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ORIGINAL ARTICLE / *ARTIGO ORIGINAL*

Quality of life of individuals with stroke and their caregivers in a city of Triângulo Mineiro

Qualidade de vida de indivíduos com acidente vascular encefálico e de seus cuidadores de um município do Triangulo Mineiro

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ABSTRACT: ***Objective:*** To compare the quality of life (QoL) of individuals with stroke and their caregivers. ***Methods:*** This is an observational cross-sectional survey, involving 83 individuals who suffered a stroke. The participants were divided into four groups: group of individuals with stroke who have caregivers (44), group of individuals with stroke without caregivers (39), group of caregivers (44) and a reference group (83) in the period of March to May 2010. To assess QoL, the instrument used was the WHOQOL-BREF. ***Results:*** The highest scores for the four fields were observed increasingly for the group of individuals with stroke with caregivers, the stroke group without caregivers followed by the group of caregivers and the reference group. The comparison of scores between groups showed that the presence of stroke and the fact of being caregiver affect QoL in all domains of WHOQOL-BREF. ***Conclusion:*** It was possible to understand the negative impact that stroke causes in the lives of the affected ones and their caregivers, in order to better target public health policies.

Keywords: Stroke. Caregivers. Quality of life. World Health Organization. /epidemiology. Public health.

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RESUMO: ***Objetivo:*** Descrever e comparar a qualidade de vida (QV) dos indivíduos com acidente vascular encefálico (AVE) e a de seus cuidadores. ***Métodos:*** Estudo observacional do tipo inquérito transversal, envolvendo 83 indivíduos que sofreram um AVE. Os indivíduos participantes foram separados em 4 grupos: grupo dos indivíduos com AVE que têm cuidadores (44), grupo dos indivíduos com AVE sem cuidadores (39), grupo dos cuidadores (44) e um grupo de referência (83) no período de março a maio de 2010. Para avaliação da QV, utilizou-se o instrumento WHOQOL-BREF. ***Resultados:*** Os maiores escores para os quatro domínios foram observados de forma crescente no grupo dos indivíduos com AVE com cuidadores, grupo de AVE sem cuidadores seguido pelo grupo de cuidadores e pelo grupo de referência. A comparação dos escores entre os grupos evidenciou que a presença do AVE e o fato de ser cuidador afeta a QV em todos os domínios do WHOQOL-BREF. ***Conclusão:*** Foi possível compreender o impacto negativo que o AVE causa na vida dos acometidos e na de seus cuidadores, para, com isso, melhor direcionar políticas públicas de saúde.

Palavras-chave: Acidente vascular encefálico. Qualidade de vida. Organização Mundial da Saúde. /epidemiologia. Saúde pública.

INTRODUCTION

In recent decades, there has been significant change in the mortality profile of the Brazilian population, with increased number of deaths caused by chronic diseases and external causes[1].

Among the numerous existing chronic diseases the cerebrovascular accident (CVA) stands out, which, according to Chagas and Monteiro[2], constitutes a disease of high incidence and high mortality and morbidity. Currently, 90% of survivors of a stroke develop some kind of disability, making it a leading cause of chronic disability in adults[3,4].

The CVA is a serious disease in Brazil, generating chronic disabilities, and cause loss of independence and often autonomy, which implies the need for someone to assist the patient in their difficulties in performing daily activities. The experience of caring for someone stricken by stroke has become increasingly common in everyday households[5]. In addition to specific training for dealing with the situation of caring for others, caregivers need social support to help them maintain their own health and to care for themselves[6].

The presence of chronic diseases not only changes the life of the affected individuals, but can also influence multiple aspects of their caretakers[7]. The CVA is considered the leading cause of disability and reduced quality of life[2].

According to the World Health Organization (WHO), the quality of life (QoL) is defined as "an individual's perception of their position in life in the cultural context and in the value systems in which they live and in relation to their goals, expectations, concerns and desires"[8]. Thus, the term QoL covers many meanings constituted by a variety of factors, objective and subjective, reflecting knowledge, experience and values of individuals and communities in a cultural, social and historical context[9].

Therefore, the CVA generates disorders in the lives of people affected, as well as their family members (often caregivers), who experience an additional burden of care targeted to patients with CVA, allowing the negative impact on their quality of life.

In Brazil, few studies assessing the quality of life of patients with CVA 3.10, as well as their caregivers were developed. To Sousa et al.[4], it is clear the need to evaluate the QoL of caregivers of chronically ill, especially those with neurological sequelae, since, in most cases, are dependent, which ends up generating family adaptations to their care and burden to their caregivers.

The objectives of this study were to describe and to compare the QoL of individuals with stroke and their caregivers.

METHODOLOGY

This is an observational cross-sectional survey type. A survey of the number of individuals affected by CVA registered in the Estrategia Saude da Família (EsSF) of a municipality of Triangulo Mineiro was performed by means of the registration data of families accompanied by the Equipes de Saúde da Família (ESF).

Participants were interviewed during the months from March to May of 2010 by a single researcher. We opted for direct interview in the application of the instrument of quality of life due to the potential difficulty of reading and literacy among participants. After approval by the Ethics and Research Committee of the Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo (FMRP-USP), protocol nº 10185/2009, those who agreed to participate in the study was requested signing the consent form.

According to the survey conducted by analyzing the charts of each ESF, 140 individuals who had a diagnosis of stroke were found, but only 83 of these met the inclusion criteria — being affected by stroke for 3 or more months, individuals of both sexes aged over 18 years. Those individuals who have suffered a stroke within 3 months who were carriers of stroke associated with other neurological diseases (like Parkinson's disease, Alzheimer's dementia), with neurological changes involving the mechanisms of language (aphasia) and understanding that were excluded prevent them from answering the questions reliably.

Of the 83 participants, 44 had caregiver and 39 did not need one. For a better QoL assessment, participants were divided into four groups: group of individuals with stroke with caregivers, group of individuals with stroke without caregivers, the caregivers' group and the reference group. For a proper appreciation of the evaluation results, it is important a comparison with a reference group consisting of socially and demographically similar people to patients and caregivers without, however, being stroke patients or caregivers. Thus, the reference group consisted of 83 individuals assisted by EsSF without being affected by a

CVA, with age and sex comparable to the group of individuals with stroke without serious chronic comorbidities and who lived nearby a group of people with stroke.

For the assessment of quality of life, the generic WHOQOL-BREF instrument was administered to all groups. The WHOQOL-BREF is an abbreviated version of the WHOQOL 100, composed of 26 questions that got the best performances drawn from this psychometric standard instrument of the WHO for assessing quality of life. Of these 26 questions, the first two are generic and do not enter the calculation of scores for any of the domains. The shortened version consists of four domains: physical, psychological, social relations and environment. The scores for the domains ranging from 0 to 100, 0 being the worst quality of life and 100 the best[11].

The questionnaires, after coded and reviewed, were entered and stored in the Excel® program. Data analysis was performed with STATA/SE-11 program. For the comparisons of the scores of the various groups it was used the Kruskal-Wallis with comparisons between contrasts and treatments. Was still employed the Wilcoxon test for paired samples in the case of individuals in the group with stroke with caregivers compared with their respective caregivers. This comparison also was made using the Kruskal-Wallis test, it was reapplied to take into account any correlations between the two groups. Once detected a rejection of the hypothesis of equality, the groups were compared two by two by the same test. Correction for multiple comparisons was used with the "Bonferroni technique". Non-parametric tests were used because they are variables resulted of scales (scores) for which these types of tests are more appropriate.

Tests were considered significant when $p < 0.05$. The p-values should be interpreted on the assumption that the sample is a simple random sample from a population with similar characteristics. To check the internal consistency of the WHOQOL-BREF in the studied sample, the Cronbach's alpha coefficient was applied.

RESULTS

Most individuals affected by stroke were male (53%) with a mean age of 61.93 years. Caregivers were mostly female (70%) and their son/daughter (39%).

The result of Cronbach's alpha coefficient for the WHOQOL-BREF instrument has proven reliable in the study sample, with $\alpha = 0.79$ results for the group of individuals with stroke and caregivers, for the reference group was $\alpha = 0.7612$.

The Table 1 refers to the first two questions of the WHOQOL-BREF, related to overall quality of life. The group of individuals with stroke who have caregivers had the lowest mean scores for quality of life. The highest mean scores were obtained for the reference group.

Table 1 also refers to the mean scores for each domain of the WHOQOL-BREF and the general quality of life for all groups. Regarding the overall quality of life, the group with stroke with caregivers had the lowest mean score. We can observe that in the physical, psychological and environmental domains the average score was lower for the group with stroke with caregivers. The highest mean scores for these three domains were observed with increasing frequency in the CVA without caregivers' group followed by the group of caregivers and the reference group that obtained the highest scores in all domains and overall quality of life. In the social relations domain, we can observe that the mean score for the CVA with caregivers' group (71.02) was slightly higher than the mean score of the CVA without caregivers' group (70.94).

The Table 2 shows the comparisons between all groups performed using the Kruskal-Wallis test.

The comparison between groups showed that in the physical domain there was no significant difference only between the group of caregivers and the reference group. In the psychological domain, there was no significant difference between the CVA with and without caregivers' groups or between the caregivers' group and the reference group. In the social domain, there is no significant difference between the CVA with caregivers' group and the caregivers' group nor between the CVA without caregivers' group and the caregivers' group. Finally, in the domain environment, there is no significant difference between the CVA with caregivers' group and the CVA without caregivers' group, between the CVA with caregiver' group and the group of the caregivers, and between CVA without caregivers' group and the caregivers' group.

Using the Wilcoxon test, the comparison between the scores of the CVA with caregivers' group and the caregivers' group showed significant differences in the groups ($p = 0.01$), psychological physical domains ($p = 0.04$) and overall QoL ($p = 0.02$).

Table 1. Distribution of mean scores and standard deviations of questions 1 and 2 and domains of the WHOQOL-BREF for all groups - Conceição das Alagoas, Minas Gerais, 2010.

Questions 1 and 2 and domains	CVA with caregivers (n = 44) Mean ± SD	CVA without caregivers (n = 39) Mean±SD	Caregivers (n = 44) Mean±SD	Reference (n = 83) Mean±SD
1) How would you rate your quality of life?	60.22 ± 1.96	66.02 ± 1.94	65.90 ± 1.71	71.98 ± 2.08
2) How satisfied are you with your health?	54.54 ± 2.96	64.7 ± 2.61	71.02 ± 2.40	81.92 ± 2.18
Physical	47.56 ± 2.29	61.17 ± 3.28	71.18 ± 2.94	75.68 ± 1.89
Psychological	61.07 ±2.79	64.42 ± 2.46	69.60 ± 3.06	75.40 ± 1.46
Social relations	71.02 ± 3.42	70.94 ± 3.95	78.78 ± 2.48	84.53 ± 1.76
Environment	58.45 ± 2.16	60.09 ± 2.55	61.36 ± 2.27	67.54 ± 1.48
Overall QOL	57.38 ± 3.20	63.38 ± 3.09	68.46 ± 2.55	76.95 ± 1.96

CVA: stroke; QoL: quality of life.

DISCUSSION

It was used the WHOQOL-BREF instrument that measures the quality of life in a global manner, being more suitable for groups as used in this research.

The discussions of the results are limited because of the lack of studies applying the WHOQOL-BREF in patients with stroke and their caregivers, especially in Brazil. It's apparently a really unexpected data, since there is intense application of the instrument in the biomedical area, but on the other hand, gives this work an increased importance for its uniqueness. Some international studies use this instrument, but it is believed that studies carried out in Brazil with this tool provide a better knowledge of the quality of life in this specific population.

The studies found in Brazil that evaluated the quality of life of individuals affected by CVA, as well as studies that evaluate the quality of life of caregivers, used mostly the SF 36 instrument (The Medical Outcomes Study Short Form 36)[3,4,13].

In some international studies[14-18] using the WHOQOL-BREF instrument, it was observed that the quality of life of an individual is greatly affected after a stroke.

Table 2. Comparisons of the scores of quality of life among various groups in each domain of WHOQOL-BREF.

Grups/Domains	Physical	Psychological	Social	Environment	Overall QoL
Test results Kruskal-Wallis´test p-value	57.953 0.0001	22.484 0.0001	16.592 0.0008	11.853 0.007	31.632 0.0001
1) CVA with caregivers X CVA without caregivers	0.002	0.30	0.438	0.321	0.058
2) CVA with caregivers X Caregivers	0.001	0.004	0.095	0.253	0.011
3) CVA with caregivers X Reference	0.001	0.001	0.003	0.001	0.001
4) CVA without caregivers X Caregivers	0.011	0.021	0.132	0.428	0.266
5) CVA without caregivers X Reference	0.001	0.003	0.009	0.009	0.001
6) Caregivers X Reference	0.118	0.127	0.027	0.013	0.004

QOL: quality of life; CVA: stroke.

In the study by Baune and Aljeesh[14], it was compared the QoL of hypertensive people with and without CVA. People with stroke had a significantly lower QoL than those hypertensive patients who have not had a CVA. Zalihic et al.[15] compared the quality of life of individuals who have suffered a CVA with individuals who have suffered an acute myocardial infarction. The quality of life was significantly worse in patients with stroke compared with those with acute myocardial infarction.

Gupta et al.[16] observed in their research with neurological patients, of whom 40% had been affected by a CVA, that the mean scores of the WHOQOL-BREF was lower in the physical domain (38.83) followed by psychological (50.76), social (48.53) and the environment (49.13). Also was concluded that all domains of quality of life are affected and those people affected need to participate in a rehabilitation program. The area most affected in the study by Pan et al.[17] was physical, followed by psychological, social relationships and environment. In the Bölsche et al.[18] study the physical domain obtained improval during his intervention, while the social relations domain was most affected.

Rombough et al.[19] conducted a review of the tools that could be used in assessing the QoL of caregivers of individuals with stroke and found nine instruments, among them the WHOQOL-BREF, which was used in only one study[20]. In the mentioned study[20], the WHOQOL-BREF was administered before and after hospital discharge and it was found that the scores of the social relations and of the environment domains of the caregiver decreased after hospital discharge.

In another related study of QoL of caregivers of individuals with CVA in Nigeria using the WHOQOL-BREF it was also found that these caregivers had significantly lower averages in the four QoL domains (physical health, psychological health, social relations and environment) when compared with the general population[20].

By analyzing all these studies assessing quality of life in individuals with stroke and their caregivers, even with the use of other instruments of research, it was found that both in national studies as in other countries, the evaluation scores of quality of life is low for these groups.

For the analysis of the WHOQOL-BREF was found that in all domains for the group of individuals with stroke who have caregivers and the group of individuals with stroke without caregivers the mean scores were lower than the mean scores of the group of caregivers and the mean score of the lowest than that of the reference group. As expected, the reference group presented the highest average scores in all domains. From this data, we noticed how the occurrence of a CVA harms the quality of life of the affected individuals, as well as his caretaker.

Regarding the scores of quality of life, they are a positive scale (higher scores indicate better quality of life), and there are no cut points to determine a score below or above in which it can be evaluated the quality of life as "bad" or "good"[21,22].

The overall QoL refers to the average between the first two questions of the WHOQOL-BREF. In question 1, we evaluated the QoL in general, and the Question 2 assess satisfaction with one owns health[23]. These questions embody important aspects of quality of life[11], the lowest averages being found in the stroke with caregivers group. This may be due to worse general health of the individual who needs a caregiver.

The analysis of data on the WHOQOL-BREF showed no negative influence on the quality of life of individuals affected by a CVA that have caregiver in one that does not require a caregiver in all domains, except in the social relations domain, where the mean score for the group without caregivers was lower than the mean score of the group with caregivers. This fact demonstrated that social relations highlight the importance of the satisfaction with the family support and friends.

According to the WHOQOL-BREF, the social relations domain relates to personal relationships, social support and sexual activity, and depends on just three issues, one being about sexual activity[23]. In this area there were individuals with stroke, especially in stroke group with caregivers, who had a little trouble answering this question, because there is no option for those who have no sexual activity and they were confused during the application not knowing what answer to choose. The majority reported that even though had no sexual activity were satisfied or very satisfied with such state. This would explain the slightly higher average score for this group, being the social relations domain the one that had the highest mean score for the group of individuals with stroke with caregivers. The group of individuals with stroke with caregivers can somehow develop greater capacity for accepting facts and resilience. Also because they require "care", family and friends came over and dispense more attention to they. This fact also highlights the importance of satisfaction with family support and friends, which can not exist in the group of individuals with stroke without caregivers.

The quality of life, according to the WHOQOL-BREF, the physical domain is: activities of the daily life, dependence on medications, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work ability[23]. This was the most affected domain in the group of individuals with stroke with caregivers, because with the occurrence of stroke, the individual starts to have limitations and/or compromises on all its functionality and performance of activities. The individual who has suffered a stroke and starts to require a caregiver presents a decrease of its autonomy. For the group of caregivers and the reference group, this was one of the domains least affected. For the Caregiver, it was possible to give this better score because it needs to be well to give physical care to the dependent person. In the group without CVA caregivers, the physical domain was the second most affected. This is due to the fact that the individual can carry out their activities without the need of a caregiver, thus preserving much of its autonomy.

The psychological domain relates to body image and appearance, feelings, self-esteem, spirituality, religion and personal beliefs, thinking, learning, memory and concentration[23]. In this research, this area was affected in both groups of patients with stroke and in the group of caregivers. In this last group, the psychological domain was the one that had the second lowest mean score. This can be explained by the fact that the activity of care cause stress and emotional overload, also privation of activities and socializing.

However, it was expected that the psychological domain was most affected in the group of caregivers. In a study[3] on caregivers of people with stroke using the SF36, the authors report that such people showed significant emotional compromises and emphasize the importance of a targeted program for them for assistance and guidance. In a study[24] evaluating the quality of life of caregivers using another assessment tool, it was observed that caregivers had a better QoL compared to people affected by stroke and also the caregiver's QoL did not increase after one year of care. We can see that the carers participants of this research could cope well with the difficult task of being a caregiver for people with stroke. Attention should be given to psychological needs, and services should be designed to improve the hard work of caregiver[25].

For individuals with stroke, the psychological aspect is how these individuals have their personal beliefs, accept their physical appearance and can develop thinking and concentration for a better relearning. The psychological impact becomes important in understanding the manifestations and impact of disease, which can often be used through individual strategies developed to circumvent limitations. The psychological well-being can promote healthy behaviors, since people endowed with a sense of self-worth believe in its power to control and are optimistic about their future, and more likely to adopt healthier habits and conscious[26].

The environmental domain is related to the improvement of financial resources, freedom, physical safety and security, accessibility and quality of social and health services; domestic environment, opportunities for acquiring new information and skills, leisure, physical environment and transport[23]. This was the domain in which they obtained the lowest scores for the group of individuals with stroke without caregivers, for the caregivers' group and the reference group. Perhaps the lowest score has been achieved in this domain due to the fact that the issues of safety and environment affect everyone. Others topics in this domain are seriously influenced by the socioeconomic issue because most of the assessed people are part of the lower classes. Thus, it is believed that the lack of funds prevents better scores to be obtained in this domain. Similar data were found in the study of Paulo et al.[26].

The environmental and social relations domains are greatly affected after a cerebrovascular accident[27]. Some of the factors that are associated with it may be depression, diet, lack of exercise, pain in the affected part, sex, marital status, financial situation, some of which are potentially modifiable. Thus, it is recommended that all affected have some group activity and self-help activities, which can help in promoting socialization and reintegration of community life.

Also according to this study, the data obtained by Fleck et al.[28] showed that issues relating to the environment also had great impact on the quality of life of individuals.

According to the Miranzi et al.[29] study regarding QoL on a scale of 0 to 100, the values for the domains that had values above 50 are considered to be a good perception of quality of life, that is, showed good scores. In the present study, only the physical domain in the stroke with caregivers' group had a mean score lower than 50. The highest values were seen in the social relations domain followed by the psychological and the environmental domains. So, overall, the participants in this study showed a good perception of their quality of life.

Two studies which assess both the quality of life of individuals with stroke and their caregivers were found, one in Sweden[13] and one in are Paulo[3], but in both studies the instrument used was the SF36.

In the study by Jönsson et al.[13], individuals with stroke and their caregivers were evaluated in two periods and it was found that the QoL of individuals with stroke improved after one year, while the QoL of their caregivers were not improved. The QoL of caregivers was worse than that of patients for emotional and mental factors. Although the physical function of the patients presented the worst QoL scores in both periods, there was improvement in QoL related to social, emotional and mental domains, attributed to better adaptation to the new life.

In the Brazilian research Makiyama et al.[3], it was concluded that almost all domains of SF36 in this study were altered compared with the control group, suggesting a reduction in quality of life in stroke patients and their caregivers. In regard to emotional and mental components, we observed a greater impact of disability on both patients and caregivers. Overall, the quality of life of these two groups was lower than the control group.

In the present study, the results were comparable to the two studies mentioned above, even if we cannot infer any direct comparison, since, although assessing the "quality of life", the instruments involved are distinct.

In a survey conducted by Adams[20] in Australia in 2003, the WHOQOL-BREF was administered to individuals with stroke and their caregivers. The most affected domain for survivors of a stroke was physical, followed by psychological, environmental and social relations. For caregivers, the WHOQOL-BREF was administered before and after hospital discharge, and it was found that the scores of the social relations and of the environment domains of the caregiver decreased after hospital discharge of the individual with stroke. This researcher concluded that caregivers need support to adapt to their new life and that to know the impact of a stroke on the caregiver's QoL is important to increase understanding of health professionals about their QoL, thus promoting the improvement of health care survivors of a CVA and their caregivers in the community.

In general, it was found that the perception of quality of life is worst for all individuals with stroke and their caregivers when compared among themselves and with the reference group.

CONCLUSIONS

It is important to emphasize the need to assess the patient holistically, considering all aspects of their health, including their opinion about it. This care can offer us great help for understanding the individual and for choosing the best form of treatment and rehabilitation.

Besides the importance of evaluating the quality of life of this population, deserved attention must be directed to those who live daily with the arduous task of care.

It is hoped that this findings provide subsidies for the implementation of new strategies of public health policies for improving the conditions of life and the health-care of that population.

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