular Cerebral**Impacto y calidad de vida en pacientes afectados por Accidente Vascular Cerebral*Igor Guedes Leite<sup>2</sup> Edvane Birelo Lopes De Domenico<sup>1</sup> Vanessa Mesquita de Oliveira<sup>2</sup> Rita Simone Lopes Moreira<sup>1</sup> Eliana Cavalari Teraoka<sup>1</sup> 

### ABSTRACT

**Objective:** to evaluate the impact and quality of life in people affected by stroke in outpatient follow-up. **Method:** cross-sectional and quantitative study, from January to April 2019, was used a questionnaire with personal, sociodemographic and clinical variables; the Stroke Scale 3.0 and the Specific Quality of Life Scale for Stroke. **Results:** 34 participants, mean age of 50.3 years, mostly women (55.8%), white skin color (52.9%), incomplete elementary school (38.2%), married (47%), ischemic type (73.5%) and left hemisphere (44.1%). In 79.4% it was the first stroke event. The most prevalent comorbidities were systemic arterial hypertension (73.5%) and dyslipidemia (61.7%). The Stroke Impact Scale instrument averaged 57.75 and the quality of life scale was 156. **Conclusion:** the impact of the disease, quality of life and perception of recovery were classified as moderate.

**DESCRIPTORS:** Quality of life; Stroke; Rehabilitation; Outpatient clinics, Hospital; Nursing.

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## RESUMO

**Objetivo:** avaliar o impacto e a qualidade de vida em pessoas acometidas por acidente vascular cerebral em seguimento ambulatorial. **Método:** estudo transversal e quantitativo, de janeiro a abril de 2019, utilizou-se um questionário com variáveis pessoais, sociodemográficas e clínicas; o *Stroke Impact Scale 3.0* e a Escala de Qualidade de Vida Específica para Acidente Vascular Encefálico. **Resultados:** 34 participantes, idade média de 50,3 anos, maioria mulheres (55,8%), cor da pele branca (52,9%), ensino fundamental incompleto (38,2%), casados (47%), tipo isquêmico (73,5%) e no hemisfério esquerdo (44,1%). Em 79,4% foi o primeiro evento de AVC. As comorbidades mais prevalentes foram hipertensão arterial sistêmica (73,5%) e dislipidemia (61,7%). O instrumento *Stroke Impact Scale* obteve média de 57,75 e a escala de qualidade de vida de 156. **Conclusão:** o impacto da doença, a qualidade de vida e a percepção da recuperação foram classificados como moderados.

**DESCRITORES:** Qualidade de vida; Acidente vascular cerebral; Reabilitação; Ambulatório hospitalar; Enfermagem.

## RESUMEN

**Objetivo:** evaluar el impacto y la calidad de vida en los pacientes afectados por accidente cerebrovascular en el seguimiento ambulatorio. **Método:** estudio transversal y cuantitativo, de Enero a Abril de 2019, se utilizó un cuestionario con variables personales, sociodemográficas y clínicas; el *Stroke Impact Scale 3.0* y la Escala de Calidad de Vida Específica para accidente cerebrovascular. **Resultados:** 34 participantes, edad media de 50,3 años, en su mayoría mujeres (55,8%), color de piel blanca (52,9%), escuela primaria incompleta (38,2%), casadas (47%), tipo isquémico (73,5%) y hemisferio izquierdo (44,1%). En el 79,4% fue el primer evento de ictus. Las comorbilidades más prevalentes fueron la hipertensión arterial sistémica (73,5%) y la dislipidemia (61,7%). El instrumento *Stroke Impact Scale* promedió 57,75 y la escala de calidad de vida fue de 156. **Conclusión:** el impacto de la enfermedad, la calidad de vida y la percepción de recuperación se clasificaron como moderados.

**DESCRIPTORES:** Calidad de vida; Accidente cerebrovascular; Rehabilitación; Servicio ambulatorio en hospital; Enfermería.

## INTRODUCTION

Stroke is one of the main causes of morbidity and mortality in Brazil and worldwide, is the leading cause of disability, and is associated with high economic costs related to health treatment and post-stroke care and rehabilitation.<sup>1</sup>

One in every four people in the world will suffer a stroke, a cause of great concern for the health field, due to the disabilities and repercussions it causes in survivors, such as physical sequelae and functional disabilities, which generate dependence in the execution of basic activities of daily living, low self-esteem, social isolation, anxiety and depression, which negatively impact recovery, quality of life and survival.<sup>2-3</sup>

Stroke can severely impair people's quality of life, causing mental, physical, functional and psychological disorders and high healthcare costs; it can cause cognitive alterations, motor disorders such as balance, strength and muscle tone, gait, proprioception and coordination, and these disorders must be included in the rehabilitation process.<sup>4</sup>

This study aimed to characterize the sociodemographic and clinical profile of people affected by stroke and to identify the impact of the disease and the quality of life in patients in outpatient follow-up.

## METHODS

This is a cross-sectional and quantitative study, conducted at the Vascular Neurology Outpatient Clinic of Hospital São Paulo (HSP) of the Federal University of São Paulo (UNIFESP), from January 2019 to April 2019.

Participants included people diagnosed with stroke in follow-up at the Vascular Neurology Outpatient Clinic of Hospital São Paulo, a university hospital of the Federal University of São Paulo, São Paulo, Brazil. Inclusion criteria were: people older than 18 years of age, diagnosis of stroke in medical records, and preserved mental conditions. Exclusion criteria were: patients with transient ischemic attack, inability to understand the questionnaire: dementia and severe aphasia.

The research was approved by the Research Ethics Committee (CEP) of the Universidade Federal de São Paulo – UNIFESP and the ethical aspects were respected, recommending Resolution 466/2012 of the National Health Council.

For data collection, an individualized interview was conducted in a private place at the HSP-UNIFESP Outpatient Clinic. The following instruments were used: Questionnaires with structured and semi-structured questions about personal, sociodemographic and disease data. To assess the impact of the disease: *Stroke Impact Scale 3.0* (SIS) validated for the Portuguese language.<sup>5</sup> To assess quality of life we used the *Stroke Specific Quality of Life Scale* (EQVE-AVE), which is specific for assessment of QoL of stroke patients, validated and cross-culturally adapted in Brazil.<sup>6-7</sup>

### Study protocol

The SIS instrument assesses the self-reported impact of stroke in eight domains: strength, memory and reasoning, emotion, communication, basic and instrumental activities of daily living, mobility, manual function, and participation. In addition, a visual analog scale ranging from 0 to 100 measures self-perceived overall recovery since stroke onset.<sup>5</sup> All items within each domain are scored on a scale of 1 to 5 points. Higher item scores indicate

a lower level of difficulty experienced with the task, except for three items in the emotion domain, which must be reversed to calculate the domain score.<sup>5</sup>

The EQVE-AVE instrument comprises 49 items, and is subdivided into 12 dimensions (energy, family role, language, mobility, mood, personality, self-care, social role, reasoning, upper limb function, vision, and work/productivity). The minimum score is 49 points and the maximum score is 245 points, and the lower the score, the greater the dependence and difficulty to perform tasks. The higher the score, the better the quality of life. Scores below 60% (<147 points) indicate low quality of life.<sup>6</sup>

The data were organized using an Excel spreadsheet and validated by double entry. Descriptive statistics were used to analyze the answers from the sociodemographic and clinical questionnaires, and the other instruments were scored according to the criteria established in the literature.

## RESULTS

Thirty-four people with stroke in outpatient follow-up participated in the study, with a mean age of 50.3 years, ranging from 21 to 86 years, being predominantly between 40 and 59 years in 17 people (50%) and with age greater than or equal to 60 years in 11 (32.3%). There was a predominance of women 19 (55.9%), white skin color 18 (52.9%), incomplete elementary school education 13 (38.2%), followed by complete high school education 9 (26.5%), married 16 (47.1%), Catholic 18 (52.9%), with benefits 16 (47.1%), no caregiver 33 (97.1%), living with 29 (85.3%), all assisted by the Unified Health System (SUS).

Most people were affected by ischemic stroke 25 (73.5%) and in the left hemisphere 15 (44.1%), in 27 (79.4%) people it was the first stroke event, 17 (50%) of the interviewees had been affected for more than 24 months. Regarding comorbidities and risk factors for stroke, 25 (73.5%) had systemic arterial hypertension, 21 (61.8%) had dyslipidemia, 10 (29.4%) diabetes mellitus, and 6 (17.6%) smoked.

The Stroke Impact Scale 3.0 (SIS 3.0) instrument assessed the impact of stroke according to the domains: strength, memory and reasoning, emotion, communication, basic and instrumental daily life activities, mobility, manual function and participation, as shown in Table 1.

The degree of impact evaluated by the SIS 3.0 instrument was moderate, the average total score of the instrument was 70.9% and the average self perceived recovery by patients was 68.1%.

To assess QL, the EQVE-AVE instrument was used, by the domains: energy, family role, language, mobility, mood, personality, self-care, social role, memory and concentration, upper extremity function, vision and work and productivity, as shown in Table 2.

The mean total scores obtained with the LVEF-LVE instrument was 156 (63.7%) out of a total of 245. Scores lower than 147 (60%) indicate low quality of life, so the population in this study was close to what is scored by the instrument as low quality of life.

**Table 1** – Impact classification in stroke patients in outpatient follow-up at a tertiary hospital according to the Stroke Impact Scale 3.0 instrument. São Paulo, SP, Brazil, 2018-2019, (n=34)

Question	Average Points
Domain 1 – Strength	<b>3,59</b>
Domain 2 – Memory and reasoning	<b>4,07</b>
Domain 3 – Mood	<b>3,5</b>
Domain 4 – Communication	<b>4,4</b>
Domain 5 – Activities of daily living	<b>4,2</b>
Domain 6 – Mobility	<b>4,12</b>
Domain 7 – Manual function	<b>3,7</b>
Domain 8 – Participation	<b>3,36</b>
<b>Perceived recovery</b>	<b>68,12</b>
<b>Total</b>	<b>70,88</b>

**Table 2** – Impact classification in stroke patients in outpatient follow-up at a tertiary hospital according to the Stroke Specific Quality of Life Scale instrument. São Paulo, SP, Brazil, 2018-2019 (n=34)

Question	Average Points
Domain 1 – Energy	<b>2,25</b>
Domain 2 – Family Role	<b>2,97</b>
Domain 3 – Language	<b>3,3</b>
Domain 4 – Mobility	<b>3,19</b>
Domain 5 – Mood	<b>3,4</b>
Domain 6 – Personality	<b>2,53</b>
Domain 7 – Self-care	<b>4,4</b>
Domain 8 – Social Role	<b>2,7</b>
Domain 9 – Memory and concentration	<b>3,03</b>
Domain 10 – Function of the upper extremity	<b>3,8</b>
Domain 11 – Vision	<b>3,25</b>
Domain 12 – Work and productivity	<b>2,83</b>
<b>Total</b>	<b>156</b>

## DISCUSSION

Most of the patients studied were female, mean age of 50.3 years, as in the study carried out in an outpatient clinic in Salvador, which showed a majority of the population with active working age<sup>8</sup>. The majority profile of this study was of married patients who had children, were retired or receiving benefits and had low education, characteristics similar to the study among people who had stroke in João Pessoa, in which 57.4% were women, 44.4% with one to eight years of schooling.<sup>9</sup>

88% of the patients reported having a religious belief. Studies point out that when facing suffering caused by severe and chronic diseases, many people seek support in spirituality or religion, which can occur through the use of religious/spiritual coping strategies.<sup>10</sup>

There was a predominance of ischemic stroke in the patients, being the first episode, corroborating with a study among post-stroke people, in which 63.6% had ischemic stroke and 80.5% had the first episode.<sup>11</sup>

A study carried out in Sweden<sup>12</sup> with 72.5% of the patients who had stroke being carriers of systemic arterial hypertension. Similarly, the present study identified the same modifiable risk factor in predominance.

Regarding the evaluations of the impact of the disease and quality of life, the SIS 3.0 and LVEF-LVE instruments showed total mean and perceived recovery that indicated the patients' quality of life as moderate. In study<sup>11</sup> QoL was affected mainly in the social and family relations domains and in study<sup>14</sup> using the SIS in stroke survivors, all domains were affected. A study that evaluated the perceived impact of the stroke, using the SIS instrument, at two moments, 1 year and 6 years after the stroke, showed that the most affected domains were participation, hand strength and function, as well as recovery from the stroke.<sup>3</sup>

When we investigated the repercussion of the stroke from the perspective of impact and quality of life, the strength domain was shown in our study to have a result similar to the findings of a Canadian study<sup>15</sup> in which the hand function domain continued to be affected after 6 and 12 months after the stroke, as well as among post-stroke patients in a neurovascular program in which the majority had impairment in motor ability.<sup>16</sup>

Regarding the assessment of the domains on memory, language and communication, our results were similar in the Swedish study among 104 patients after 1 month of stroke, the perceptions of emotional health, communication skills and ability to remember were very good with a mean score of 83-8617, in contradistinction to the Canadian study<sup>15</sup>, after 6 months of stroke, communication, memory and thinking remained affected, and after 12 months communication remained impaired.

The limitations in cognitive function influence the general impairment of the patient; the greater the impairment of cognitive function, the worse the general state of the patient is in relation to the clinical variables.<sup>16</sup> In relation to the mood domain, in a multicentric study in two Scandinavian regions, the problems in cognitive, social, and emotional function stood out in relation to the physical functions.<sup>18</sup>

When the person affected by stroke is faced with a chronic disease, feelings such as fear, frustration, feelings of uselessness, concern and affliction are introduced into their daily lives; such feelings result from the loss of status, social relationships and dependence, and contribute to the delay in accepting the disease and its complications, hindering and delaying their rehabilitation.<sup>19-20</sup> Patients who after stroke had depression had significantly more affected quality of life ( $p \leq 0.05$ ), the most affected domains were energy, family roles, mobility, self-care, social roles, upper limb functions, and work productivity.<sup>21</sup> Retrospective case-control study with 560 ischemic stroke survivors, people with post-stroke depression had worse mobility, longer hospitalization and rehabilitation time, and insufficient

response to rehabilitation efforts compared to people who after stroke did not have depression.<sup>22</sup>

The results of our study in the energy domain were lower than the study conducted in a Long Term Care Unit in which patients on admission had a mean score of 6.5 and then 9.6 at hospital discharge.<sup>23</sup>

Regarding the domains of activity of daily living and self-care, they are similar to the Canadian study<sup>15</sup> in which after 12 months the domain showed to be affected among people and in the study<sup>3</sup> in which there was a higher perceived impact at 6 years compared to 1 year in the whole group of activity of daily living and in all subgroups of the domain. The importance of investigating these domains is because it is highly common, even in patients with successful clinical recovery, to have impairment of executive functions<sup>24</sup> as high as 54.4% in a cohort from a university hospital in Finland.<sup>25</sup>

The results of the mobility domains were similar to the study<sup>15</sup> in which the mobility domains were also shown to be affected after 12 months; and in the study<sup>3</sup> in which participants who had mild and moderate stroke reported significantly greater impact at 6 years than at 1 year in the domains activity of daily living and mobility. The functional deficiency is frequently associated with depression after the stroke, as a psychological reaction to the physical loss.<sup>21</sup> The evaluation of these domains is extremely important, once it has been reported that the physical limitations cause changes not only in the daily tasks, but also in self-esteem, in the capacity to work with consequences to the social and financial life<sup>20</sup>, and must be object of action for rehabilitation in early stages.<sup>26</sup> Regarding the result of the evaluation of the manual function domain of the SIS 3.0 instrument, the average was lower when compared to the study with patients from a Family Health Program, who had an average of 9 in this domain.<sup>27</sup>

A Nigerian study<sup>28</sup> obtained higher results regarding the vision domain scores, with a mean of 9.41. The patients presented low visual impairment, but in a systematic review study, the overall prevalence of visual impairment soon after the stroke was estimated in 65%, ranging from 19% to 92%; visual field loss ranged from 5.5% to 57%, ocular motility problems from 22% to 54%, visual inattention from 14% to 82% and reduced central vision reported in up to 70% of the studies.<sup>29</sup>

The domains of participation, family role and social role in our study showed similar results to the literature, in the Para study<sup>30</sup>, family role (54.2%) and social role (44.8%) stand out as the most affected domains. A study focused on the social support of people with stroke sequelae<sup>9</sup> highlighted social support problems associated with the family, which is the main source of support and often unprepared to face the patient's dependence, contributing to feelings that hinder the family or that they are a burden, generating difficulties in recovery. A qualitative study carried out with stroke survivors<sup>20</sup>, reported an improvement of the clinical picture in patients who feel more sheltered and with a strengthened family bond.

The nursing professional stands out in the development of an individualized care and prevention plan that must aim at lifestyle management, changes in health beliefs and self-care behavior.<sup>13</sup> The quality of life assessment contributes to a better understanding of the impact of stroke on the affected individuals, since by looking at the patient holistically, one can see that they are not isolated problems. Nursing, in its substantial role in recovery after stroke, benefits from studies in this area, since it has the potential to provide a global profile of the functional, psychosocial and perception of life conditions by the subject, guiding rehabilitation, collaborating to improve this process and the perception of health-related quality of life, and allowing the formation of subsidies and policies to improve the quality of health care.<sup>11</sup>

Another limitation was the period after the stroke in which 50% of the participants had already had more than 2 years of the disease, which makes it difficult to generalize the results for the different phases of rehabilitation after the disease.

The research brings contributions to nursing by the results that show the need for planning and implementation of interventions for the rehabilitation of the person after the stroke, with a multidisciplinary focus, aiming at improving quality of life and actions that reduce its impact on activities of daily living. The study also showed that 50% of the studied patients had a stroke more than 2 years ago, showing the importance of their follow-up to prevent new episodes and for their rehabilitation.

## CONCLUSION

It can be concluded that the impact of the disease and the quality of life of the affected patients was moderate, as well as the self-perception of recovery.

We emphasize the importance of nurses in the rehabilitation process of people after stroke, and the need to implement multi-professional care in the affected areas for a better quality of life.

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