

Correlation between quality of life and morbidity of the caregivers of elderly stroke patients

CORRELAÇÃO ENTRE QUALIDADE DE VIDA E MORBIDADE DO CUIDADOR DE IDOSO COM ACIDENTE VASCULAR ENCEFÁLICO

CORRELACIÓN ENTRE CALIDAD DE VIDA Y MORBILIDAD DEL CUIDADOR DE ANCIANO SON ACCIDENTE CEREBROVASCULAR

Nilce Maria de Freitas Santos¹, Darlene Mara dos Santos Tavares²

ABSTRACT

The objective of this study was to describe the sociodemographic characteristics and the quality of life of the caregivers of elderly individuals with a stroke history, and correlate morbidity with the caregivers' quality of life scores. This is a cross-sectional household survey that interviewed the caregivers of elderly individuals using the following tools: a semi-structured instrument; the World Health Organization Quality of Life-BREF; and the Brazilian Multidimensional Functional Assessment Questionnaire. Descriptive analysis and Pearson's correlation ($p < 0.05$) were performed. Most participants were female (93.5%), with a mean age of 55.4 ± 14.17 years, married or living with a partner (58.7%), with four to eight years of education (28.3%), and an income equivalent to one minimum wage salary (34.8%). The highest quality of life score was in the social relations domain (67.57) and the lowest was in the environmental domain (54.82). The highest number of caregiver morbidities correlated with the lowest scores in all quality of life domains.

DESCRIPTORS

Caregivers
Quality of life
Stroke
Aged

RESUMO

Este estudo objetivou descrever as características sociodemográficas e a qualidade de vida dos cuidadores de idosos com histórico de acidente vascular cerebral e correlacionar o número de morbididades com os escores de qualidade de vida do cuidador. Inquérito domiciliar transversal que entrevistou cuidadores de idosos utilizando-se de instrumentos: semi-estruturado; World Health Organization Quality of Life-abreviado e Brazilian Multidimensional Functional Assessment Questionnaire. Foi realizada análise descritiva e correlação de Pearson ($p < 0,05$). Prevaleceu o sexo feminino (93,5%), idade média de $55,4 \pm 14,17$ anos, casados ou moram com companheiro (58,7%), com 4|–8 anos de estudo (28,3%) e renda de 1 salário mínimo (34,8%). O maior escore de qualidade de vida foi no domínio relações sociais (67,57) e, menor no meio ambiente (54,82). O maior número de morbididades do cuidador correlacionou-se com menores escores em todos os domínios de qualidade de vida.

DESCRITORES

Cuidadores
Qualidade de vida
Acidente vascular cerebral
Idoso

RESUMEN

Este estudio objetivó describir las características sociodemográficas y calidad de vida de los cuidadores de ancianos con historia de accidente cerebrovascular y correlacionar el número de morbilidad con los puntajes de calidad de vida del cuidador. Investigación domiciliar transversal que entrevistó cuidadores de ancianos utilizando los instrumentos: semiestructurado; World Health Organization Quality of Life abreviado y Brazilian Multidimensional Functional Assessment Questionnaire. Fue efectuado análisis descriptivo y correlación de Pearson ($p < 0,05$). Prevalció el sexo femenino (93,5%), promedio etario de $55,4 \pm 14,17$ años, casados o viviendo en pareja (58,7%), con 4|–8 años de estudio (28,3%) y renta equivalente a un salario mínimo (34,8%). El mayor puntaje de calidad de vida se ubicó en el dominio "relaciones sociales" (67,57) y el menor, en "medio ambiente" (54,82). El mayor número de morbilidades del cuidador se correlacionó con menores puntajes en todos los dominios de calidad de vida.

DESCRIPTORES

Cuidadores
Calidad de vida
Accidente cerebrovascular
Anciano

*From the dissertation "Qualidade de vida e sobrecarga de estresse do cuidador de idoso com histórico de Acidente Vascular Encefálico", stricto sensu Program in Healthcare of the Triângulo Mineiro Federal University, 2010. ¹Physiotherapist. Master's in Healthcare Limeira do Oeste, MG, Brazil. nilcemfsantos@hotmail.com ²Registered Nurse. PhD in Nursing. Associate Professor of the Undergraduate Nursing Course of the Nursing in Education and Community Health Department of the Triângulo Mineiro Federal University. Uberaba, MG, Brazil. darlenetavares@enfermagem.ufm.edu.br

INTRODUCTION:

A stroke is conceptualized as a *focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death) and of presumed vascular origin*⁽¹⁾. Annually, 15 million people worldwide suffer a stroke, of these, five million die and another five million are disabled to some degree, generating functional incapacity⁽¹⁾. The persistence of disabling sequelae generates motor and sensory limitations, as well as difficulties in comprehension and the expression of thoughts. The dynamics of the life of the elderly person are changed, restricting their activities of daily living (ADLs) and often making them dependent on others to move and act with more or less independence. This requires a redefinition of roles among family members, as well as choosing someone to take responsibility for the care, with the figure of the informal caregiver emerging⁽²⁾.

The caregiver is a person of the family or the community, with or without remuneration, who performs the care for someone with physical or mental limitations⁽³⁾. Their function is to monitor and assist the individual to take care of him/herself and to carry out only the activities that the individual cannot perform alone. Some activities performed by the caregiver are: To listen, to be aware and to be supportive of the cared for individual, to help with personal hygiene, feeding, movement, and physical activity, to stimulate leisure and occupational activities, to change the position in bed and in the chair and to perform massage. Further tasks of the caregiver are to administer the medication, as prescribed and directed by the healthcare team, and to communicate changes in the health status to the healthcare team, among others⁽³⁾.

The demands originating from the act of caring can result in stress factors such as: direct, continuous, intense care and constant vigilance; ignorance or lack of information for the performance of the activity; work overload; exacerbation or the emergence of family conflicts; difficulty adapting the demands of the care situation to the resources available, including financial resources; reduction of social and professional activities; and the abandonment of leisure activities, among others⁽⁴⁾. This unease and tension are not tolerated over a long period of time, therefore the caregiver tends to create new ways of responding to overcome the crisis, possibly leading to positive adaptations or to unhealthy adjustments with negative emotional repercussions⁽⁴⁾, which influence their quality of life (QoL).

The comprehensive and complex concept of QoL is related to the multidimensional aspects of health, independence, the social relationships and the characteristics of the environment⁽⁵⁾. Quality of life is defined as *the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns*⁽⁵⁾. It is important to note that often the caregiver, due to the

level of involvement in caring for the elderly person, stops paying attention to his/her own personal needs. From this, physical problems start to appear due to the failure to perform self-care⁽⁶⁾. In recent years, the informal or family caregiver, has been the object of various studies⁽⁷⁻¹¹⁾. However, studies addressing the caregivers of elderly stroke victims, especially regarding their QoL are scarce^(7,11).

The investigation of the QoL of caregivers of elderly stroke victims and the possible associated factors, as proposed in this study, helps to identify the changes in life for this person after becoming a caregiver. The results may support actions directed towards the caregivers, aiming to contribute to an improvement in their QoL. Thus, the aims of this study were: To describe the sociodemographic characteristics and the QoL of the informal caregivers of elderly stroke victims, and to correlate the number of morbidities with the quality of life scores of the caregivers.

METHOD

...often the caregiver, due to the level of involvement in caring for the elderly person, stops paying attention to his/her own personal needs. From this, physical problems start to appear due to the failure to perform self-care.

This cross-sectional, observational study, carried out in the homes of the subjects, with a quantitative approach, was performed in the urban area of Uberaba-MG. To define the population (caregivers of dependent elderly stroke victims) data regarding elderly people who were hospitalized at the Hospital de Clínicas (HC) of the Triângulo Mineiro Federal University (UFTM), between July of 2003 and December 2008 was requested from the Department of Systems and Methods. The selection was based on the International Classification of Diseases (ICD) categories: I60, I61, I62, I63 and I64. The data requested were: name, address, telephone number, date of birth, date of hospitalization, development of discharge and place of hospitalization. During this period 1549 elderly people were hospitalized in the HC of the Triângulo Mineiro Federal University. Of these, those who lived in the city of Uberaba-MG and were 60 years of age or older at the date of admission were selected. Duplicate records were excluded. After this selection, 606 elderly people remained, who were contacted by telephone, aiming to identify those who were dependent on others and had informal caregivers. The inclusion criteria adopted were: To have been the informal primary caregiver for the elderly stroke victim for at least one year since the first episode, and to agree to take part in the study. Of the 606 elderly people who were contacted by telephone, 174 had died; 123 were independent and needed no caregiver; 60 had had their caregivers for less than 1 year; 11 did not agree to participate in the study; 35 had been institutionalized; and 157 had moved. Therefore, the study was conducted with 46 caregivers who met the inclusion criteria.

Data were collected in their homes, in the period April to June 2010. For the sociodemographic characteristics a semi-structured, previously tested instrument was used. The variables studied were: gender (male and female);

age in years; marital status (married or living with a partner, separated/divorced, widowed and single); housing situation (living alone, only with the elderly person they care for, only with the spouse, with others of the same generation, with children, with grandchildren, other arrangements, do not know); education, years of schooling (no schooling, 1|-4, 4|-8, 8, 9|-11, 11 and more), individual income in minimum wages (no income, <1, 1, 1-|3, 3-|5); and time as a caregiver in years.

To evaluate the functional capacity and to identify the morbidities of the elderly person part of the Brazilian Multidimensional Functional Assessment Questionnaire (BOMFAQ) was used, which was adapted and translated for Brazil⁽¹²⁾ from the questionnaire Older Americans Resources and Services (OARS). Functional capacity was measured through the ability to perform self-care activities (getting out of bed, eating, combing hair, dressing, bathing, walking, climbing a flight of stairs and cutting the toenails) and activities of daily life (going to the bathroom in time, preparing meals, taking medication at the right time, shopping, walking close to the house, cleaning and driving), and composed a score between 15 and 60 points, with a higher value equating to a more severe compromise⁽¹²⁾. To evaluate the morbidity of the elderly person and the caregiver, the caregiver answered questions as to whether or not certain morbidities existed, quantified with a total sum of between zero and 27⁽¹²⁾.

Regarding the quality of life (QoL) of the caregivers, the World Health Organization Quality of Life - BREF (WHOQOL-BREF) instrument was used, which is composed of four domains: Physical (pain and discomfort, energy and fatigue, sleep and rest, mobility, activities of daily living, dependence on medication or treatment, and work capacity); Psychological (positive feelings, thinking, learning, memory and concentration, self-esteem, body image and appearance, negative feelings, spirituality, religion, and personal beliefs); Social Relationships (personal relationships, social support, sexual activity); and Environment (physical security and protection, home environment, financial, health and social resources: availability and quality, opportunities to acquire new information and skills, participation in and opportunities for recreation/leisure, physical environment: pollution, noise, traffic, weather and transport)⁽¹³⁾.

A spreadsheet was constructed using Excel® and the data collected were entered in duplicate, in order to verify the consistency between the two databases. The data were analyzed using the "Statistical Package for the Social Sciences" (SPSS) version 17.0. program. Each domain of the WHOQOL-BREF was analyzed separately, using the syntax provided by the WHO. The scores ranged from 0 to 100, with the higher scores representing a higher QoL. Descriptive analysis was performed using absolute frequencies and percentages for the categorical variables and mean and standard deviation for the quantitative variables. Pearson's correlation test was used to verify the correlation between the number of morbidities and the QoL scores of the caregivers. The intensity of the Pearson's correlation coefficient was interpreted as: perfect positive ($r = 1$), strong positive ($0.8 \leq r < 1$), moderate positive (0.5

$\leq r < 0.8$), weak positive ($0.1 \leq r < 0.5$) and negligible positive ($0 < r < 0.1$), null ($= 0$), negligible negative ($-0.1 < r < 0$), weak negative ($-0.5 < r \leq -0.1$), moderate negative ($-0.8 < r \leq -0.5$), strong negative ($-1 < r \leq -0.8$), perfect negative ($r = -1$). Results were considered significant when $p < 0.05$. The study was approved by the Human Research Ethics Committee of the Triângulo Mineiro Federal University under protocol No. 1512. All the participants signed the Terms of Free Prior Informed Consent.

RESULTS

Table 1 presents the sociodemographic characteristics of the study population.

Table 1 - Frequency distribution of the sociodemographic variables of the caregivers of elderly stroke victims - Uberaba, MG, 2010

Variables	N	%
<i>Gender</i>		
Female	43	93.5
Male	03	6.5
<i>Marital status</i>		
Married or living with partner	27	58.7
Separated/Divorced	03	6.5
Widowed	04	8.7
Single	12	26.1
<i>Housing situation</i>		
Living alone	03	6.5
The elderly person under their care only	04	8.7
Spouse	04	8.7
Others of the same generation (with/without spouse)	04	8.7
Children (with/without spouse)	21	45.7
Grandchildren (with/without spouse)	03	6.5
Other arrangements	07	15.2
<i>Education (in years)</i>		
No schooling	05	10.9
1 -4	09	19.6
4 -8	13	28.3
8	08	17.4
9 -11	03	6.5
11 and more	08	17.4
<i>Income</i>		
No income	14	30.4
< 1	05	10.9
1	16	34.8
1- 3	09	19.6
3- 5	02	4.3

*Minimum wage = R\$ 510.00

The majority of the caregivers of the elderly stroke victims were female (93.5%) had a mean age of 55.4 years ($SD \pm 14.17$), had 4|-8 years of study (28.3%); were married or lived with a partner (58.7%); shared a house with children and/or spouse (45.7%); and were in the situation of caregivers for a mean of 3.2 years ($SD \pm 1.408$). In relation to income, 34.8% of the caregivers received one minimum wage and 30.4% had no income. The source of income was mainly from other sources (63%), as well as pensions and the salary as a caregiver, Table 1.

In the self-assessment of the quality of life the caregivers considered it as good (50%); neither bad nor good (37%); very bad (6.5%); and very good (6.5%). Concerning the self-assessment of the caregivers in relation to their satisfaction with their health, 41.2% said they were satisfied, 19.6% were dissatisfied, 19.6% very satisfied, 13% neither satisfied nor dissatisfied and 6.5% very dissatisfied.

Table 2 presents the scores of the QoL domains and their correlation with the number of morbidities of the caregiver.

Table 2 - Mean values and standard deviation of the quality of life domains correlated with the number of morbidities of the caregiver - Uberaba, MG, 2010

Quality of life domains	Mean	Standard deviation	Correlation number of morbidities	
			r	p
Physical	64.52	1.82	-0.556	<0.001
Psychological	56.34	1.26	-0.512	<0.001
Social Relationships	67.57	1.65	-0.280	0.059
Environment	54.82	1.49	-0.365	0.013

The highest quality of life score was in the social relationships domain (67.57) and lowest in the environment domain (54.82) (Table 2). There was moderate negative correlation between the number of morbidities and quality of life scores in the physical ($r = -0.556$; $p < 0.001$) and the psychological ($r = -0.512$, $p < 0.001$) domains, i.e. the higher the number of morbidities the lower the quality of life scores of the caregiver in the physical and psychological domains. The higher number of morbidities of the caregiver correlated weakly with lower quality of life scores in the environment ($r = -0.365$; $p = 0.013$) and social relationships ($r = -0.280$; $p = 0.059$) domains (Table 2).

DISCUSSION

The mean age of the caregivers was 55.4 years ($SD \pm 14.17$), similar to that found in studies conducted in São Paulo (56.72; $SD \pm 15.35$)⁽⁹⁾, Salvador (54 years)⁽¹⁴⁾ and Israel (54.9; $SD \pm 15.23$)⁽¹⁵⁾. The observation that the caregivers were mostly middle-aged can be related to the fact that it is culturally implicit in Brazilian society that it falls to the children and spouses to care for the elderly⁽¹⁶⁾. The higher percentage of women as the main caregiver corroborates other national^(11,14,17-18) and international⁽¹⁵⁾ studies, both with caregivers of elderly stroke victims and caregivers of elderly people with Alzheimer's disease⁽¹⁹⁾. Women have historically played the role of the primary caregiver, even with their entrance into the labor market. In general, this activity is socially accepted as natural, therefore, to care for elderly family members is another of the domestic roles that women assume⁽²⁰⁾. In this context, attention is drawn to the expectations of the women, since they had worked all their lives and would have liked to retire to enjoy the quiet of the home or to perform certain activities they had always wanted to do and never had the opportunity. They had developed various roles throughout life,

such as work, caring for small children and the husband, in addition to performing household chores and, at this stage of life, they were faced with the necessity of caring for an elderly dependent, postponing their dreams again. Conversely, some of these women felt comfortable and accomplished with the situation, considering that retirement would bring a feeling of worthlessness.

Concerning the marital status, the percentage of people married or living with a partner was similar to that of a study conducted in Ceará (50%)⁽²¹⁾ and lower than those of studies in São Paulo (74.3%)⁽¹⁰⁾ and Rio Grande do Sul (62.2%)⁽¹⁷⁾. In a study conducted in Sao Paulo with caregivers of patients with Alzheimer's disease a higher percentage (64.3%) was found⁽¹⁹⁾. In the majority of cases, the spouse took care of their companion, mainly motivated by a matrimonial obligation, the common life project and a commitment to be together in sickness and in health⁽²⁰⁾.

Considering education, a similar result was obtained in a study conducted in Rio Grande do Sul where 37.1% of the caregivers had 3-8 years of study⁽¹⁷⁾. A different result was found in another study, where 48.9% of the caregivers of elderly people had 11 years of study⁽⁴⁾. It is important to know the education level of the caregivers, because it is them that are receiving information and guidance from the healthcare team. It is emphasized that effective comprehension of health educational activities is related to the learning capability of people. Thus, low levels of education interfere, directly or indirectly, in the provision of care to the elderly. Misunderstanding the proposed therapy may compromise the quality of the service, because the caregiver needs to follow diets, prescriptions and handle medication, among other functions⁽¹¹⁾. However, changing this reality is not easy, although its recognition provides subsidies for healthcare professionals to develop strategies directed towards overcoming the difficulties encountered. The nursing team can assist the caregiver, accompanying their activities, identifying their learning requirements, developing health education and helping to prevent errors.

In relation to the individual monthly income, a lower mean (0.78 MW) was obtained in a study conducted with caregivers of dependent elderly people⁽¹⁰⁾. The fact that the majority of the caregivers had income from sources other than retirement and the salary as a caregiver indicates that there is an accumulation of activities, because the home care to the elderly stroke victim is performed in addition to the formal work carried out by the caregiver. However, financial stability is considered a necessity for everyone. Studies show that the disease has an impact on financial stability. The presence of a family member with a chronic illness entails extreme economic limitations for the family. These limitations are due to the fact that the chronic disease involves the continuous use of medication, which is not always available through the public health service. In addition, there may be a reduction in the family income due to the abandonment of formal employment in order to perform the function of caregiver⁽⁸⁾.

The mean length of time as a caregiver was higher than that of 2.3 years found in a study conducted in Fortaleza⁽¹⁴⁾.

A study with caregivers of elderly people with Alzheimer's disease obtained a mean length of time as a caregiver of 3.5 years⁽¹⁹⁾, similar to the present study. The length of time as a caregiver illustrates the chronic character of the disease. There is evidence that a longer length of time as a caregiver correlates to fewer psychological complaints, i.e. time is seen as a protective factor. Adaptation by the caregiver in the face of challenging situations has been observed⁽⁴⁾. A study obtained similar results regarding the self-assessment of the QoL by caregivers, with 39.4% self-reporting their QoL as good and 37.8% as neither good nor bad⁽¹⁰⁾. Regarding the self-assessment of health, the result differed, with 47% of the caregivers reporting being satisfied and 31.8% neither satisfied nor dissatisfied⁽¹⁰⁾.

The higher QoL score in the social relationships domain corroborates a study conducted with caregivers of dependent elderly people (60.85)⁽¹⁰⁾. However, in a study with caregivers of elderly people with Alzheimer's disease the highest score was in the functional capacity domain (63.6)⁽¹⁹⁾. The social relationships domain evaluates aspects related to personal relationships, social support and sexual activity⁽¹³⁾. Taking care of a dependent elderly person alone is not an easy task, with caregivers having a variety of feelings, as well as adding new activities to their usual routine. In this context, social support is highlighted, which provides feelings of support and protection for the caregiver through interpersonal, group and community relationships, which in turn lead to psychological well-being and stress reduction.

The lower QoL score in the environment domain corroborates studies performed in São Paulo (52.5)⁽¹⁰⁾ and Rio Grande do Sul (54.4)⁽⁴⁾. In a study conducted in São Paulo with caregivers of elderly people with Alzheimer's disease using the SF-36 instrument, the lowest scores were in the physical (58.1) and social relationships (58.1) domains⁽¹⁹⁾. The environment domain covers aspects related to physical security, home environment, financial resources, leisure, physical environment, and transport⁽¹³⁾. One study found that the family caregivers had their leisure and cultural activities altered due to the act of caring. A decrease in activities was reported, which represented considerable deterioration, as many believed that at that stage of their lives they should be enjoying leisure time, which could improve their QoL and indirectly favor the person being cared for⁽²²⁾. Concerning the differences of the caregivers of elderly people with Alzheimer's disease, a study concluded that they are more likely to have psychiatric symptoms, health problems, and family and work conflicts, when compared to people of the same age who do not perform this role⁽¹⁹⁾.

Regarding the home environment, the elderly stroke victim needs adaptations to carry out their activities of daily living. These adaptations are carried out in order to minimize the difficulties, providing the elderly person greater comfort and quality in their quotidian, as well as providing the caregiver with the appropriate assistance⁽²²⁾. However, such adjustments incur great expense, which is combined with the fact that the elderly require continuous expenditure for medical treatment. In the present study a low

income was encountered, which can make the adaptations to the home that promote the care difficult, and therefore negatively impact on the QoL of the caregivers.

It was observed that the greater the number of morbidities of the caregiver, the lower the QoL score in the physical domain. It is possible that the caregivers have limited time for their self-care because their attention is focused on the elderly stroke victim. The high degree of involvement with the care of the elderly person and self-care deficit demonstrate that to be a caregiver often entails putting aside their own life to take responsibility for the other person. Another aspect concerns the financial changes, which make the caregiver pay less attention to their personal needs and lead to the emergence of health problems⁽⁶⁾. The appropriate treatment of the morbidities and adherence to disease prevention activities can contribute to improving the quality of life of the caregiver, favoring the continuity of the home care and reducing or eliminating the institutionalization of elderly stroke victims.

It was observed that the greater the number of morbidities of the caregiver the lower the QoL score in the physical domain. Morbidities can affect the QoL of the caregiver leading to them present negative feelings regarding their body image and self-esteem, the aspects considered in the psychological domain⁽¹³⁾. The care can be assessed as onerous or a pleasure, dependant on how the caregiver manages to perform it. The caregiver sees the caring as a burden, not only due to performing the tasks themselves, but also due to the dedication required to meet the needs of the other person, to the detriment of their own needs. The caregivers stop caring for themselves and develop negative feelings about their body image. Quality care will only be carried out when the one who provides it is in good condition⁽⁶⁾. In this context, the healthcare team must be able to identify the potentials of the caregivers, and from this, encourage them to value their skills and feelings in order to reverse this condition and improve both their self-care and the care provided to elderly stroke victim.

A higher number of morbidities of the caregiver correlated with a lower score in the environment domain. From this perspective, it is presupposed that the care takes into consideration a transfers of resources from the caregiver to the elderly person. Donating time, money and the sharing of the physical space are some of the aspects evaluated in the environmental domain⁽¹³⁾. Furthermore, there was a decrease in leisure activities and opportunities for a social life when taking responsibility for the care of the elderly person. The nursing team can contribute to improving the QoL of caregivers in the environment domain by offering quality health and social care, and opportunities to acquire new information and skills. The use of strategies such as training, guidelines on ergonomics and adaptation of the home environment are intended to facilitate the techniques of care and to improve accessibility for the elderly.

It should be noted that higher numbers of morbidities of the caregiver correlated with lower QoL scores in the social relationships domain. The care is able to generate

effects that are felt in the personal life of the caregiver, affecting the elderly person, the family and the other social institutions. When there is no informal and formal support, the caregiver can be more exposed to illness, depression, negative emotional states and the disorganization of their life. Furthermore, the family feels possible material and social restrictions. As a result the elderly person can be subject to inadequate and ineffective care, can be institutionalized and can even be mistreated^(4,22). The healthcare services may be constituted as support units, providing the caregiver the opportunity to recognize and expand their social networks through activities which involve the elderly

person cared for, the family members and the community. Another aspect that must be considered is the emotional support, because often the caregiver needs someone to listen to them, to provide comfort and resilience.

CONCLUSION

These data can offer support for healthcare teams in the proposal of health strategies aimed at improving the quality of life of the caregiver and, therefore, qualifying the care provided to elderly stroke victims.

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