



Informal caregivers of people with aphasia: reflections about the impact on daily life

Cuidadores informais de sujeitos com afasia: reflexões sobre o impacto no cotidiano

Cuidadores informales de personas con afasia: reflexiones sobre impacto en la vida diaria

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Abstract

Introduction: People with acquired brain injury may present motor and language sequelae that affect their lives and their relatives' lives, especially when relatives assume the function of informal caregivers. **Objective:** to discuss the impact of individuals' motor and aphasic sequelae on relatives/informal caregivers' daily lives. **Methods:** an exploratory and cross-sectional study, with a qualitative approach. Participated in the study relatives/informal caregivers of individuals with motor and language sequelae resulting from brain injury, who participated on an interdisciplinary peer group. Speeches about the impact of this situation in their everyday life were recorded. The data treatment was from orthographic transcription to a thematic analysis/content analysis. **Results:** The study included five female relatives/informal caregivers, being them housekeepers (four wives and one daughter), with age range of 33 to 74 years-old. The time of care varied from one year and six months to five years. They referred difficulties in domestic routine, caregivers' personal and social lives, and in the family financial condition. In the cases of subjects with aphasia, caregivers reported difficulties with comprehension and expression, as well as problems to handle the relative's humor. **Conclusion:** the results emphasize the difficulties experienced

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by relatives/informal caregivers of individuals with motor and language sequelae resulting from acquired brain injury, and the importance of peer group with multiprofessional care team inter/transdisciplinary, expanding the possibilities of investigations of speech therapy, while health area that studies language and the repercussions of aphasia in the uniqueness of the affected individuals and their relatives/caregivers.

Keywords: Family; Caregivers; Brain injury; Aphasia

Resumo

Introdução: Pessoas com lesões neurológicas adquiridas podem apresentar sequelas motoras e de linguagem que afetam sua vida e a de seus familiares, principalmente quando os últimos assumem a função de cuidadores informais. **Objetivo:** discutir o impacto das sequelas motoras e afásicas no cotidiano de seus familiares/cuidadores informais. **Método:** estudo exploratório, transversal, com abordagem qualitativa. Participaram do estudo familiares/cuidadores informais de sujeitos com sequelas motoras e de linguagem, decorrentes de lesões neurológicas que frequentavam o grupo interdisciplinar de convivência. Foram gravados os discursos sobre o impacto dessa situação em seu cotidiano. O tratamento dos dados deu-se a partir da transcrição ortográfica seguida da análise temática/análise de conteúdo. **Resultados:** O estudo incluiu cinco familiares/cuidadores informais do sexo feminino, do lar (quatro esposas e uma filha), com faixa etária entre 33 e 74 anos. O tempo de cuidado variou de um ano e seis meses a cinco anos. Foram referidas dificuldades na rotina doméstica, vida pessoal e social das cuidadoras assim como nas condições financeiras da família. No caso de os sujeitos apresentarem afasia, obtiveram-se relatos de dificuldades de compreensão e expressão, bem como de lidar com o humor. **Conclusão:** os resultados evidenciam dificuldades vivenciadas por familiares/cuidadores informais de sujeitos com sequelas motoras e de linguagem, decorrentes de lesão neurológica adquirida e a importância de grupos de convivência com equipe multiprofissional de cuidado inter/transdisciplinar, ampliando as possibilidades de investigações na fonoaudiologia, enquanto área da saúde que estuda a linguagem e as repercussões da afasia na singularidade dos sujeitos acometidos e de seus familiares/cuidadores.

Palavras-chave: Família; Cuidadores; Lesão cerebral; Afasia

Resumen

Introducción: Personas con lesiones neurológicas adquiridas pueden tener consecuencias motor y del lenguaje que afectan sus vidas y la vida de sus familias, especialmente cuando estos asumen el papel de cuidadores informales. **Objetivo:** analizar el impacto de las secuelas motor y afásicas en la vida cotidiana de sus familiares/cuidadores informales. **Método:** estudio exploratorio, transversal, con enfoque cualitativo. Participaron en el estudio los familiares/cuidadores informales de personas con consecuencias motor y del lenguaje resultante de lesiones neurológicas que participaron de un grupo interdisciplinario de convivencia. Fueron registrados discursos sobre el impacto de esta situación en su vida diaria. El tratamiento de datos fue realizado a partir de la transcripción ortográfica seguida por análisis temática/análisis del contenido. **Resultados:** El estudio incluyó cinco familiares/cuidadores informales del sexo femenino, amas de casa (cuatro mujeres y una hija), con edades comprendidas entre 33 y 74 años. El cuidado osciló entre un año y seis meses a cinco años. Fueron referidas dificultades de rutina doméstica, la vida personal y social de los cuidadores así como la situación financiera de la familia. En el caso de los sujetos con afasia, se obtuvieron informes de dificultades en la comprensión y la expresión del familiar, así como de manejar su estado de ánimo. **Conclusión:** Los resultados mostraron dificultades experimentadas por los familiares/cuidadores informales de personas con consecuencias motor y del lenguaje resultante de una lesión neurológica adquirida y la importancia de los grupos de convivencia con equipo multidisciplinario de la atención inter/transdisciplinario, la ampliación de las posibilidades de investigación en terapia del habla, mientras que la salud estudio de la lengua y el impacto de la afasia en la singularidad de las personas afectadas y sus familiares / cuidadores.

Palabras clave: Familia; Cuidadores; Lesión cerebral; Afasia

Introduction

Encephalic vascular accidents (EVA), especially cerebrovascular accidents (CVA), as well as traumatic brain injury (TBI), central nervous system's tumors and infections (CNS) are a group of conditions named Acquired Brain Injury (ABI). These injuries have a specific development according to the subject affected; they usually result in impairment of sensory and motor (hemiparesis or hemiplegia, quadriplegia), cognitive (agnosias, apraxia, amnesia and aphasia) and emotional/behavioral functions^{1,2,3}.

Aphasias are the most frequent ABI disorders; they are characterized by changes in the linguistic processes of meaning of articulatory and discursive origin, caused by acquired focal lesion of zones responsible for language, and aphasic conditions may or may not be associated with changes in other cognitive processes - praxis, gnosis, memory, for example⁴. Individuals with aphasia may present difficulties to produce and/or comprehend verbal language, which cause changes in family and extended social interaction^{5,6}.

Besides language impairments and other cognitive processes, subjects with aphasia often present motor deficits, especially right hemiplegia, which causes limitations in daily living activities in home and socio-community environment, making them (more or less) dependent on caregivers⁷.

By 'caregiver' we refer to the person whose function is to assist and/or provide appropriate care to people with limitations to basic daily living activities. Currently there are formal caregivers (specialized training to provide assistance) and informal caregivers (without training). This is an assignment that includes assistance in activities such as feeding, personal hygiene and locomotion, as well as communication, cognition and emotional cares⁸. Sometimes the caregiver function is assumed by family members (informal caregivers) and, in this condition, they become a mediator between the patient and the external environment and, not infrequently, live under constant physical and emotional stress and, for that reason, should also be taken as a focus of attention by professionals and health services^{9,10,11}.

In the assistance of professionals focused on the caregiver, psychotherapeutic or psychoeducational methods, it is appropriate to approach the implementation of strategies and resources for

dealing with daily care situations, such as the understanding and acceptance of neurological condition, as well as promoting opportunities for sharing and expression of feelings related to the new condition of coexistence^{10,12}.

There are several factors that impact the relationship between the affected individual and relative/caregiver, such as the degree and duration of the illness, economic restrictions, reduction of social and leisure activities, besides behavior/humor conditions (anxiety and depression). In addition, the caregiver may have musculoskeletal pain, tension headache, tiredness, fatigue, sleep disturbance and other health conditions¹². National^{13,14} and international^{15,16} studies have addressed the impact of aphasia on daily life of relatives/caregivers, but only a few described the care given to relatives through interdisciplinary and group approach. In this perspective, the objective of the present study is to analyze the impact of motor and aphasic sequelae on daily life of relatives/informal caregivers.

Method

This exploratory, transversal and qualitative study follows the ethical guidelines established by Resolution 466/12 of National Health Council, which regulates research involving human beings; this investigation has been approved by the Research Ethics Committee of a University in Rio Grande do Sul state under No. 0324.0.243.000-11. All participants were informed about the objectives, methods, risks and benefits of the study and signed the Informed Consent Term.

Relatives/informal caregivers were included in the research, that is, those who did not receive payment to perform the function and who assisted subjects with neurological injury participating in an interdisciplinary group of coexistence. Formal caregivers (unrelated to the subject with neurological injury and who were paid for the function) were excluded.

It should be clarified that the interdisciplinary group of coexistence works as an outpatient clinic free of charge to subjects with neurological damage. Group's sessions are weekly, lasting two hours and thirty minutes, coordinated by a speech therapist and with participation of scholars and volunteer students of Speech-Language Pathology and Occupational Therapy courses, as well as post-graduate physiotherapists and occupational

therapists. The dynamics of the group, based on the assumptions of Discursive Neurolinguistics (DN), includes activities such as: conversation group (sharing news), games with verbal and nonverbal language, physical activities, feeding and others. Parallel to the coexistence group, with biweekly regularity, there is a group for relatives/caregivers, characterized as a specialized support space. In this group, participants expose daily situations (positive and negative experiences, personal considerations and others); they are also encouraged and experience activities related to self-care (demands and solutions of the group itself, for example, they receive and/or provide manicure and make-up), handicraft making and they also participate in discussions on health-related issues (caregiver and/or patient) and a range of other activities. The group is monthly assisted by a psychologist; if necessary (personal demand and/or professional evaluation), relatives/caregivers receive individual psychological monitoring.

Data were collected together with all relatives/caregivers, by an interview addressing relatives'/caregivers' perception on the conditions of familiar and extended social (co)existence after the neurological injury in their families. Identification data were collected (name, age, occupation); as well as family composition (marital status, degree of relationship, children); and changes in personal and family routines after the neurological injury. It had been questioned the time acting as caregiver, the difficulties and facilities with respect to general care and communication, besides changes in the financial condition of the family. Finally, we questioned about possible improvements in both family and social relationships after their participation in the coexistence group and its meaning for each relative/caregiver participant of the group.

Interviews were recorded in audio (Sony Px240 recorder) and transcribed orthographically. Data analysis was performed by thematic analysis, a modality of content analysis¹⁷. Analysis of transcriptions had been performed individually by all researchers involved and, later, in a group, in which our impressions were confronted and the categories of analysis for the results section were established. After the initial and exhaustive reading of caregiver's responses and identification of relevant data for the study, the following categories were established: 1) Family routine before and after the neurological injury; 2) Family and social condi-

tions; 3) Pre- and post-injury financial conditions; 4) Care; 5) Communication and 6) Participation in the coexistence group. The statements of research subjects that did not fall into the established categories were excluded.

Caregivers were identified by the letter C followed by a number, thus preserving their identities.

Results

Five female relatives/informal caregivers have participated in this study, four wives and one daughter; they were: C1 - 33 years old, daughter, has been assisting with help from her sister for two years; C2 - 53 years old, wife, main caregiver for 3 years; C3 - 51 years old, wife, main caregiver for one year and six months; C4 - 74 years old, wife, main caregiver for 5 years and C5 - 47 years, wife, main caregiver for 5 years.

The following are excerpts of speech related to the established categories:

1. Relative's pre- and post-neurological home routine

"It changed everything, it changed the entire routine, things are harder... 99%... Because always needs care" (C1)

"It changed many things in my life, I don't go out anymore, I'm always caring him, before the stroke I used to go out, but not anymore, what a shame" (C4)

"It changed everything, for example, and I'm not complaining, but my life stopped to live his life instead, I care him 24 hours a day. My friends go out and I can't" (C5)

2. Pre- and post-neurological home routine of relatives

"Sometimes [he] is rebel... [His] resistance impedes doing my stuff... It's hard planning to go out... to parties, because sometimes [he] doesn't want to go out" (C1)

"Before it was easier; [he] was more active" (C3)

"Hmm, he was angrier; very stressed. Had no dialogue with the kids, didn't try to talk with them. What he said should be right, he taught he was always right. He was the same with his friends, he was

fighting with anyone for anything, today he doesn't have friends anymore, nobody looks for him" (C4)

"It was good, really good, we had lots of friends, but now [no one]" (C5)

3. Financial conditions

"She has free assistance, by government... It's not a problem because there is also social security and the SUS [unified health system]" (C1)

"He receives the security... Locomotion is the problem... Has a private speech therapist. He stopped physical therapy because there was no transportation" (C2)

"Financially, we don't have too much, but we're good" (C3)

"It changed many things, it changed a lot... He had his salary, but when was in a business trip he received more for that, which increased our income, but now he is retired, has just the salary and pays alimony to his ex-wife" (C5)

4. The care offered

"He is independent... But had seizures... So I'm scared, he could fall and hurt himself... I'm always watching... [...] most of the time... It's only me... Her daughters work" (C2)

"I'm restricted to him. It's just both of us. I had this chance to start yoga classes, but I can't due to the hour, it's too early... he is in first place... I would have to change his medicine routine" (C3)

"It's nothing easy, counts on me for everything. Complains about everything, nothing is good, it's hard to live like this, he is stubborn" (C4)

5. Communication

"If she is quiet, communication happens... But only without noise and kids. I talk to her on the cellphone" (C1)

"Many times he speaks and I don't understand... When he is quiet, he can talk better" (C2)

"Hmm, it's hard, I don't understand him and he gets angry; it's terrible, he has no patience" (C4)

"It's hard, so hard, but I try to understand him, I ask, I try again, I don't let him talk while I fake that I'm understanding" (C5)

6. Participation in the coexistence group

"Psychological support is very important" (C1)

"I really like activities, it reduces stress, I spend time with other relatives, with the whole team that assists us... learn so many things [...]" (C4)

"For me, it's not good a group of relatives/caregivers without the patients. Because he can't understand well, if I don't go to the group and there is a trip, a party, I don't get those news, because he can't talk, explain... So I don't know what happens. I don't think the relative group is bad, but I prefer to be with him" (C5)

Discussion

In this study, the predominance of female sex in the position of caregivers of subjects with neurological injury was verified, in agreement with other studies^{18,19}. Possibly, this is due to the historical and cultural role attributed to the woman who, in past times, was the only responsible for the family and domestic activities^{20,21}.

The interviewees reported changes in relation to the personal routine (caregivers abandoned their projects) due to the demand of time for caring the relative, that is, their role as caregiver became the priority of their lives.

Changes in behavior of patients with neurological injury have also been reported, for example, their distancing from social and family relationships, possibly motivated by their particular condition comparing to their lives before the neurological injury. This condition overloads the family organization, impacting on the routine, requiring adjustment of projects and ways of life of the subject affected by neurological injury and other members of their family nucleus, especially the main caregiver⁸.

Studies^{22,23} reveal that the caregiver's burden is associated with variables such as psychoemotional disorders, lack of information, time dedicated to care and degree of dependence of each individual. In the case of subjects with aphasia, a study²³ points out that their caregivers present higher levels of

stress, depressive symptomatology, loneliness and other emotional problems, when compared to caregivers of people affected by CVA, but not aphasic. This situation was evidenced in the speech of C2 (*Many times he speaks and I don't understand*), C4 (*Hmm, it's hard, I don't understand him and he gets angry*) and C5 (*It's hard, so hard, but I try to understand him, I ask, I try again, I don't let him talk while I fake that I'm understanding*). Among other factors, this is fundamental for the regular monitoring of relatives/caregivers; such as the neurologically affected subjects, relatives/caregivers need professional support aimed at knowing processes (alternative or not) of meaning produced by aphasic subjects⁶.

Another study²⁴, focused on relatives/caregivers of aphasic patients, found that there was worsening in caregivers' health (fact not observed in the subjects of our study) and leisure time (also found in our research), as well as in financial situation of family (financial worsening was evidenced in a single case, in which retirement decreased the subject's income).

The relatives/caregivers of this study demonstrated difficulties in dealing with humor and complications due to the neurological injury of their relative. It cannot be ignored that, in addition to the physical overload, antisocial behavior of subjects with neurological injury can emotionally destabilize caregivers, for example, causing insecurity, anguish, fear and impotence in the face of uncertainties related to health and treatment of the family member neurologically affected. The physical and psychological overload demands support from different orders²⁵ and that is why it is convenient to know the previous history of the family relationship in order to understand how the current relationship between the relative/caregiver and the affected subject occurs. A study²⁶ revealed that relatives/caregivers suffer from watching the suffering of the affected family member.

Regarding communication, it was verified that relatives/caregivers have difficulties in communicating with aphasic subjects. As observed in another research¹⁹, it was revealed that most caregivers have difficulties in dialoguing with their aphasic relatives, a fact that reinforces the importance of caregivers being informed about characteristics of aphasia and the potential of rehabilitation. For this, it is necessary to listen carefully and know the demands of caregivers and, together

with them, to reflect on and define viable practices for home living.

A study²⁷ on difficulties experienced by relatives/caregivers in the communication with their aphasic family members showed feelings of anguish (due to the lack of understanding of the caregivers on aphasia and their needs) and mourning (a feeling that can be understood as a preparation phase – of the subject with aphasia and their relatives – for the new situation of rehabilitation and reorganization of family relationships, as well as dealing with the difficulties experienced and to be experienced).

In this sense, there is the convenience of performing relatives/caregivers group in parallel to the therapeutic process of aphasic subjects. This study is consistent with another⁸ in which relatives/caregivers affirmed finding in the relative/caregiver group the necessary support to face the domestic situation, a safe place to share feelings, doubts, experiences and learning. The complexity of health commitments that require the need for an interdisciplinary approach has been discussed by several authors^{28,29,30}. The multidimensionality of subject's constitution requires integrated professional practices that may favor the lives of those affected and their families. This fact implies the need to offer services prepared to the dynamic adjustment of health team, family members and subjects with aphasia.

Conclusion

This study evidenced the transformations that occur after acquired brain injury during adult phase in the family routine, personal, social and economic life of subjects with aphasia and their relatives. Caregivers of subjects with aphasia deal with difficulties of understanding and expression of their family members and their changes in behavior and humor and, additionally, tend to prioritize caring the affected subject. These results reaffirm previous studies and open a range for new investigations, especially in the care involving different professional teams in coexistence groups.

Relatives/caregivers coexistence groups whose multiprofessional team works according to inter/transdisciplinary methods provide space for sharing feelings, experiences and learning. This care resource deserves greater attention from health professionals.

There are many possibilities of studies in Speech-Language Pathology, as a health area that studies language, care and repercussions of aphasia in the uniqueness of the affected individuals and their relatives/caregivers.

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