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Brief Communication
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Effects of a short educational program about aphasia (SEPA) on the burden and quality of life of family caregivers of people with aphasia

Efeitos de um programa educacional breve sobre afasia (PEBA) na sobrecarga e qualidade de vida de familiares cuidadores de pessoas com afasia

Keywords

Aphasia
Caregivers
Speech, Language and Hearing Sciences
Education
Rehabilitation

ABSTRACT

Purpose: To develop a short educational program about aphasia (SEPA) for family caregivers of people with aphasia and verify its effect in their burden and quality of life. **Methods:** This is a quantitative experimental study. The participants included in the study were family caregivers of people with aphasia. They completed the Zarit interview scale and WHOQOL-Bref instruments pre- and post-intervention. The intervention was a short educational program about aphasia, administered in a group setting and conducted in two didactic sessions. **Results:** Four participants were included in the study. In the group analysis, there was no significant difference in any measure. However, looking into the individual performances, all participants presented a trend for improvement in most of the scores. **Conclusion:** Possibly, family caregivers of people with aphasia might benefit from the SEPA. It would be relevant for future studies to include larger samples and consider new strategies to improve inclusion of participants.

Descritores

Afasia
Cuidadores
Fonoaudiologia
Educação
Reabilitação

RESUMO

Objetivo: Desenvolver um programa educacional breve sobre afasia (PEBA) para familiares e cuidadores de pessoas com afasia, e verificar o efeito deste programa na sobrecarga e na qualidade de vida destes participantes. **Método:** Este estudo se caracteriza como experimental quantitativo. Foram incluídos neste estudo familiares de cuidadores de pessoas com afasia. Todos participantes realizaram a escala de sobrecarga do cuidador de Zarit e o WHOQOL-bref nos momentos pré e pós intervenção. A intervenção foi constituída de um programa educacional breve sobre afasia e foi administrada em grupo durante dois encontros didáticos. **Resultados:** Quatro participantes foram incluídos no estudo. Na análise de grupo, não foi encontrada diferença significativa em nenhuma das medidas. Porém, quando as performances foram analisadas individualmente, todos participantes apresentaram uma tendência para melhora em quase todos escores. **Conclusão:** É possível que familiares cuidadores de pessoas com afasia sejam beneficiados pelo PEBA. É importante que os estudos futuros incluam amostras maiores e considerem novas estratégias para melhorar a inclusão de participantes.

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INTRODUCTION

Aphasia is an acquired neurogenic language disorder caused by an injury in the brain and involves varying degrees of impairment in language expression and/or comprehension(1). The communication handicap caused by aphasia leads to changes in the functionality and social relationships of these individuals and, consequently, patients and their relatives are more susceptible to neuropsychiatric disorders(2,3). The prevalence of depressive disorders among people who suffered a stroke is about 33%(4), while approximately 60% of people with stroke aphasia may have depression(2) and 44% may present significant anxiety(5).

Relatives, friends and caregivers of people with aphasia need to adjust to the new communication condition of their loved ones. However, they may not be naturally prepared for this adjustment, which may lead to stress and increase the burden and frustration for both sides of the relationship. Thus, treatment of people with aphasia should ideally extend to their care. Interventions that aim to involve family and friends might consist in education-oriented information, counseling and support, and communication skills training(6).

Previous studies on programs that have focused on education of family members of people with aphasia have shown benefits. These studies employed different approaches and methods, but in general they suggested that educational programs might improve communication between family and aphasic partners(7), family relationships, functional activity level, and knowledge of aphasia(8).

The main objective of educational intervention is to share information about aphasia and other aspects involved in it that are important to understand and manage this condition. The type of information shared in interventions has to be of interest to its target population. Therefore, a previous study has aimed at identifying the information needs of relatives of people with aphasia using a qualitative approach. The study identified three thematic information areas: aphasia, psychosocial information and hopefulness. Specific information about aphasia included knowledge about stroke and aphasia, aphasia treatment, prognosis, co-existing behaviors and medical conditions and resources(6).

Short educational programs that involve those thematic information areas might be of special interest for public health systems in low- and middle-income countries due to three reasons. First, most of the population in those countries has a low level of education and limited access to information, which may limit the understanding of aphasia and stroke. The inequities in health care that occur in these countries affect primarily those with lower socioeconomic status(9). Second, the high demand imposed on public clinics and hospitals limits the time that health professionals (physicians, speech and language pathologists, nurses) can dedicate properly to patients and families, preventing patients from receiving proper care(10). Third, not all healthcare services offer speech and language pathologists and there is a discrepancy in the distribution of these professionals across services and throughout demographic regions(11). Because of this, access to speech and language pathologists is hampered by long waiting lists. In brief, short educational programs about aphasia may be a low-cost and realistic way to mitigate those problems. In this study, we developed a short educational program on aphasia (SEPA) for family caregivers of people with aphasia and verified its effect on caregiver burden and quality of life through a pilot study implemented in a public health setting.

METHODS

Study design and ethics

This is a quantitative experimental pilot study. The research project was approved by the ethics committee of Faculdade Nossa Senhora de Fátima (project number 65166417.0.0000.5523). Written consent was obtained from all participants.

Participants

Participants were caregivers of people with aphasia recruited from a waiting list of a speech and language clinic from Caxias do Sul-RS, which pertains to the Unified Health System (Sistema Único de Saúde – SUS). The inclusion criteria were: being a family caregivers of a person with aphasia; the aphasia of the participant's relative was stroke-induced; they lived at least 4 hours per day with the person with aphasia; and they agreed to participate in the study. Illiteracy and the impossibility to contact the person by phone were reasons to exclude participants.

Assessments

We first conducted an interview to collect personal and sociodemographic data of the participants and their aphasic relative, which we used to describe our sample. Pre- and post-intervention assessments were carried out to measure the impact of the intervention on participants, using the following instruments:

- Zarit burden interview scale: this instrument is used for burden assessment of caregivers of people with different mental and physical illnesses, such as caregivers of people with dementia or stroke survivors. The 22-item instrument assesses the caregiver's burden associated to the patient's functional and behavioral disability and to the situation at home. Its items measure the objective and subjective burden reported by caregivers regarding health, social and personal life, financial situation, emotional well-being, and interpersonal relationships. The caregiver assigns each item a score from 0 to 4 using a Likert scale. The higher the final score, the higher the caregiver's burden(12);
- WHOQOL-Bref: This short instrument assesses quality of life and is composed of 26 questions divided into four domains: physical, psychological, social relationships and environment. The respondents need to classify their answers using a Likert scale from 1 to 5. The higher the final score, the higher the quality of life(13).

An undergraduate student and a certified speech and language pathologist carried out the assessments. The pre-intervention assessment was performed 30 minutes before the beginning of the session, while the post-intervention was conducted after one month of the second section. The post-intervention assessment was made with the aim of verifying the effect of the intervention by comparing performance on the instruments between the pre- and post-intervention times.

Intervention

The intervention consisted of a short educational program about aphasia for family caregivers of people with aphasia. It was administered in a group setting and divided into two didactic sessions of one hour each. The first session covered the topics: neural substrates of language, stroke and other brain diseases, and aphasia (concept, types, symptoms, consequences). After 7 days, the second session was carried out and covered the topics: relationship between people with aphasia and caregivers, strategies to improve communication, and general orientation about quality of life and health. At the end of each session, 30 minutes were dedicated to questions and an open discussion.

The intervention was carried out by the same undergraduate student and speech and language pathologist who performed the assessments.

Data analysis

The data were analyzed using the statistical analysis software SPSS, version 20. The scores obtained by participants were presented individually for each subject, while the group performance was expressed using medians. Comparisons between the pre- and post-intervention times were performed using the Wilcoxon non-parametric test due to the small sample size. The level of significance was set at 5% ($p \leq 0.05$).

RESULTS

Ten potential participants were selected from the waiting list. However, only 4 agreed to participate in the study. The 4 participants who were included in the study attended both intervention sessions.

The average age of the participants was 61 years, and ranged from 28 to 64. Three participants were women (75%). Table 1 shows further information about the participants.

Table 2 presents the individual performance of participants at pre- and post-intervention moments, as well as the comparisons between group medians. There was no statistical difference in any measure tested.

In addition to the statistical comparison between the groups, we looked carefully at the individual performance of each subject. Observing the results of participant 1, we verified improvement of the total scores and scores per domain of Zarit scale and WHOQOL-Bref at the post-intervention assessment. Participant 2 showed improvement in the total score and in each domain of the WHOQOL-Bref, except in the social domain, which presented the same score at the pre- and post-intervention times. A better performance was also observed in the total score of the Zarit scale. Participant 3 showed better performance in

Table 1. Descriptive data on participants

	P1	P2	P3	P4	Median
Sex	M	F	F	F	-
Age (years)	58	64	63	28	61
Education	ES	HS	C	ES	-
Degree of family relationship with the aphasic partner	brother in law	sister	wife	daughter	-
Time of relationship with the aphasic partner (years)	22	64	45	28	43
Did the participant know the aphasic partner before the stroke?	yes	yes	yes	yes	-
Amount of daily hours living with the aphasic partner (hours)	24	24	24	6	24
Sex of the aphasic partner	M	M	M	F	-
Age of the aphasic partner	65	65	67	52	65
Education of the aphasic partner	ES - incomplete	ES - incomplete	HS	ES - incomplete	-
Time since the event that caused aphasia (months)	48	48	12	2	30
Type of aphasia	BA	BA	BA	BA	-

Caption: BA = Broca's aphasia; C = college; ES = elementary school; F = female; HS = high school; M = male; P = participant

Table 2. Performance in Zarit and WHOQOL-Bref at pre- and post-intervention times

	Pre-Intervention					Post-Intervention					p
	P1	P2	P3	P4	Median	P1	P2	P3	P4	Median	
Zarit Scale											
Total score	47.00	47.00	31.00	31.00	39.00	15.00	15.00	24.00	34.00	19.5	0.141
WHOQOL-Bref											
Total score	65.40	61.30	69.60	56.50	63.35	79.90	79.90	67.90	66.70	73.9	0.144
Physical	60.70	60.70	78.60	50.00	60.70	82.10	82.10	82.10	75.00	82.10	0.066
Psychological	66.70	66.70	70.80	54.20	66.70	79.20	79.20	62.50	58.30	70.85	0.269
Social relationships	75.00	58.30	66.70	75.00	70.85	83.30	58.30	83.30	83.30	83.30	0.102
Environment	59.40	59.40	63.50	46.90	59.40	75.00	75.00	68.80	50.00	71.90	0.066

Caption: P = participant

the Zarit scale and better performance in the physical, social and environment domains of the WHOQOL-bref instrument. There was no improvement in the total WHOQOL-Bref protocol score. Finally, when we analyzed the scores of participant 4, there was an improvement in the total score and domains of WHOQOL; however, there was no improvement in the Zarit scale.

DISCUSSION

Effective communication is essential for human social interaction because it enables individuals to express themselves and to show their feelings. Aphasia compromises this interaction, thus limiting the communication of people with aphasia and their interactions with the environment in which they live. Educational programs can benefit people with aphasia and their families, reducing communication barriers, and improving mental health and quality of life(7,8,14). Currently, there are no studies about short educational programs for caregivers of people with aphasia in public health systems of developing countries. Thus, the current study aimed to develop a short educational program for that population and to verify its effect by means of a pilot study.

When we analyzed the effects of the SEPA on the sample as a group, the results did not show a statistical difference between the pre- and post-intervention times, despite greater median values at the post-intervention moment. It is possible that the absence of significant results is linked to the reduced size of our sample and the consequent lack of statistical power, since we could observe improvements in some of the measures studied at an individual level. The low number of participants was due to the lack of adherence of the family caregivers invited to participate in this research, for reasons such as difficulty of mobility (few transportation options, for example), lack of interest, and impossibility of the caregiver to leave the side of the person with aphasia.

At the individual level, there was a trend for improvement in several measures. The caregiver burden (Zarit scale) was the only measure presenting a trend for improvement in three participants, and no change in the other one. There was improvement in the physical and environmental domains of the WHOQOL-Bref for all participants. The WHOQOL-Bref total score and the social domain improved for three participants, while the psychological domain improved for two. Participant 3 presented a worse performance in the psychological domain of the WHOQOL-Bref after the intervention, which probably contributed for a worsening in the total score. The psychological domain assesses the acceptance of body and physical image, the occurrence of positive and negative feelings, religion, personal beliefs and thinking about oneself. It is likely that the psychological domain was more affected for this caregiver because the program propitiated a reflection about this condition, resulting in a more intense and negative perception of the psychological aspects. Only participant 4 presented a trend for improvement in all measures. This was the youngest participant and the caregiver of the aphasic person with fewer years of aphasia. This finding suggests that younger caregivers and people with aphasia that begin interventions as early as possible may benefit more from this type of intervention.

The researchers made qualitative and informal observations that reinforce the benefits of this educational program. All participants of the study participated actively in the discussions and demonstrated willingness to understand aphasia by giving examples of their experiences and posing several questions about different topics. They also reported that their participation in this educational program had been positive.

In addition, most of the participants were women. This corroborates other studies that evaluated the caregiver profile in the Brazilian population, which observed a female prevalence in this role. It seems that the male figure is still regarded as a source of income for the family, while the woman is seen as responsible for the home and care of relatives, thus fitting the role of caregiver(15).

The limitations of this study were the small sample size and absence of a control group. Given that this is a pilot study and the results indicate a potential for future studies, we suggest that a larger sample and control group be considered for the next investigations. In order for this to happen, more effective strategies for participant inclusion should be planned.

CONCLUSION

The results of the present study indicate a trend for improvement of the quality of life and a reduction in caregiver's burden after enrollment of the participants in the SEPA. This indicates that family caregivers of people with aphasia may benefit from participating in an educational program about aphasia. Based on this, it is worth investing in future studies with larger samples to confirm the benefit and in new strategies to increase the number of participants.

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Author contributions

BHM: study design, data collection and writing of the manuscript; RFD: co-advisor of the study and review of the manuscript; BCB: advisor of the study, data analysis and review of the manuscript.