



# Correlation between quality of life of the aphasic patient and his family

## Correlação entre a qualidade de vida do paciente afásico e de seu familiar

## Correlación entre la calidad de vida de paciente afásico y su familia

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### Abstract

**Introduction:** Stroke is defined as the sudden death of brain cells due to lack of oxygen, caused by blockage of blood flow or rupture of an artery to the brain. Aphasia is a language impairment which occurs when someone suffers an injury in the brain related to this area. The loss of communication presented by aphasic person will reflect on social activities and daily life. The family involved also is affected by changing their quality of life. **Purpose:** to investigate the main factors that affect the quality of life of aphasic person and their families post stroke and to verify the correlation between these factors. **Method:** cross-sectional study approved by local ethics committee (FOB-USP). The population was composed of 24 participants, 12 aphasic individuals and 12 family members. Quality of life questionnaires were applied. First it was used the Stroke Specific Quality of Life Scale in the aphasic individuals and the World Health Organization Quality of Life - Abbreviated Instrument with family members. **Results:** the mobility and personal care were the least affected, language and behavior the most affected compared to aphasics. For family members, the least affected areas were personal relationships and psychological and the most affected were physical and environment. There was a statistically significant correlation between the quality of life for aphasic individuals and their families. **Conclusion:** findings revealed the damages in the family and aphasic individuals' quality of life after the stroke episode but also the influence of the life quality of the aphasic on the life quality of their families.

**Keywords:** Quality of Life; Aphasia; Caregivers; Stroke.

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## Resumo

**Introdução:** O Acidente Vascular Encefálico é definido como um rápido desenvolvimento de sinais clínicos de distúrbios focais ou globais da função cerebral trazendo como consequência sintomas com duração superior a 24 horas. Afasia é um comprometimento de linguagem, que ocorre quando alguém sofre um prejuízo no cérebro relacionado a esta área. Os prejuízos de comunicação apresentados pela pessoa afásica irão refletir nas atividades sociais e de vida diária. Os familiares envolvidos também se sentem afetados, alterando sua qualidade de vida. **Objetivos:** investigar os principais fatores que interferem na qualidade de vida dos afásicos após acidente vascular encefálico e de seus familiares e verificar se há correlação entre estes fatores. **Método:** Estudo transversal aprovado pelo Comitê de ética local (FOB-USP). A população foi composta por 24 participantes, sendo 12 sujeitos afásicos e 12 familiares. Foi realizada aplicação dos questionários de qualidade de vida, sendo utilizada com os sujeitos afásicos a Escala Específica de Qualidade de Vida em Doenças Cerebrovasculares e com familiares o Instrumento Abreviado de Avaliação de Qualidade de Vida da Organização Mundial da Saúde. **Resultados:** os domínios mobilidade e cuidados pessoais foram os menos afetados e linguagem e comportamento os mais afetados em relação aos afásicos. Para os familiares, os domínios menos afetados foram relações pessoais e psicológico e os mais afetados foram físico e meio ambiente. Houve correlação estatisticamente significativa entre a qualidade de vida dos indivíduos afásicos e de seus familiares. **Conclusão:** observou-se prejuízo tanto na qualidade de vida do familiar como também do indivíduo afásico após o episódio de acidente vascular encefálico, além da influência da qualidade de vida do afásico na qualidade e vida do seu familiar.

**Palavras-chave:** Qualidade de Vida; Afasia; Cuidadores; Acidente Vascular Cerebral.

## Resumen

**Introducción:** El Accidente Cerebrovascular se define como desarrollo rápido de signos clínicos de alteraciones focales o globales de la función cerebral teniendo como consecuencia síntomas que duren más de 24 horas. La afasia es un trastorno del lenguaje, que se produce cuando una persona sufre una pérdida en el cerebro, relacionada con esta área. Las pérdidas de la comunicación presentadas por la persona afásica se reflejarán en las actividades sociales y en la vida cotidiana. Los miembros de la familia involucrados también se sienten afectados y su calidad de vida se altera. **Objetivos:** Investigar los principales factores que afectan la calidad de vida de los pacientes afásicos decurrente de un accidente cerebrovascular y de sus familias y comprobar si existe una correlación entre estos factores. **Método:** Estudio transversal aprobado por el comité de ética local (FOB-USP). La población estuvo conformada por 24 participantes, 12 sujetos afásicos y 12 familiares. Fueron aplicados cuestionarios de calidad de vida y se utilizó, con los sujetos afásicos, la Escala Específica de Calidad de Vida en las Enfermedades Cerebrovasculares y con la familia, el Instrumento Abreviado de Evaluación de Calidad de Vida de la Organización Mundial de la Salud. **Resultados:** para las personas afásicas, movilidad y cuidado personal fueron los dominios menos afectados, lenguaje y comportamiento los más afectados. Para los familiares, los dominios menos afectados fueron relaciones personales y psicológico, los más afectados fueron físico y medio ambiente. Hubo una correlación estadísticamente significativa entre calidad de vida de los individuos afásicos y de sus familiares. **Conclusión:** Se observó pérdida tanto en la calidad de vida de la familia, como en la del individuo afásico después del accidente cerebrovascular; además de la influencia de la calidad de vida del afásico en la calidad de vida de su familia.

**Palabras clave:** Calidad de vida; Afasia, Cuidadores; Accidente Cerebrovascular.

## Introduction

The World Health Organization (WHO) defines stroke as the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. It has no other apparent cause than vascular origin<sup>1</sup>. In Brazil, about 30% to 48% of the survivors have a disability and are unable to return to work, especially in the first year after the stroke, and often get dependent on aid for daily activities at different levels of care<sup>2</sup>.

Aphasia can be defined as a disorder in language processing due to brain damage<sup>3</sup> and it happens to one-third of people affected by stroke in the acute phase<sup>4,5</sup>. It can cause changes in the social networks, the individual may depend on others to perform tasks that previously it was performed alone, and feel excluded from the active adult role in the family and other social environments<sup>6-8</sup>.

Family members involved are also affected because they are not prepared to deal with those limitations that change their quality of life<sup>9,10</sup>. Aphasia often puts the caregiver in the role of individual interpreter of the person whose language was affected by neurological damage. The caregiver becomes the mediator between the person they care after and the outside world<sup>11</sup>.

Caregivers of stroke sequel patients live with physical and emotional burden constantly, by working the liabilities, financial burdens and uncertainties<sup>12</sup>. The damages of the caregivers' life quality (physical and mental) interferes negatively in the rehabilitation process of the person cared<sup>13</sup>, considering the physical and psychological limits<sup>14</sup>.

The rehabilitation planning has to consider quality of life and the interactions of patients in their daily lives as well as the quality of their relationships in their routine<sup>11</sup>.

Measuring instruments of quality of life related to health seek to maintain the multidimensional character and also evaluate the general perception of quality of life, although the focus is usually the symptoms, disabilities or limitations caused by the illness<sup>15</sup>. Those instruments were developed for various purposes and may be applied through general health scales and specific scales related to the disease<sup>16</sup>.

The objectives of this study were to investigate the main factors that affect the aphasic individual

and their families' quality of life, describing the most affected areas in each questionnaire and to verify the correlation between life quality of the aphasic individual and the quality of life of their families.

## Method

A The study was approved by the Ethics Committee on Human Research of the home institution, process no. 31/2009, respecting the resolution 196-96.

This is a cross-sectional study in which 40 patients' records were reviewed to select the sample from the total number of patients who are in treatment at the Clinic of Speech Therapy in Adult Language internship. The inclusion criteria for selection were: aphasia due to stroke; patients with no change in language comprehension verified by the assessment described in medical records; adults and elderly without restriction age groups and education levels. Exclusion criteria for this group were: aphasia due to traumatic brain injury and / or degenerative diseases. The time of injury, type of aphasia and period that the individual is taking speech therapy sessions were considered for sample characterization, not being part of the statistical analysis. Therefore, the variables of interest in this research were aphasic individuals and their families. After analyzing the records, 28 were excluded for not fitting the inclusion criteria. The group one was composed by 12 aphasic individuals, five females and seven males.

To form group two, 12 family members of aphasic individuals from group one were selected. Nine women and three men following the inclusion criteria: daily contact with the aphasic; have family relationship and to be the main caregiver of the aphasic individual; adults and elderly without restriction age groups and education levels. All participants signed the Informed Consent (IC) before participating in the research.

This study was conducted in the Speech Language Pathology Clinic of the Dentistry Faculty of Bauru, University of São Paulo (FOB-USP).

To assess the patients' quality of life after the stroke episode, the Stroke Specific Quality of Life Scale (SSQOL)<sup>17</sup> was applied to aphasic individuals. Its translation and cultural adaptation were performed in 2000 and validated by the same author in 2007<sup>18,19</sup>. The World Health Organization Quality

of Life - Abbreviated Instrument (WHOQOL-Bref) was applied to the family caregivers.

SSQOL contains 49 items divided into 12 areas and it has two parts. The first part includes 27 questions that evaluates the degree of difficulty of the individual in such abilities as: mobility (M - six items), the upper limbs function (FMS - five items), work / productivity (T / P - three items), the vision (V - three items), language (L - five items) and personal care (CP - five items). The response options and their scores for this first part are: impossible to perform (one point), too much trouble (two points), some difficulty (three points), little difficulty (four points) and without any difficulty (five points). The second part consists of a list of 22 statements in which the individual must infer opinion on: energy (E - three items), mood (A - five items), social relations (RP - five items), family relationships (RF - Three items), thinking (MP - three items) and behavior (C - three items). The response options and their scores can be: strongly agree (one point), partially agree (two points), and do not agree nor disagree (three points), partially disagree (four points) and strongly disagree (five points). Quantitation of responses is performed according to the Likert point scale from one to five points, considering the minimum score of 49 points and the maximum score of 245 points<sup>19</sup>.

To assess the quality of life of aphasic individuals' family caregivers, the World Health Organization Quality of Life - Abbreviated Instrument (WHOQOL-Bref)<sup>20</sup> was applied due to the need for instruments that require less time to fill out the information and to maintain the qualities of the WHOQOL-100 psychometric characteristics. The abbreviated version of this scale was adapted. This instrument consists of 26 questions; two general questions; one concerning quality of life and the other on the general health. The remaining 24 questions represent each one of the 24 aspects

found in the original instrument (WHOQOL-100) and they are divided into four domains: physical, psychological, social relations and environment<sup>20,21</sup>.

For both groups the questions and the response options were read. When the participant did not understand what was asked, the researcher rephrased the question being careful not to modify the original meaning. It is significant that the family members were asked to answer the questions according to the changes in their routine after the patient's illness.

For the statistical analysis of this study it was used the Microsoft Excel 2007 program and the statistical program SPSS 16.0. To correlate the questionnaires of aphasic individuals and the family members, it was used the Spearman correlation coefficient. In all statistical procedures it was adopted a significance level of 5% ( $p < 0.05$ ).

## Results

Group one had an age average of 66 years old and a standard deviation of 10.40 years old and group two, presented an age average of 54.67 years old and standard deviation of 14.29 years old.

The average injury time was two years and 9 months, and the average duration of exposure to the rehabilitation was of two years. All aphasic individuals participants of this study, attended speech therapy sessions before reaching one year of injury from the date of cerebral injury.

Aphasia type found in this study was Transcortical Motor (50%), followed by Broca (33%) and Anomic (17%).

### General quality of life of aphasic individuals

To set the individual final scores of aphasic subjects it was performed the sum of the numerical score for each domain (Table 1).

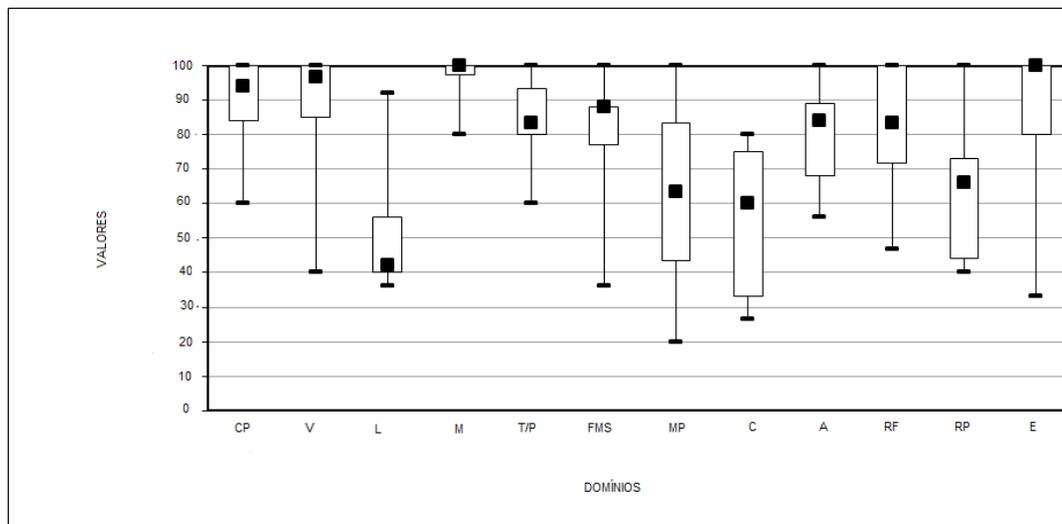
**Table 1 - Description of the individual scores for each domain and the total score of the specific scale of quality of life in cerebrovascular diseases applied with aphasic individuals**

Individual	CP	V	L	M	T/P	FMS	MP	C	A	RF	RS	E	TOTAL
1	21	6	9	30	14	21	8	12	22	11	11	15	180
2	25	15	14	30	13	22	4	10	23	15	19	15	205
3	25	11	10	30	12	23	15	12	22	15	25	15	209
4	21	15	11	30	15	22	14	11	25	15	16	15	210
5	25	15	14	30	15	22	15	8	17	15	18	15	209
6	25	13	18	30	14	22	7	3	25	15	10	15	197
7	15	12	10	27	9	9	11	5	14	7	13	15	147
8	25	25	23	30	13	25	12	4	21	12	24	8	222
9	20	15	8	27	12	14	12	6	18	10	17	9	168
10	22	14	10	24	12	22	7	5	17	13	10	15	171
11	25	15	11	30	9	21	3	11	16	10	17	5	173
12	21	14	10	30	13	14	5	12	21	12	11	13	176

CP= personal care; V= vision; L= language; M= mobility; T/P= work, productivity; FMS= upper limbs functions; MP= way of thinking; C= behavior; A= mood; RF= familiar relations; RP= Social Relations; E= energy.

In descriptive statistics it was presented the 1st quartile values, minimum, median, maximum and 3rd quartile of quality of life related to aphasic

subjects. The areas with higher values were mobility and energy and the areas with lower values were language and behavior (Figure 1).



**Figura 1 - 1st quartile values, minimum, median, maximum and 3rd quartile of each domain in this specific range of quality of life in cerebrovascular diseases**

**Overall family quality of life**

To set the individual final scores of family

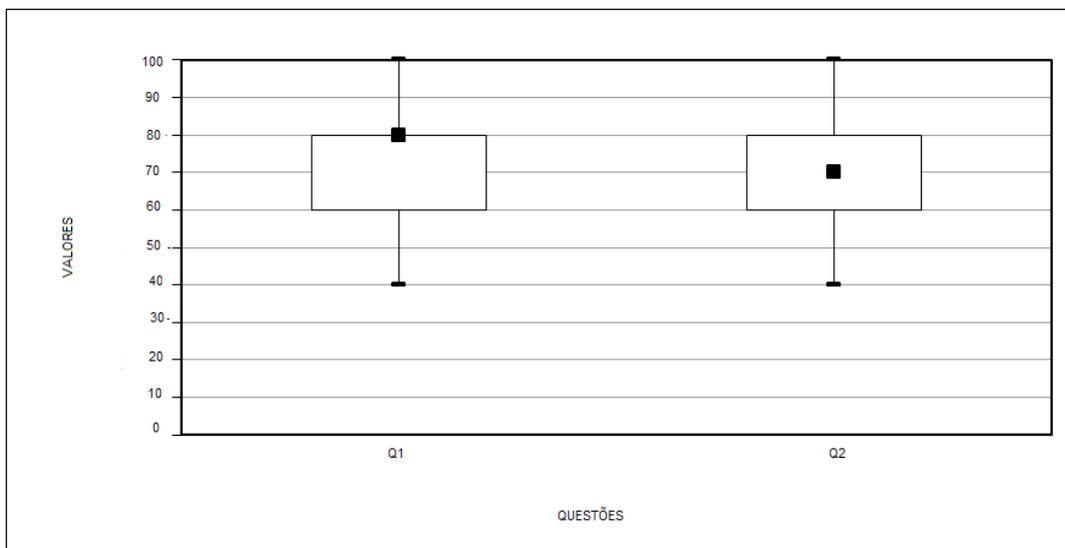
members, it was calculated the percentage of each domain (Table 2).

**Table 2 - Description of the individual scores for each domain and the total score of the World Health Organization Quality of Life - Abbreviated Instrument (WHOQOL-Bref) applied to family member**

Individual	Physical Domain	Psychological Domain	Environment Domain	Personal Relations Domain	Total
1	54,29	66,67	55	80	60,77
2	82,86	83,33	75	100	81,54
3	71,43	86,67	80	100	83,85
4	71,29	70	72,5	66,67	71,54
5	94,29	90	80	93,33	87,69
6	82,86	70	80	86,67	80
7	42,86	53,33	52,5	40	47,69
8	88,57	76,67	75	80	79,23
9	85,71	76,67	75	80	78,46
10	82,86	76,67	65	93,33	76,92
11	54,29	56,67	55	66,67	57,69
12	54,29	70	70	80	65,38

Descriptive statistical analysis was also performed presents the 1st quartile values, minimum, median, maximum and 3rd quartile of

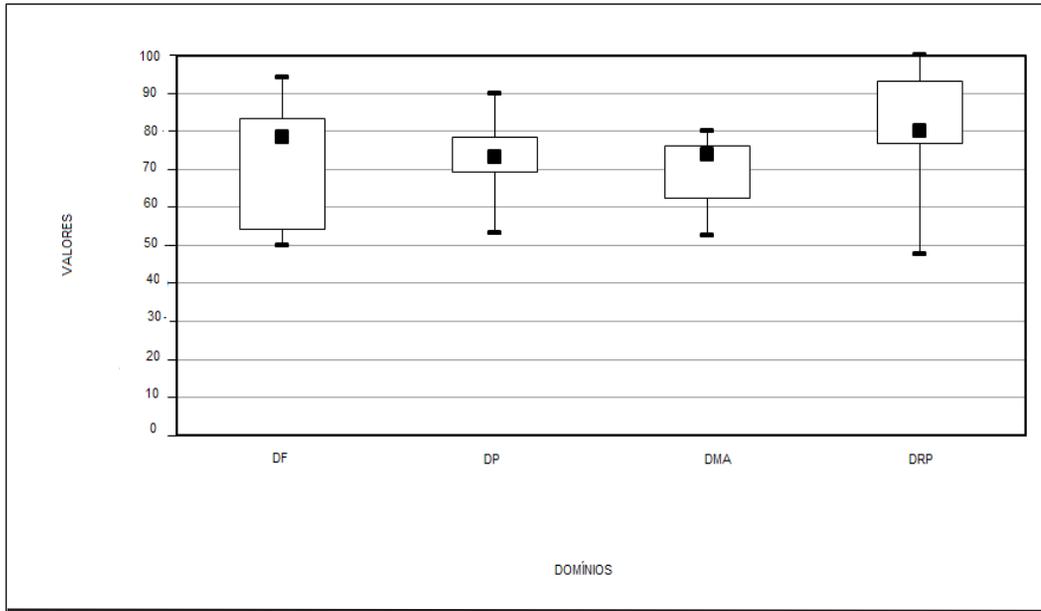
quality of life related to the quality issues of general life (Q1) and health (Q2) (Figure 2).



**Figure 2 - 1st quartile values, minimum, median, maximum and 3rd quartile of the quality issues of general life present in the World Health Organization Quality of Life - Abbreviated Instrument (WHOQOL-Bref)**

The descriptive statistical analysis shows the 1st quartile values, minimum, median, maximum and 3rd quartile quality of life related to family. It is observed that psychological and

personal relations domains had the best values, while the physical and environmental domains obtained the lowest values (Figure 3).

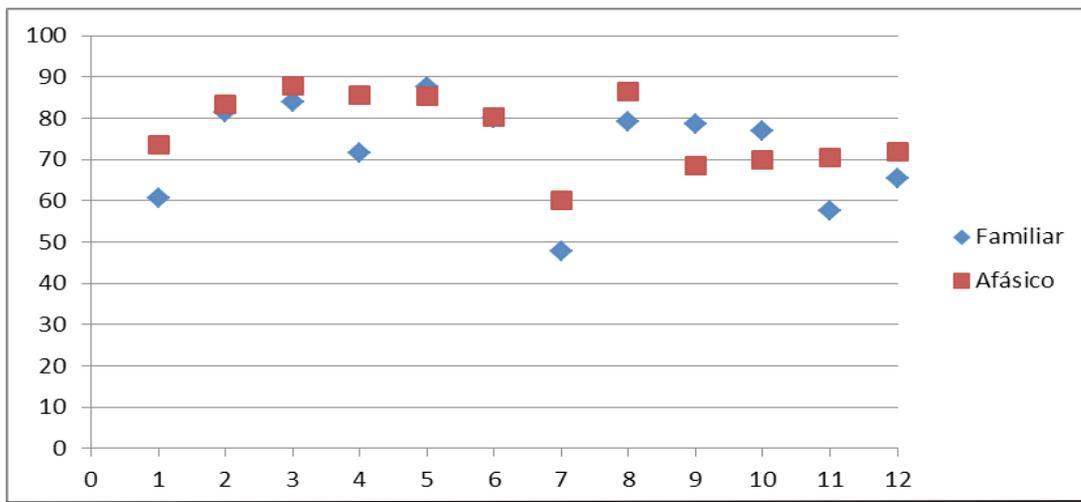


**Figura 3 - 1st quartile values, minimum, median, maximum and 3rd quartile of each domain of the World Health Organization Quality of Life - Abbreviated Instrument (WHOQOL-Bref)**

#### Correlation between quality of life of aphasic individuals and family members

The corresponding values of the individual scores for each aphasic individual and family

member clearly show the relationship of quality of life among groups. The correlation is statistically significant ( $r = 0.65$ ;  $p = 0.022$ ) (Figure 4).



**Figure 4 - scatter plot showing the correlation of the total scores of quality of life of aphasic individuals and their families**

It is relevant that the family member that had the lowest score is the caregiver of the aphasic individual who also had the lowest score. The two family members who had higher scores are caregivers of aphasic individuals who also had the

highest scores, indicating thereby the influence of the quality of life of the aphasic individual on the quality of life of their family members and vice versa.

## Discussion

In this study it was investigated the quality of life of aphasic individuals and their family caregivers, emphasizing those matters presented in both questionnaires that would be most affected.

Regarding the quality of life of post-stroke aphasic individuals, results revealed that the most affected areas were: language, behavior, way of thinking, social relations, and upper limbs functions. The least affected were: mobility, personal care, vision, energy, work productivity and family relations. Similar results showed vision and personal care as the least affected areas and social relations as the most affected ones<sup>17</sup>. Another study relates the domains of vision and family relationships as being the least affected areas and social relations as the most affected<sup>22</sup>. Finally, according to literature findings, mobility and personal care were the least affected areas and behavior one of the most affected<sup>19</sup>. It is worth highlighting that this last study<sup>19</sup> revealed language domain as the least compromised, but patients with language disorders were excluded, making this domain not rated as one of the most affected. All of the studies above used SSQOL, as the tool to measure the quality of life, the same instrument used in this study.

One study using the questionnaire on quality of life SAQOL-39, an adapted version of the questionnaire SSQOL also found similar results to this research for the domain language as the most affected, and data related to personal care and mobility as less affected<sup>10</sup>.

A study using the Aachen Quality Life Inventory (ALQI) to measure the quality of life of post-stroke aphasic individuals, also showed similar results to previous studies, bringing as less affected categories: self-care, movement and family relations and communication as the most affected category, data also corroborate to the present study<sup>23</sup>.

Interviews with post-stroke subjects showed communication as one of the most affected areas by the disease<sup>14</sup>, which also corroborates to the study presented here.

A study that evaluated the quality of life of aphasic individuals using WHOQOL-Bref, observed the personal relations domain as more affected<sup>24</sup>, confirming the findings of this study. Another author also found the social domain as most affected<sup>16</sup>. However, the authors<sup>16,24</sup> separated the

results by gender, so this result was identified in men, a distinction that it was not performed for this study.

Another less affected area was family relations<sup>23,25</sup>, showing that these can reflect positively on patient's quality of life. Regarding the quality of life of family members of aphasic individuals after stroke, personal and psychological relations domains presented themselves as the least affected, while the physical and environmental domains as the most affected.

It may be highlighted the importance of the speech therapy in rehabilitation and its role to the social context of aphasic individuals. The speech therapist work the reintegration of these individuals in social and occupational groups, since the majority of aphasic individuals stop working after the episode of stroke, staying at home without activities or even performing everyday activities.

Another study using WHOQOL-Bref to measure the quality of life of family members of aphasic individuals found the environment as the most affected domain, and the least affected area was the personal relations<sup>24</sup>, as expected by the findings of this research.

However, the same data were not found in the study using the SF-36 questionnaire to measure the quality of life of family aphasic individuals<sup>11</sup>. Although the population studied is the same, the physical aspects were less affected and the most affected aspects were emotional. Findings that contradict the study presented here. This differences found in the results with a similar population can be justified by the greeting and support the family members of this study received by the professionals who participated in the rehabilitation process of aphasic individuals. While patients were in speech therapy, an orientation group was offered to their families coordinated by the researcher of this study with a psychologist, providing support and assistance to all participants. Results suggest that this activity had a positive influence in the psychological and social relations of the quality of life of families of individuals evaluated.

The family of aphasic individual has physical and emotional burdens, requiring assistance as much as the aphasic individual<sup>26</sup>. These data reinforce the importance of acceptance and support offered to the families of this study as well as the positive impact of this activity on their lives.

For the family, having a member suffering from the stroke consequences, the whole family dynamic system is affected. New demands are generated due to the illness and the family needs to reorganize and redefine roles to meet these needs and preserve their balance<sup>27,28</sup>. These data may justify the low scores in the physical domain, as the disruption of the family structure that happens with this new situation interferes in family dynamics and daily life activities, energy, ability to work, sleep and rest, related characteristics that affected this domain.

Although the psychological domain has been presented as one of the least affected, the last issue presented in this area (Q.26), refers to the frequency of negative feelings experienced by families. It was observed that 75% of families reported having negative feelings very often, data corroborate the literature<sup>8</sup>, which state that the feelings were reported by family concerns, anxiety and sadness, negative feelings towards the caregiver situation.

There are studies that also suggest the creation of stroke caregivers groups, where these family members can share experiences and support each other<sup>28</sup>.

Another important item was the correlation between the quality of life of the aphasic individual and the quality of life of their family members. It was observed that the quality of life decline of the aphasic individual influenced negatively the family's quality of life, and the opposite is also true.

When the individual suffers a loss in expressive and / or receptive language and the integrity of this ability is required to perform the job service, get disability absence from work. This fact may affect the economic situation, thus causing a disruption in the financial and family structure. As a result, the family feels overwhelmed and that can damage the health in general, often requiring medical treatment as seen in this study. However, it is known that the involvement of the family is critical to the success of the rehabilitation process. If their quality of life is affected, certainly their involvement and commitment will be lower; negatively affecting the process of rehabilitation and thus affecting the quality of life of the aphasic individual.

There is a relationship between the most affected aspects of both questionnaires, and it suggests that both the aphasic individuals and their family deserve attention and care for the losses to be

minimized and thus promoting better quality of life for both. It is relevant to highlight that there were not found in the literature studies that correlate the family quality of life with the aphasic individual or this influence.

These recent studies reinforce the importance and necessity of acceptance and support offered by the speech language therapist to family members of these individuals, improving in the family's quality of life and thus contributing to the improvement of quality of life the aphasic individual.

Importantly, there is no specific tool for assessing the quality of life of the family of post-stroke aphasic individual. Therefore, in this paper; the choice of a validated generic questionnaire is justified. But even with the guidelines offered during the questionnaire, some items certainly have been influenced by other factors such as previous diseases, to assume the role of caregiver, who did not have relations with the disease of aphasic individual, since the questionnaire does not bring specific questions on this issue but, more general questions about the quality of life.

The small number of participants may be a limitation of the study. Despite selected 40 patients, only 12 fit the criteria for inclusion in this study, being the alteration of understanding and also the association of other diseases to stroke, such as traumatic brain injury and Alzheimer's disease, affecting the final sample amount.

Considering the above, it can be observed a variety of questionnaires used to measure quality of life, as well as the use of subjective evaluations of both aphasic individuals and their families. Also, it could be noted the use of generic questionnaires to measure quality of life of aphasic individuals. Therefore, this research shows the importance of studies using specific questionnaires related to the studied pathology, as well as the importance of studying the impacts caused by stroke and the aphasia in both groups.

## Conclusion

Based on the analysis of the results of this research, it was concluded that the least affected areas considering the quality of life questionnaire applied with aphasic individuals (SSQOL) were mobility (96.67%) and personal care (90%). The

most affected areas were language (49%) and behavior (55%); the most affected areas relating to the questionnaire of quality of life applied to the family (WHOQOL-Bref) were physical (72.38%) and the environment (69.58%), while the least affected areas were personal relations (80%) and psychological (76.06%). In addition, there was a statistically significant correlation between the quality of life of aphasic individuals and their families.

It is suggested to continue the studies in the area, emphasizing the correlation between the quality of life of family and aphasic individual, which intend to cover a larger number of the sample in order to allow confirmation of the findings from this study.

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