ABSTRACT

Objective: to investigate the domains of quality of life most affected in survivors of stroke according to specific evaluation tools. Method: this is an integrative literature review in MEDLINE, CINAHL and Lilacs, of which seven were selected. Results: the articles were grouped according to the scale used: in the Stroke Impact Scale. The most affected domains were physical function, social participation, emotion. In the Stroke Specific Quality of Life Scale, they were work/productivity, family and social relationships, thinking, energy, language. In Health-related Quality of Life in Stroke Patients Questionnaire, they were eco-social, intellectual, physical interaction. Conclusion: the quality of life of survivors is impaired in a global and multifaceted way. There is need to expand research with specific measurement instruments, as they assess areas of special interest, demonstrating a comprehensive profile of functional and psychosocial conditions of the survivors, and thus contributing to improved care for their health. Descriptors: Stroke, Quality of life, Survivors.

RESUMEN

Objetivo: investigar los dominios de la calidad de vida más afectados en sobrevivientes de accidente cerebrovascular de acuerdo con instrumentos de evaluación específicos. Método: se trata de una revisión integradora de la literatura en MEDLINE, LILACS y CINAHL, en el que se seleccionaron siete artículos. Resultados: los artículos fueron agrupados conforme a la escala utilizada en la Stroke Impact Scale. Los dominios más afectados fueron función física, participación social, emoción. En la Stroke Specific Quality of Life Scale, fueron trabajo/productividad, relaciones familiares e sociales, modo de pensar, energía, lenguaje. En la “health-related quality of life in stroke patients questionnaire” fueron interacción ecossocial, intelectual, físico. Conclusion: la calidad de vida de los supervivientes es prejudicada de forma global y multifacética. Há necesidad que sejam ampliadas pesquisas com instrumentos específicos de medida, pois estes avaliam dominios de especial interesse, demonstrando um perfil integral das condições funcionais e psicosociais dos sobreviventes, e podem, assim, contribuir para melhoria da atenção à sua saúde. Descritores: Acidente vascular cerebral, Calidad de vida, Sobrevivientes.

RESUMO

In the past two centuries, the economic and social transformations arising from the industrial and technological revolution resulted in a major shift of population mortality profile. The increase in life expectancy and, consequently, population aging has increased exposure to factors responsible for the emergence of non-communicable chronic diseases (NCCDs).  

NCCDs are the leading causes of deaths worldwide, with a high number of premature deaths, decreased quality of life due to the major limitation in work and leisure activities, in addition to causing economic impacts on families, communities and society, which leads to greater inequalities and increases poverty.

Among these diseases, stroke has emerged as the second leading cause of death worldwide, with a tendency to remain in this position until the year 2030. In Brazil, in 2010, cerebrovascular diseases caused 99,732 deaths. In 2012, there were 165,899 hospitalizations for stroke, with costs that exceed R$ 163 million reais with hospital services. It is, therefore, a highly costly disease.

Stroke is the focal or global neurological impairment that occurs suddenly, probably of vascular origin and that leads to death or has greater than 24 hours duration. Its symptoms include a wide variety of neurological deficits, which will depend on the location of the lesion, the size of the area that is with poor perfusion and the amount of collateral blood flow.

Brain injuries produced by stroke, when they do not cause death, often result in significant functional disorders, such as hemiplegia, aphasia, blindness, tactile, proprioceptive, mental and cognitive changes. These consequences can lead to total or partial disability of the person, with major implications for their quality of life due to disability, years of productive life lost and the high financial costs involved.

For these reasons, it is greatly important to perform studies on quality of life and stroke. Quality of life is an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept, largely influenced by physical and psychological health, independence, social and environmental relationships, values and beliefs of the person.

Quality of life can be evaluated by instruments developed for the most varied purposes; the scales may be generic for health ranges or specific for certain diseases. Compared with generic measures, specific instruments to assess quality of life for people affected by stroke were more valid to observe significant changes in quality within the dimensions of the observed symptoms, indicating that these scales are more directed to particularities and domains commonly affected by illness.
Assessing quality of life in stroke patients is essential because it allows knowing the impact of stroke on the lives of individuals by providing grants to improve the quality of health care to stroke and support for caregivers and family members. However, we observed little reference to studies that approach to assessment of quality of life and stroke using disease-specific instruments, triggering the need for further studies with this aim.

Given the importance in investigating quality of life and stroke, the aim of this study is to investigate the domains of quality of life most affected in survivors of stroke according to specific instruments to assess quality of life. Its completion is justified by the negative impact of the disease on quality of life of people suffering.

**METHOD**

This is an integrative literature review, whose objective is to gather and synthesize the results of studies on a given topic, systematic and logically, aiming to deepen the knowledge about the topic. The methodological approach has six steps: choosing the topic and formulate a hypothesis or question for drafting the review; determining criteria for inclusion and exclusion of studies; categorizing them; assessment of included studies; interpretation of results and synthesis of knowledge.

To guide this review, we prepared the following question: “What are the domains of quality of life most affected in people stricken by stroke according to specific assessment instruments for quality of life?”. Data collection was performed with a survey of articles published in journals indexed in the Virtual Health Library (VHL), using specifically data from MEDLINE and Literature Latin American and Caribbean Center on Health (Lilacs), and CINAHL. We used the following key words: brain stroke, cerebrovascular accident, quality of life, and survivors with Boolean marker.

In selecting studies, the following criteria were considered: articles indexed in the cited databases (a); in Portuguese, English and Spanish languages (b); published in the last 10 years (c). Exclusion criteria: articles with abstracts and full text not available online, by the impossibility of analyzing their results (d); that are duplicated in the database (f); and found articles from the selected descriptors, but not related to the purpose of the study (g).

In a survey conducted in July 2014, 432 articles were found. After applying the inclusion (a, b, c) and exclusion (d, f) criteria, 76 articles were selected, whose abstracts were read, performing a critical evaluation in accordance with the objectives of the study. At the end, seven studies that met the research objectives were obtained (according to Figure 1).
RESULTS AND DISCUSSION

Characterization of the studies

On the characterization of the studies, the articles present different characteristics with respect to countries that they have been conducted, the sample size and the specific instrument for assessment of quality of life for stroke used.

The studies were performed in Nigeria, United States, Australia, Germany, Switzerland, and country with the largest number of articles was Brazil, with two publications. The samples varied from a small number of survivors of stroke (15 people) to a more numerous sample (260 people with stroke).

Regarding the specific instrument for assessing quality of life used, the instrument most commonly used was the Stroke Impact Scale (SIS), in four studies; followed by

Figure 1: Flowchart of survey of articles for this review.

Search VHL

126 publications found

Applieed the inclusion criteria (a), (b) and (c) and the exclusion criteria (d) and (f)

63 articles followed for reading the titles and abstracts

Applied the exclusion criteria (g) / Critical Assessment

7 items selected

Search CINAHL

306 publications found

13 articles followed for reading the titles and abstracts

No item selected
the Stroke Specific Quality of Life Scale (SSQOL) used in two articles \(^{13,15}\), and the Health-Related Quality of Life in Stroke Patients Questionnaire (HRQOLISP), used in one research.\(^9\)

**Characterization of people affected by stroke**

According to the selected articles, people affected by stroke were more commonly male \(^{10-12,14-15}\), mean age ranging from 55.9 years old \(^{14}\) to 67.5 years old \(^{11}\), most had had only one episode of stroke \(^{9,11-12}\), suffered an ischemic stroke type \(^{9,12,14}\), was married \(^{11,14-15}\) and low education (no scholarity) \(^9\), basic education \(^{12}\), average of 8.4 years of education \(^{14}\), high school \(^{15}\).

**Stroke Impact Scale (SIS)**

The Stroke Impact Scale (SIS), version 3.0, was designed to be a more comprehensive measure of health outcomes for people with stroke. It integrates significant dimensions of quality of life in a questionnaire of specific self-report to people who survived the disease. It has 59 items divided into eight domains, four areas address aspects of physical function, including strength, hand function, mobility and activities of daily living that can be combined to obtain an overall score of physical function component; the remaining domains reflect mood and emotion, communication, memory and thinking and social participation.\(^{16-18}\)

Each domain uses a rating scale of 5 points and the scores range from 0 to 100, with higher scores indicating better quality of life. SIS has been shown to be valid, reliable, has less floor and ceiling effects, and is more sensitive to changes in quality of life for stroke survivors compared to more general measures often used.\(^{16-18}\)

SIS was the most frequent adopted scale in four studies selected. In these studies, the domains of quality of life most affected by stroke were the physical function component \(^{10-11,14}\), particularly strength and hand function\(^{11,12,14}\). Other areas were also severely damaged, such as social participation (in all studies using this scale \(^{10-12,14}\)) and emotion.\(^{11-12,14}\)

**Stroke Specific Quality of Life Scale (SSQOL)**

It is a specific instrument for the assessment of QOL in patients with stroke, developed in a study that evaluated QOL in people suffering sequels of stroke. Their items were drawn from interviews with stroke survivors, who identified the areas most commonly affected by the disease.\(^{19}\)

The instrument contains 49 items divided into 12 domains. The first part includes questions about the respondents’ degree of difficulty regarding: mobility (M), upper limb function (LF), vision (V), language (L), work/productivity (W) and personal care (PC). The second part contains a list of information about which the respondent must give their opinion about: energy (E), behavior (B), thinking (T), mood (M), social (SR) and family relationships (FR).\(^{20}\)
In SSQOL, responses were quantified on a scale Linkert type, 1-5 points (higher scores represent more normal function), with scores ranging from 49 to 245 points. In the first part of the instrument (the domains M, LF, V, L, W and PC), the scores mean: 1, impossible to accomplish; 2, much difficulty; 3, some difficulty; 4, little difficulty; and 5 without any difficulty. In the second part, which includes the domains E, B, T, M, SR and FR, the scores are: 1, strongly agree; 2, partially agree; 3, neither agree, nor disagree; 4, partially disagree; 5, strongly disagree. The answers have as a point of reference the previous week.\(^{19,20}\)

In the selected articles of researches performed in Brazil, the most affected areas were work/productivity and family relationships\(^{15}\); in a study conducted in Switzerland, the most affected domains were thinking, energy and language\(^{13}\), in both, the social relations domain stood out for with low scores.\(^{13,15}\)

The Health-related Quality of Life in Stroke Patients Questionnaire (HRQOLISP)

The Health-related Quality of Life in Stroke Patients Questionnaire (HRQOLISP) is another scale for measuring specific quality of life for people affected by stroke. It is a reliable and valid, multicultural generated, multifaceted, holistic, with excellent psychometric properties. It comprises 7 domains and 102 items, divided into 2 dimensions. The physical dimension includes physical, psychological, cognitive and eco-social interactions domains, while the spiritual dimension comprises soul, mind, and spiritual interaction domains. The score ranges from 0 (worst health) to 100 (best health status) for each.\(^{21}\)

In the selected study that uses HRQOLISP to assess quality of life, among the seven domains of the instrument, the most affected domains were eco-social, intellectual and physical interaction.\(^8\)

CONCLUSION

Survivors of stroke are affected in multiple areas of their life, facing challenges to adapt to their new condition, often with permanent disabilities. In this context, the nurse stands out as an important professional in their recovery, since they accompany all phases of treatment, and may encourage and promote it, listening to them, questioning them and supporting them emotionally, performing interventions to prevent complications, in addition to guiding the caregiver of the person affected to perform their tasks in the best way possible without overloads.

From the integrative review conducted, it was observed that the quality of life of survivors of stroke is always impaired, in a global and multifaceted way, especially in
physical and cognitive functions, social interaction and emotion. Identifying the areas most affected by the disease is crucial for the routine assessment of rehabilitation needs, prognosis and response to various therapies of the patient. Observing the most affected domains of quality of life, it appears that attention should be multidimensional, directed not only to the physical aspect but also to the cognitive, emotional and social aspect in the rehabilitation of the person after stroke.

Assessing quality of life of stroke survivors can provide a comprehensive profile of functional and psychosocial conditions, directing their rehabilitation and working to improve this process and the quality of life, encouraging the creation of appropriate interventions by health professionals in order to improve health care to those affected by stroke, their caregivers and their families.

In nursing, there is little reference to studies on the subject, and these are more often related to the caregiver of the affected person, so it is essential to conduct more studies to explore the quality of life of the person surviving the disease. Furthermore, generic measures are commonly used for this evaluation, so there is need for further research with specific tools, since they assess areas of particular interest to people in this condition and, thus, small changes can be more easily identified.

REFERENCES


