Revista
Brasileira
de Enfermagem
REBEn

RESEARCH

Stroke: patient characteristics and quality of life of caregivers

Acidente vascular encefálico: características do paciente e qualidade de vida de cuidadores
Accidente vascular encefálico: características del paciente y calidad de vida de los cuidadores

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How to cite this article:
Costa TF, Gomes TM, Viana LRC, Martins KP, Macêdo-Costa KNF. Stroke: patient characteristics and quality of life of caregivers. Rev Bras Enferm [Internet]. 2016;69(5):877-83. DOI: http://dx.doi.org/10.1590/0034-7167-2015-0064

Submission: 07-01-2016 **Approval:** 07-10-2016

ABSTRACT

Objective: to investigate the association between the domains of health-related quality of life of family caregivers and sociodemographic characteristics of individuals with stroke sequelae. **Method:** descriptive, cross-sectional, quantitative research, conducted with 136 family caregivers of individuals with stroke sequelae by means of home interviews from April to June 2013. **Results:** we found that caregivers of individuals aged under 65 years, married, with 10 to 12 years of formal education, presented higher scores, respectively, in the domains 'Social aspects', 'Emotional aspects', and 'Mental health'. However, caregivers of patients with higher degree of disability obtained lower score in the 'Mental Health' domain. **Conclusion:** the results foster reflection on the need of including the family caregivers of individuals with stroke sequelae in the planning of care provided by health professionals.

Descriptors: Nursing; Stroke; Caregivers; Quality of life; Characteristics of population.

RESUMO

Objetivo: investigar a associação entre os domínios da qualidade de vida relacionada à saúde dos cuidadores familiares e as características sociodemográficas dos indivíduos com sequelas de AVE. **Método:** pesquisa descritiva, transversal, quantitativa, realizada com 136 cuidadores familiares de indivíduos com sequelas de AVE, mediante entrevistas domiciliárias de abril a junho de 2013. **Resultados:** verificou-se que os cuidadores de indivíduos com idade inferior a 65 anos, casados, com dez a 12 anos de escolaridade, apresentaram maiores escores, respectivamente nos domínios 'Aspectos sociais', 'Aspectos emocionais' e 'Saúde mental'. Entretanto, os cuidadores de pacientes com maior grau de incapacidade obtiveram menor escore no domínio 'Saúde mental'. **Conclusão:** os resultados permitem refletir acerca da necessidade de inserir os cuidadores familiares de indivíduos com sequelas de AVE no planejamento de cuidados prestados pelos profissionais de saúde.

Descritores: Enfermagem; Acidente Vascular Encefálico; Cuidadores; Qualidade de Vida; Características da População.

RESUMEN

Objetivo: investigar la asociación entre los dominios de la calidad de vida relacionada con la salud de los cuidadores familiares y las características sociodemográficas de los individuos con secuelas de accidente vascular encefálico (AVE). **Método:** estudio descriptivo, transversal y cuantitativo realizado con 136 cuidadores familiares de personas con secuelas de AVE a través de entrevistas domiciliarias a partir de abril hasta junio de 2013. **Resultados:** se encontró que los cuidadores de las personas menores de 65 años, casados, y con diez a 12 años de estudio tenían las puntuaciones más altas, respectivamente, en los dominios 'Aspectos Sociales', 'Aspectos emocionales' y 'Salud mental'. Sin embargo, los cuidadores de pacientes con niveles más altos de discapacidad tuvieron menor puntuación en el dominio 'Salud mental'. **Conclusión:** los resultados permiten reflexionar sobre la necesidad de integrar los cuidadores familiares de personas con secuelas de AVE en la planificación del cuidado por parte de profesionales de la salud.

Descriptores: Enfermería; Accidente Vascular Encefálico; Cuidadores; Calidad de Vida; Características de la Población.

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INTRODUCTION

Cerebrovascular accident (CVA), also referred to as stroke, is the third cause of death in the world, preceded only by heart diseases in general and cancer. This event is defined as an interruption of blood flow to the brain, damaging neurological function(1). It is the leading cause of long-term disability; survivors generally live one to eight years after the stroke and most experience varying degrees of chronic disabilities that limit their cognitive and functional abilities, affecting daily life activities (DLA)(2).

According to the degree of compromise caused by the sequelae, the affected patient will need frequent care and, then, the role of the caregiver emerges, which may be a professional or family member(3). In most cases, the patient's family suffers routine changes to adapt to the new needs and, thus, engages fully in the care provided to the sick family member(4).

The care provided to a patient is highly stressful and may affect the physical and psychological well-being of caregivers. Studies demonstrate that family caregivers are at risk of developing depressive symptoms, anxiety and sleep disorders, which lead to reduced quality of life(3,5). All these aspects accelerate the caregiver's health deterioration process, causing deleterious effects, such as appearance or worsening of diseases(3).

According to the World Health Organization (WHO), quality of life (QOL) is an individual's perception regarding position in life within the cultural context and system of values in which an individual lives in relation to objectives, expectations, concerns, and wishes(6).

Considering the key role in the life of a patient, the caregiver needs to maintain his or her well-being and lead a healthy lifestyle, obtaining health care and guidance, so proper care can be provided to the family member in need. In this sense, evaluating the caregiver's quality of life and the factors that can influence its reduction, such as the patient's characteristics, becomes relevant so the health care professional knows the needs, establish objectives and implement actions to minimize the negative aspects of the care process.

In this context, it should be noted that health-related quality of life was included in studies, in recent decades, and has become fundamental regarding the context of health status, or variation of the impact caused by a disease on an individual's life, according to this individual's perception(7). Therefore, it is an effective tool in assessing the changes related to the caregiver's health, in particular in the event of overload.

In line with this reflection, it is clear that this type of health problem requires the development of specific care policies, which should be integrated into the various levels of health care to have both patient and caregiver involved in the care process, transcending the hospital sphere, thus involving all levels of service(8).

Therefore, this study aims to investigate the association between the domains of quality of life related to the health of family caregivers and the sociodemographic characteristics of individuals with stroke sequelae.

METHOD

Ethical aspects

All ethical and legal aspects concerning research with human beings were observed, as established by Resolution 466/12 of the National Health Council(9). This project was submitted to the Research Ethics Committee, Health Sciences Center, Federal University of Paraíba, and approved under Protocol No. 0279/13.

Study design, location, and period

This is a descriptive, cross-sectional, quantitative research, conducted in the city of João Pessoa-PB, from April to June 2013.

Population, sample, inclusion criteria and exclusion criteria

This research comprised family caregivers of individuals with stroke sequelae registered in Family Health Units (FHU) of this municipality, which is composed of five health districts and 181 FHU, distributed as follows: district I (45 FHU); district II (36 FHU); district III (55 FHU); district IV (26 FHU); and district V (19 FHU).

For sample calculation, we used margin of error of 5% (*error* = 0.05), with 95% confidence level ($\alpha = 0.05$, which provides $Z_{0.05} = 1.96$), considering the real proportion as 50% ($p = 0.50$). Sample size was estimated based on the total number of patients registered in the FHU and that had suffered stroke. According to a survey conducted in the five health districts, in 2012, the year preceding that of the research, 204 stroke patients were assisted in the FHU. Thus, the result of sample calculation was, at least, 134 family caregivers of stroke patients. Therefore, interviews were conducted with 136 caregivers.

Random sampling was carried out in some Family Health Units in each district, with a survey of the number of stroke patients registered in the FHU, based on registration data of families that receive follow-up assistance. Inclusion criteria for individuals with stroke sequelae comprised: being aged 18 years or older, having at least two compromised daily life activities (DLA), having been initially evaluated by Barthel scale, already validated in Brazil(10), and having a family caregiver. For caregivers, the inclusion criteria comprised: being aged 18 years or older and being the primary caregiver for more than six months.

Study protocol

Data collection was carried out by means of home interviews with caregivers. Initially, we applied the Barthel scale to identify individuals with at least two compromised DLA, meeting one of the inclusion criteria. In a 2010 study, Barthel scale showed excellent reliability level(11). The instrument comprises ten items that assess, specifically, bladder and bowel sphincters control, personal hygiene, independence in bathroom, alimentation, transfer from chair, walking, ability to dress and bathe, and ability to climb stairs. Such information were collected by data reported by caregivers. The final sum of scores with scores from zero to 20 indicates total dependence; from 21 to 60, severe dependence; from 61 to 90, moderate dependence; from 91 to 99, mild dependence; and 100, independence(12).

To determine the sociodemographic profile of the stroke patient and family caregiver, we used semi-structured questionnaires, including the following variables: age, sex, marital status, educational level, employment status, personal income. Health-related quality of life was assessed by applying the Short-Form-36 (SF-36) questionnaire, which contains eight domains: functional capacity, physical aspects, emotional aspects, mental health, social aspects, vitality, pain, and general perception of health. The score ranges from 0 to 100, with higher values indicating better quality of life(13).

Analysis of results and statistics

Statistical analysis of the data was performed using the application SPSS (Statistical Package for Social Science) version 18.0. With the aim of achieving the proposed objective, it was necessary to apply two statistical techniques: correlation analysis and Student's t-test and F-test to compare the means.

RESULTS

Regarding sociodemographic characteristics of the individuals with stroke sequelae, females were prevalent with 51.40%, mean age of 70.43 years, married (48.53%), with educational level of one to four years of formal education (27.94%), retired (80.88%), with personal income of two to three minimum wages (61.76%). As for functional incapacity, the study showed that: 35 (25.74%) individuals had mild dependence; 35 (25.74%) had very severe dependence; 28 (20.59%) had severe dependence; and 27 (19.85%) had moderate dependence.

As for the characteristics of caregivers, it was found that most were female (84.50%), had children (51.47%), mean age of 34 to 47 years, married (57.35%), with educational level of five to nine years of formal education (51.47%). As for the employment status, most caregivers were unemployed (45.59%), with personal income of one to three minimum wages (58.09%).

As for the family caregivers' health-related quality of life, as presented in Table 1, the lowest means of SF-36 scores were observed in the domains 'Pain' (40.16), 'Mental health' (53.62) and 'Social aspects' (54.12); the domains with the highest means were 'Functional capacity' (73.09), 'Vitality' (65.39) and 'Emotional Aspects' (60.54). The domains 'General health status' and 'Physical aspects' had means of 54.19 and 55.37, respectively. Specifically for the domain 'Emotional aspects', the median was 10 (the maximum value observed for this domain), which means that 50% of informants rated this topic with maximum score, i.e., 50% of older adults have no difficulties with their work due to emotional problems.

Association between health-related quality of life of family caregivers and sociodemographic characteristics of individuals with stroke sequelae

Regarding the association between the HRQOL scale domains and the sociodemographic characteristics of the patients, there was no significant difference between the sexes in any of the eight domains. With respect to the age group, according to Table 2, caregivers of patients aged under 65 years (60.00) presented statistically higher score for quality of life, when compared to the others in the 'Social aspects' domain.

Table 1 – Distribution of scores for the domains of health-related quality of life – João Pessoa, Paraíba, Brazil, 2013

Domains of health-related quality of life	Mean ± sd(1)	Median	Observed variation
Physical aspects	55.37 ± 43.66	75.00	0 – 100
Emotional aspects	60.54 ± 45.76	100.00	0 – 100
Pain	40.16 ± 27.18	33.33	0 – 100
Functional capacity	73.09 ± 24.82	80.00	0 – 100
Social aspects	54.12 ± 19.49	60.00	0 – 100
Mental Health	53.62 ± 20.03	57.14	0 – 100
Vitality	65.39 ± 17.75	66.67	0 – 100
General health status	54.19 ± 19.5	53.84	0 – 100

Note: (1)standard deviation.

Table 2 – Comparison of mean scores for the domains of the scale for health-related quality of life, according to the age group of patients, João Pessoa, Paraíba, Brazil, 2013

Domains of health-related quality of life (1)	< 65 years (n = 44)	65–80 years (n = 61)	> 80 years (n = 31)
Physical aspects	53.41 ^{a}	59.17 ^{a}	50.81 ^{a}
Emotional aspects	52.27 ^{a}	69.40 ^{a}	54.84 ^{a}
Pain	42.12 ^{a}	38.80 ^{a}	40.14 ^{a}
Functional capacity	77.50 ^{a}	72.70 ^{a}	67.58 ^{a}
Social aspects	60.00 ^{a}	49.84 ^{b}	54.19 ^{a,b}
Mental Health	50.32 ^{a}	56.91 ^{a}	51.84 ^{a}
Vitality	65.45 ^{a}	64.92 ^{a}	66.24 ^{a}
General health status	56.29 ^{a}	52.71 ^{a}	54.09 ^{a}

Notes: (1) For each domain, different letters (a, b) indicate that the mean scores are statistically different.

As for marital status, according to Table 3, there was significant difference between the mean scores of single/divorced/widowed patients compared with married patients (69.57) for the 'Emotional aspects' domain, while, for all other domains, the mean scores for quality of life observed between the two categories were always very close.

Table 3 – Comparison of mean scores for the domains of the scale for health-related quality of life, according to the marital status of patients, João Pessoa, Paraíba, Brazil, 2013

Domains of health-related quality of life(1)	Single/divorced/widowed (n = 67)	Married/other (n = 69)
Physical aspects	52.65 ^{a}	57.97 ^{a}
Emotional aspects	51.24 ^{a}	69.57 ^{b}
Pain	40.13 ^{a}	40.20 ^{a}
Functional capacity	71.79 ^{a}	74.35 ^{a}
Social aspects	52.54 ^{a}	55.65 ^{a}
Mental Health	52.99 ^{a}	54.24 ^{a}
Vitality	65.07 ^{a}	65.70 ^{a}
General health status	55.57 ^{a}	52.84 ^{a}

Notes:(1) For each domain, different letters (a, b) indicate that the mean scores are statistically different.

Table 4 – Comparison of mean scores for the domains of the scale for health-related quality of life, according to the educational level of patients, João Pessoa, Paraíba, Brazil, 2013

Domains of health-related quality of life(1)	Illiterate/ literate (n = 61)	Elementary school (n = 38)	High School (n = 24)	Higher Education (n = 13)
Physical aspects	55.33 ^{a}	48.65 ^{a}	65.63 ^{a}	55.77 ^{a}
Emotional aspects	57.92 ^{a}	61.40 ^{a}	59.72 ^{a}	71.79 ^{a}
Pain	44.63 ^{a}	39.18 ^{a}	31.48 ^{a}	38.46 ^{a}
Functional capacity	70.74 ^{a}	71.32 ^{a}	77.71 ^{a}	80.77 ^{a}
Social aspects	55.08 ^{a}	54.21 ^{a}	52.50 ^{a}	52.31 ^{a}
Mental Health	48.59 ^{a}	56.20 ^{a,b}	52.98 ^{a}	70.88 ^{b}
Vitality	64.59 ^{a}	64.21 ^{a}	66.67 ^{a}	70.26 ^{a}
General health status	56.12 ^{a}	54.45 ^{a}	50.64 ^{a}	50.89 ^{a}

Notes: (1) For each domain, different letters (a, b) indicate that the mean scores are statistically different.

Regarding educational level, no statistically significant correlation was observed between the mean scores of illiterate/literate patients (48.59) and the others, as to the domain of 'Mental health'.

Association between the SF-36 domains with the total scores of the Barthel scale of patients with stroke sequelae

As presented in Table 5, functional incapacity, assessed by Barthel index, had statistically significant correlation with almost no dimension of the scale of quality of life (SF-36). The only exception was for the 'Mental health' domain, which was correlated positively with the Barthel scale scores.

Table 5 – Correlation Analysis (Spearman coefficient) of the SF-36 domains scores for family caregivers with the Barthel scales total scores directed to the patient, João Pessoa, Paraíba, Brazil, 2013

Domains of health-related quality of life	Barthel	
	R	*p* value
Physical aspects	0.061	0.4822
Emotional aspects	-0.049	0.5702
Pain	-0.141	0.1028
Functional capacity	-0.031	0.7238
Social aspects	0.111	0.1974
Mental Health	0.176	0.0404*
Vitality	0.133	0.1220
General health status	0.006	0.9468

DISCUSSION

The act of taking care of someone becomes more and more frequent in everyday family life. The experience of suddenly becoming a caregiver raises concern and wear, which are directly related to emotional and physical exhaustion(14); thus, these aspects reflect negatively on the well-being and cause reduction in the quality of life of those who provide care for dependent persons.

Health-related quality of life is considered synonymous with the term "perceived health status" and has been widely evaluated, both nationally and internationally, by the instrument Short Form 36 (SF-36). The scores of the population, in general, range from 80 to 100, with scores near 50 indicating median condition for health and quality of life. From this perspective, it was found that the family caregivers showed compromise in almost all domains, except in functional capacity (73.00)(15).

The 'Pain', 'Mental health' and 'Social aspects' domains presented lower scores, i.e., they represented the greatest impact on the caregivers' quality of life. In a study conducted with caregivers of older adults in two outpatient segments of the city of Campinas-SP, the domain 'Pain' also showed lower score. However, when comparing the scores obtained in this study with others conducted with family caregivers, but of individuals not affected by stroke, there were, in general, lower scores in almost all dimensions(16-17). Such results may be related to functional and cognitive impairment that stroke can cause, impacting not only the life of the individual affected, but also that of their caregivers.

In this regard, a study on the evaluation of the quality of life of caregivers of patients functionally independent showed that all eight domains assessed by SF-36 were low, especially 'Pain' and 'Vitality', which obtained the lowest scores(18). However, the 'Mental health' and 'Social aspects' domains were the second and third, respectively, that obtained lower scores. This indicates a significant psychological and social impact on the caregivers' quality of life, which leaves them more prone to signs and symptoms of depression and anxiety.

A study on caregivers of older adults that rely on home health care, revealed, based on the evaluation of quality of life by SF-36, that the caregivers who changed their routine to provide care for older adults obtained a lower score in the 'Mental health' domain, when compared with those with no change in routine. This occurs because providing a dependent person with care brings changes to the caregiver's lifestyle, who starts to live in accordance with the needs of the other(19).

Ferreira(19) emphasizes the importance of developing formal and informal social support programs intended to prevent emotional, physical, interpersonal and occupational problems in family caregivers, in order to contribute to better quality of life of these people.

In the analysis of sociodemographic characteristics of individuals with stroke sequelae, related to the HRQOL domains, we observed no significant difference as for sex. However, Loureiro(20) emphasizes that men worry less about maintaining health, which makes them more susceptible to the occurrence of chronic problems that can evolve with functional impairment and more dependence. Moreover, they find it more difficult to accept the condition of dependence and the need for care, which contributes to worsening the caregivers' quality of life.

As for the age group, in this study, caregivers of individuals aged under 65 years showed better quality of life in the 'Social aspects' domain, compared with caregivers of older individuals, which suggests lower impact on the social life of this group of caregivers, after they take this function. Despite this aspect, Fernandes and Garcia(21) emphasize that the age of the dependent individual, itself, is not considered a deficit that can have an impact on the lives of caregivers; however, it constitutes an important risk factor for many diseases that can generate increased level of dependence and, consequently, greater demand for care.

In this context, simultaneously to the stroke sequelae, the process of senescence of older individuals contributes to worsen the stroke-related loss of functional capacity to perform daily life activities, which reinforces the need for continuous care, with negative influence on the caregivers' quality of life(22).

In addition, in this study we observed the highest scores for the 'Emotional aspects' domain in caregivers of married patients. The presence of the spouse in the life of a patient with some degree of disability or dependence, whether this spouse is the caregiver or not, seems to provide the patient with a strong emotional and coping support after the stroke. Amendola(23) points out the same reflection on caregivers when arguing that the presence of a partner, who can be the patient or not, can bring benefits in relation to feeling less lonely and more supported.

With regard to educational level, there were higher scores in the 'Mental health' domain in family caregivers of individuals who completed higher education. Educational level is of fundamental importance for an individual's capacity for comprehension, adherence and self-care(22). Thus, persons with higher educational levels tend to have more independence and autonomy, which contributes to lower demand for care and reduced overload for caregivers.

Functional incapacity of the patient with stroke sequelae, measured in this study by Barthel index, also results in higher demand for care for the caregiver. In this context, this study showed that caregivers of individuals with higher level of dependence for daily life activities showed deficit in the 'Mental health' domain, which culminated in compromised psychological sphere in this group of caregivers. The psychological dimension seems to be the first one affected in a situation of dependence, resulting in subsequent compromise of the physical state.

It is necessary to point out that the presence of a chronic disease, such as the post-stroke health condition, results in a major change in the everyday life of the patient's family. Becoming a caregiver is most often a stressing factor, and this causes loss of mental and physical health throughout the process of care and rehabilitation of the family member. The deterioration of health and self-care favors the development of diseases and/or pathological conditions in the caregiver. A research found that 65% of the sample of caregivers of dependent older patients present health problem(19).

Another study with the aim of determining the relation between the presence of morbidities and caregivers' quality of life using the WHOQOL instrument observed that the higher the number of morbidities of a patient, the lower the scores for the physical, psychological, environmental and social relations domains. These results demonstrate that the caregiver has limited self-care due to dedication, sometimes exclusive, to the patient, transferring attention, energy, time and activities to the objective of providing care to the other(24).

In a study of 13 groups of caregivers, whose main objective was to understand the construction of care in the Bedridden Patient Home Care Program (PADA), it was observed, in the report of all caregivers, the presence of guilt, stress, emotional and financial overload, suffering and desperation that were experienced on a daily basis(25).

Study limitations

We highlight that several factors may have influenced the results of this study and should be considered in interpreting such results. Using a cross-sectional design did not enable the examination of causal relations; moreover, the study does not allow us to determine if physical or cognitive attributes contribute to most of the association with outcomes.

Contributions to the field of nursing, public health or public policy

Stroke patients and their families should be included in the health professionals' care plan and context, with active listening actions, care and dialogue, among other important factors for humanization of assistance. Furthermore, effective strategies should be proposed with the objective of improving the caregiver's quality of life, mitigating the negative factors that reduce such quality, and, consequently, improving the care provided to patient in need(24).

The development and implementation of educational programs for caregiver support in which they can be heard and provided with information concerning the problems they face, during meetings and lectures before discharge and support via telephone, have shown significant difference in the caregivers' health, decreased overload, decreased symptoms of depression and improved quality of life(26).

Thus, this research is of great importance, since it broadens the knowledge and visibility of issues related to the family caregiver, providing health professionals and Government agencies with information in planning and developing support programs and policies, based on the specific needs of each caregiver and family. This research may also provide nursing care with information, within the sphere of primary care, as it will serve as theoretical support to redirect their view to this multidimensional phenomenon that involves the dependent patient, the caregiver and the family, in order to extend their assistance to the development of strategies and interventions to minimize the impact of the condition of dependence on the caregiver.

CONCLUSION

The health-related quality of life of family caregivers presented as compromised in almost all domains. As for the association between the caregivers' quality of life and sociodemographic characteristics of individuals with stroke sequelae, it was found that caregivers of individuals aged under 65 years, married, with 10 to 12 years of formal education, showed higher scores. However, caregivers of patients with higher degree of disability obtained lower score in the 'Mental health' domain.

The results of the research enabled reflection on the current context of health care, which requires modification in order to insert family caregivers of individuals with stroke sequelae in the care planning and actions provided by professionals in the various levels of health care. In this context, nursing professionals should be aware of the caregivers' health needs, providing holistic assistance and proper information whenever necessary.

However, to enable this practice to be implemented, the public spheres, in all hierarchical levels, need recognize this problem and be aware of the necessity of creating and implementing health policies geared to provide health care to caregivers, considering their quality of life. With this purpose, an initiative is the development of further research regarding the issue of the caregiver's quality of life, with a view to promoting comprehensive awareness raising concerning the relevance of this subject in the current context of health care.

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