

The impact on the quality of life of caregivers inserted in an aphasia group environment therapy

O impacto na qualidade de vida de cuidadores inseridos em um ambiente de terapia grupal para afásicos

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ABSTRACT

Purpose: The present study compared the quality of life and the perception of caregivers of aphasics in a context of group therapy for people with aphasia. Methods: This is a cross-sectional, observational, and quantitative study, carried out with 13 aphasic caregivers who received group care and 13 aphasic caregivers who did not receive a group speech therapist. For data collection, individual interviews with caregivers were carried out, using the Burden Interview - Zarit. Results: It was found that 45.2% of caregivers reported moderate to severe burden. However, the burden assessed by means of the questionnaire was mild to moderate and there was no significant difference between the group with and without speech therapy. Conclusion: There is an important impact on the quality of life of caregivers of patients with aphasia. Further studies are needed to deepen the role of group speech therapy in the quality of life of caregivers.

Keywords: Stroke; Aphasia; Caregiver; Quality of life; Health of specific groups

RESUMO

Objetivo: o presente estudo comparou a qualidade de vida e percepções de cuidadores de sujeitos afásicos inseridos em um contexto de terapia grupal para afásicos. Métodos: trata-se de um estudo transversal, observacional e quantitativo, realizado com 13 cuidadores de indivíduos afásicos que receberam atendimento grupal e 13 cuidadores de sujeitos afásicos que não receberam atendimento fonoaudiólogo grupal. Para coleta dos dados, foram realizadas entrevistas individuais com os cuidadores e utilizou-se o Questionário de Sobrecarga do Cuidador (Burden Interview – Zarit). Resultados: constatou-se que 45,2% dos cuidadores referiram sobrecarga de moderada a severa. No entanto, a sobrecarga avaliada por meio do questionário foi de leve a moderada e sem diferença significativa entre o grupo com e sem terapia fonoaudiológica. Conclusão: existe importante impacto na qualidade de vida de cuidadores de pacientes com afasia. Novos estudos são necessários para aprofundamento do papel da terapia fonoaudiológica em grupo na qualidade de vida de cuidadores.

Palavras-chave: Acidente vascular cerebral; Afasia; Cuidador; Qualidade de vida; Saúde de grupos específicos

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INTRODUCTION

About one third of stroke patients have aphasia ⁽¹⁾. Aphasia is characterized by communication difficulty, which can change family and social life, as well as decrease the quality of life of people with aphasia ⁽²⁾ and their caregivers ⁽³⁾. Group therapy (GT) for patients with aphasia has been widely used ⁽⁴⁾ and, due to its interaction and socialization characteristics, it allows these subjects to be inserted in a conversational setting ^(5, 6). However, little is known about the influence of GT in improving the quality of life of caregivers of aphasia patients involved in group therapy.

Patients with aphasia often face emotional suffering due to communication limitations ⁽⁷⁾, with a tendency to present anxiety, loneliness, and frustration ^(8,9). Such situations lead to a more restricted social participation, with cases of depression and mood swings ⁽¹⁰⁾, as well a lesser likelihood of returning to work ⁽¹¹⁾. Thus, the effects of aphasia can cause significant changes in the quality of life of the affected subjects ⁽⁷⁾ and of their caregivers. Regarding the impact of aphasia on caregivers' lives, it is known that they are more likely to develop depression and experience a variety of psychosocial consequences after starting to live with someone with aphasia ⁽¹²⁾. In addition, the act of caring generates a decrease in time and energy for their own usual communal activities ⁽¹³⁾, resulting in social isolation ⁽¹⁴⁾.

The caregivers are considered individuals who have the function of helping and/or providing the appropriate attention to people who present limitations to the basic activities of daily living, stimulating their independence and respecting their autonomy (15). The process of caring is marked by tiredness, stress, and exhaustion, which puts the family caregiver in the position of needing care and attention (12). It is in the rehabilitation phase that family members, caregivers and the patient fully experience the impact of the stroke, since the changes caused in the lifestyle of aphasic individuals reflect in the lives of their caregivers (16).

The contact with a therapy group, both for patients with aphasia and for their caregivers, is an effective form of interaction ^(6,17), as the process of group therapy allows the subjects to awaken to unknown and/or unconscious issues, discuss, reflect, and transfer important knowledge to their lives that can help them to be agents of their own health, during or after the therapy period ^(17,18). With this interaction and support that occur in a group, it is assumed that there is a better quality of life for the caregiver and for patients with aphasia after group care ⁽⁵⁾. Besides enhancing the quality of life of these caregivers, by means of GT, caregivers can increase their understanding about stroke and aphasia, favor a greater contact with other caregivers and exchange experiences.

Considering the small number of studies related to the impact of group therapy on the quality of life of caregivers, there is a need to expand the knowledge about the implications of the dynamics of GT for aphasic subjects to their caregivers. Thus, the present study sought to evaluate the impact on the quality of life of caregivers of people with aphasia who are inserted in a group therapy context.

METHODS

This is a cross-sectional, observational study, using a semi-structured interview and application of the Zarit Burden Interview ⁽¹⁹⁾. The participants were selected by a non-probability convenience sampling process.

Caregivers of fluent and non-fluent patients with aphasia who attended a speech therapy group for at least three months at the clinic-school of Faculty of IELUSC, Joinville (SC), were included in this study. The comparative group consisted of caregivers of patients with aphasia (PWA) who had not yet started group speech therapy. All PWA included had mild severity, with a score of 4 to 5 by the Boston Diagnostic Aphasia Examination Short Form (BDAE-SF) (20). All caregivers were also residents of the city of Joinville (SC) and aged 18 years or older.

The participants who did not fit the criteria of caregivers and/or the caregivers whose PWA had other diagnosed neurodegenerative diseases were excluded from the study.

By means of the semi-structured interview, the caregivers' variables were analyzed, such as age, gender, education, degree of kinship, and how long they had been performing the role of caregiver. Data were also collected from participants with aphasia, such as age, gender, and time after stroke. The Zarit Burden Interview is an instrument with 22 questions, with the objective of evaluating the burden perceived by the caregiver, and encompasses the areas of health, social and personal life, financial situation, emotional well-being, and interpersonal relationships. The questions are scored on a scale of 0 to 4 points, represented as follows: never (0), rarely (1), sometimes (2), frequently (3), and always (4). The last question of the questionnaire refers, in a generalized manner, to the intensity with which the caregiver feels overloaded by caring for the patient, being scored from 0 to 4 as: not at all (0), a little (1), moderately (2), very much (3), and extremely (4) (19). The questionnaire was applied to caregivers of patients with aphasia: from the therapy group (GWT) and not from the therapy group - control group (CG).

The interaction with the caregiver occurred during the group therapy process, which lasted 24 sessions (in average, three months), twice a week, for a period of one hour and 30 minutes. In the final 15 minutes of each session, the caregivers participated in an integration moment with the patients and therapists. During this integration, they were given orientation about the activities developed during therapy, tasks to be done at home, and strategies or techniques to establish an effective communication between the aphasia patient and his or her caregiver. The caregivers also participated in two large meetings, in which themed parties were held, in addition to the speech therapy. Another moment that brought aphasia patients and caregivers together was the writing of a book. During the writing period, both had to talk, think, and write, thus having a unique moment to reflect on post-stroke life, difficulties, joys, and a change in outlook on life.

The study was approved by the Research Ethics Committee of IELUSC, under protocol 3.424.234, and all individuals, or their legal representatives, signed the Informed Consent Form (ICF).

Statistical analysis

Qualitative variables were presented by their absolute number and percentage, and quantitative variables by mean

and standard deviation or median and interquartile range, according to the variable distribution. The Student's T or the Mann-Whitney U test were used to compare the quantitative variables. The chi-square or Fisher's exact tests were used to compare the frequencies of each variable. SPSS software, version 23, was used to perform the analyses.

RESULTS

Among the 26 caregivers participating in this study, a predominance of the female gender (80.8%) was found. Of these, 10 were the patients' wives, 9 were daughters, 1 was a mother, and finally, 1 was a daughter-in-law. As for the men (19.2%), all of them were husbands of patients with aphasia (Table 1).

The overall mean age of the caregivers interviewed was 55.6 years, being that 34.6% of them were between 30 and 45 years old, 26.9% were between 46 and 60 years old, and 38.4% were over 60 years old.

Regarding the level of education, there was a prevalence of caregivers who had high school education (65.4%), followed by complete elementary school (19.2%).

As for the patients with aphasia, the mean age was 67.3 years and the aphasia severity was 4.6, mild, according to the BDAE-SF classification, in which there are minimal disadvantages such as loss of fluency or comprehension, but which are not significant limiting factors for the patient to express his or her ideas. Of the overall sample, 57.7% of the patients had some motor impairment.

As far as the time of care provided to the aphasic patient is concerned, the average was 8.2 months, and the time performing the role of caregiver ranged from 3 to 24 months.

As for the Zarit Burden Interview, the general mean score found was 33.5, classified as mild to moderate burden (0 to

20 points = no burden; 21 to 40 points = mild to moderate burden; 41 to 60 points = moderate to severe burden and over 61 points = intense burden).

When the caregivers were questioned about how much they felt overloaded, 8 (30.7%) reported not feeling any overload, 6 (23%), little overload, 7 (26.1%), moderate overload, 4 (15.3%), a lot of overload and only 1 caregiver felt extremely overloaded (3.8%).

In Table 2, the variables between the groups (GWT and CG) are shown. Regarding gender, both groups showed a prevalence of the female gender occupying the role of caregiver. Regarding the level of education, both groups presented a higher rate of complete high school education (GWT = 69.2% and GC = 61.5%).

When the characteristics of patients with aphasia were analyzed, it was found that most of the affected patients were male, in both groups (GWT = 53.8% and GC = 76.9%, p= 0.411). There was no significant difference in motor impairment between the groups (p=0.418).

Regarding the Zarit Burden Interview, it was found that the means were similar in both groups, with the GWT finding a mean of 36.23 and in the GC, 30.84 (p=0.37), both, therefore, classified as having a mild to moderate burden. The mean of aphasia severity was similar in the groups (4.5 in the GWT and 4.7 in the GC, p=0.584), as well as the mean age of the caregivers (56.8 years in the GWT and 54.5 years in the GC, p=0.683).

An important data in the research was the length of time in the caregiver role. In the GWT, the mean was 10.4 months, while in the GC, it was 6 months (p=0.034), finding that, in the GWT, the caregivers had been playing the role of caregiver for longer than those in the GC.

Table 1. General characteristics of the sample

Variables	Frequency or mean	Percentage or Standard Deviation
Caregiver's gender:		
Male	5	19.2%
Female	21	80.8%
Caregiver's age	55.6	13.5
Caregiver's education level:		
Illiterate	2	7.7%
Elementary School	5	19.2%
High School	17	65.4%
Higher Education	2	7.7%
How long have you been a caregiver	8.2	5.2
Gender of patient with aphasia:		
Male	17	65.4%
Female	9	34.6%
Age of patient with aphasia	67.3	12.1
Motor impairment		
No	11	42.3%
Yes	15	57.7%
Group therapy		
Yes	13	50%
No	13	50%
Severity of aphasia	4.6	0.7
Zarit Burden Interview	33.5	13.4

Table 2. General characteristics between caregivers with and without group speech therapy (n=26)

	Group with Therapy		Group without Therapy		
-	Frequency or Mean	SD	Frequency or Mean	SD	P value
Caregiver's gender					
Male	23.1%		15.4%		1.00
Female	76.9%		84.6%		
Caregiver's age	56.8	12.8	54.5	14.6	0.638
Caregiver's education level					
Illiterate	15.4%		0%		
Elementary School	15.4%		23.1%		
High School	69.2%		61.5%		
Higher Education	0%		15.4%		
Time given by caregiver	10.4	6	6	3	0.034
Zarit Burden Interview	36.2	12.6	30.8	14.1	0.317
Gender of patient with aphasia					
Male	53.8%		76.9%		0.411
Female	46.2%		23.1%		
Age of patient with aphasia	64.5	13.5	70	10.4	0.260
Severity of aphasia	4.5	0.6	4.7	0.7	0.584
Motor impairment					
No	30.8%		53.8%		0.418
Yes	69.2%		46.2%		

Subtitle: n = number of subjects; SD = standard deviation

DISCUSSION

The study explored the burden of caregivers of patients with aphasia and identified that there was no difference between GWT and GC. All caregivers presented mild to moderate burden and with a higher prevalence of the female gender playing the role of caregiver. In addition, the study pointed out, in a significant way, that the longest time as caregiver was associated to the patients in the sample who underwent speech therapy.

It is known that being an informal caregiver means an abrupt change for the whole family. Having a stroke survivor at home who presents motor sequelae and speech impairment is a challenge. Aphasia generates more burden to the caregiver and this communication difficulty can affect the relationship of the subject with the family, because the family cannot understand what the aphasic is trying to express (21). With the communication impairment generated by aphasia and the caregiver's overload, it is necessary that the caregivers also be involved in a group context that provides interaction with other caregivers, re-signifying their feelings and exchanging experiences (22).

In this study, it was evidenced that all caregivers, regardless of being inserted in a group therapy environment or not, had mild to moderate physical and emotional burden. However, during the interviews, even though the questionnaire contained only objective answers, the caregivers who were inserted in the group reported about their routine and difficulties, which was not observed in the GC. Many caregivers in the GWT vented about their anxieties, the limitations with dealing with the aphasic, and the impact of aphasia on their lives. Some also reported a greater sense of competence, achievement of gains, and better understanding of their situation. Caregivers who were wives of patients reported a sense of "relief" and "hope"

when comparing their partner's situation to that of others in the group, either because they were older, had longer strokes, or had greater motor impairment, which agrees with a review by Attard et al. (2013) that reports caregivers' talk in a similar way. The caregiver distress seen in this study corroborates the findings of other studies in the area (23, 24). The caregivers go through abrupt changes in lifestyle, having to modify their routine and their plans and, with that, many need to leave their jobs (12) and neglect the care of themselves due to the emotional overload. In addition, many put aside their wishes and desires to care for their family member (25), needing someone to stay with them so that they can enjoy some of their own activities (13).

It is also known that caregivers, when inserted into a rehabilitation environment, increase their interest in understanding more about aphasia and how to communicate better with the patient ⁽¹²⁾, thus being able to minimize the stress and the risks of depression presented by caregivers of aphasic patients ^(13, 26). Therefore, it is noticed that many experiences acquired throughout life are shared in a speech therapy group ⁽²⁷⁾. A therapeutic group is classified as a group of people that share the same interest and/or common objective, and in which there is interaction and emotional bonding by the subjects involved ⁽²⁸⁾. Being inserted in a therapeutic context provides the caregiver with a shared exchange of experiences, as well as safety when realizing that they are not the only one going through that situation, and the exchange of positive thoughts, which can contribute to their well-being and improvement in their quality of life ⁽²⁷⁾.

This study also evidenced that most of the caregivers were female, which may be related to the sociocultural representation of women in society, in which the practice of care is usually directed to the wife, due to the marriage commitment, or to the daughter (21, 24, 29), and this is constituted within a domestic sphere, which confirms the data obtained in this study.

The caregiver's education also has a lot of relevance to the therapy process, since, after becoming a caregiver, it is necessary that the caregiver seeks information and receives orientations as to the care of the patient (29), which can influence the patient's rehabilitation process, since the higher the education level, the more access to information the caregiver has (29).

This study also significantly pointed out that longer time as a caregiver was associated with patients who underwent speech therapy. Considering the limitation of local vacancies for group therapeutic care, individuals with longer aphasia and, consequently, caregivers with longer time of care could represent the waiting time for the beginning of care. However, the possibility, that caregivers with longer time of care are more engaged in this new routine of caring and seek rehabilitation services more, cannot be ruled out (30).

Another finding of this study was that most patients presented motor disability, thus, it can be inferred that patient, even with motor limitation, seeks care for communication disorder. Such search may be favored by the presence of the caregiver itself in understanding more about the disease and the need for rehabilitation, helping the patients in the search for speech therapy care. It is also important to stress that all the patients with motor impairment had therapy with a physiotherapist, suggesting that there is an appreciation and greater care for these patients by caregivers.

The limitations of this study were the small sample size and the lack of a stronger bond with the GC caregivers, which may have caused a reporting bias in this group. It is suggested, in future studies, a larger sample and the addition of open questions to the caregivers, broadening the view on their burden. It is understood that there is a considerable burden in the lives of caregivers of aphasia patients and the therapeutic group can be an opportunity to help these individuals.

CONCLUSION

This study showed that there is a mild to moderate physical and emotional burden on caregivers of aphasics in general. After becoming a caregiver, the individual suffers from emotional, physical, and financial overload, in addition to lifestyle changes. These factors, associated with ineffective communication, can generate greater emotional distress for caregivers of aphasic patients. It reinforces the need to look to the caregivers of patients with aphasia, aiming at a better quality of life. As the number of caregivers is restricted in this study, further studies are needed to deepen and better understand other processes involved in this function and the role of the speech therapy group in the quality of life of caregivers.

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