



# Speech therapy and psychological orientation program to families of brain injured patients

## Programa de orientação fonoaudiológica e psicológica para familiares de pacientes lesionados cerebrais

## Programa de orientación fonoaudiológica y psicológica para familiares de pacientes lesionados cerebrales

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### Abstract

**Introduction:** Language is responsible for one to interact with others, with the world and with himself/herself. Language disorders can cause losses to the individual in their family and social relationships. **Objective:** to develop and evaluate the Speech Therapy and Psychological Orientation Program to families of brain injured patients. **Methods:** It were invited to participate in the program all family members of patients treated in training course of adult language, at speech therapy clinic. The program was developed in the period from September to November 2010, with 21 family members in 9 meetings lasting 50 minutes each, being 3 with themes of speech therapy and 6 of psychology. In all the meetings were present the speech therapist and psychologist. Were used newsletters prepared by researchers. At the end of the meetings, a questionnaire was applied for a quantitative and qualitative evaluation of the program. **Results:** The questionnaire was responded by 18 family members, 100% said that the Orientation Program has met the expectations of the group, 89% have had the opportunity to transmit the issues discussed in that meetings to other family members and 83% the availability to participate in all meetings. **Conclusion:** The benefits of the program to the family members were detected, with emphasis on aspects about the topics covered.

**Keywords:** Family relations; Language Disorders; Psychology

### Resumo

*Introdução: A linguagem é responsável pela interação com o outro, com o mundo e consigo mesmo. A dificuldade de linguagem pode causar ao indivíduo prejuízos em suas relações familiares e sociais. Objetivo: desenvolver e avaliar o programa de orientação fonoaudiológica e psicológica aos familiares de pacientes lesionados cerebrais adultos. Método: Foram convidados a participar do programa todos*

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os familiares de pacientes atendidos no estágio de linguagem em adulto, na clínica de fonoaudiologia da instituição de origem. O programa foi desenvolvido no período de setembro a novembro de 2010, com 21 familiares, em 9 encontros com duração de 50 minutos cada encontro, sendo 3 com temáticas da Fonoaudiologia e 6 da Psicologia. Em todos os encontros estavam presentes a fonoaudióloga e a psicóloga. Foram utilizados boletins informativos elaborados pelas pesquisadoras. Ao término dos encontros, foi aplicado um questionário final para uma avaliação quantitativa e qualitativa do programa. Resultados: Responderam ao questionário 18 familiares, 100% afirmaram que o programa de orientação atendeu as expectativas do grupo, 89% tiveram a oportunidade de transmitir os assuntos abordados nesses encontros para outros familiares e 83% a disponibilidade para participar de todos os encontros. Conclusão: Os benefícios do programa foram constatados pelos familiares, com ênfase nos aspectos sobre os temas abordados.

*Palavras-chave:* Relações familiares; Transtorno de linguagem; Psicologia.

### Resumen

*Introducción:* El lenguaje es responsable por la interacción con los demás, con el mundo y consigo mismo. La dificultad del lenguaje puede causar daño al individuo en sus relaciones familiares y sociales. *Objetivo:* desarrollar y evaluar el programa de orientación fonoaudiológica e psicológica para las familias de pacientes adultos con lesiones cerebrales. *Metodos:* Se invitó a participar del programa todos los miembros de la familia de los pacientes en tratamiento en la práctica clínica de lenguaje para adultos, en la clínica de fonoaudiología de la institución de origen. El programa se desarrolló en el periodo de septiembre a noviembre de 2010, con 21 miembros de las familias, en 9 reuniones de 50 minutos cada. Fueron 3 reuniones con temas de fonoaudiología y 6 con temas de Psicología. En cada reunión estuvieron presentes la fonoaudióloga y la psicóloga. Se utilizaron boletines informativos producidos por las investigadoras. Al final de las reuniones, se aplicó un cuestionario para evaluación cuantitativa y cualitativa del programa. *Resultados:* Completaron el cuestionario 18 miembros de las familias, 100% dijo que el programa de orientación ha respondido a las expectativas del grupo, el 89% han tenido la oportunidad de transmitir los temas tratados en estas reuniones a otros miembros de la familia y el 83% tubo la disponibilidad para asistir a todas las reuniones. *Conclusion:* Los beneficios del programa fueron constatados por los miembros de la familia, con énfasis en los aspectos de los temas tratados.

*Palabras clave:* Relaciones familiares; Trastornos del lenguaje; Psicología.

### Introduction

The language enables interaction with others, with the world and with him/herself<sup>1</sup>. Difficulties in communication cause a burden that often leads the person to avoid social situations<sup>2</sup>, in addition this situation causes damage to family relationships<sup>3</sup>.

There are several diseases that affect the nervous system and they can cause consequences such as language disorders. The disease shows increasing needs from a situation that it was not chosen, setting up a burden on the family system, changing the routine and the intimacy of the aphasic individual with the family<sup>4</sup>. Due to the unfamiliarity of the current situation, the family struggles to move forward to new challenges<sup>2</sup>.

Living with people who require care, even when these actions are carried out with attention, affection and tenderness it can also be marked by fatigue, stress and exhaustion, which puts the

family in the position of needing care and attention<sup>5-7</sup> as often the caregiver becomes the mediator between the person in their care and the outside world<sup>8</sup>.

The commitments of the caregiver quality of life interfere negatively in the rehabilitation process of the cared person<sup>6</sup>, since the overload tests the physical, psychological limits, and coping attitudes towards life<sup>9</sup>.

A study examined the quality of life of caregivers of aphasic people, using the WHOQOL - Bref and "Specific Scale for cerebrovascular diseases - SSQOL" noted losses in aphasic individual's quality of life as well as their family's<sup>10</sup> pointing physical and emotional burden, indicating the need for care and intervention as the aphasic him/herself<sup>10, 11</sup>. The sooner the diagnosis of the lesion is completed, earlier interventions can be initiated<sup>12</sup>

The impact of an orientation program / multi-professional education in burden and quality

of life of the caregivers was evaluated by using the WHOQOL - Bref and the Caregiver Burden Inventory. The program was developed in five modules of four hours each relying on professionals from different areas like architecture, nursing, physical therapy and speech therapy. The results showed an improvement in the quality of life of caregivers, but there was no statistical significance on the burden<sup>13</sup>.

Literature brings the report of an experience on a group for family members of elderly people with dementia. The purpose of this group was hosting the family member, guide them on care for the elderly with dementia and promote an exchange among family members. The group included the coordination of a nurse and a psychologist, who conducted the meetings talking about experiences of each family. It was possible to observe the aid provided to caregivers favoring their well-being and also his relative with aphasia<sup>14</sup>.

Other advantages related to the educational aspects of the caregiver were evidenced in orientation programs for caregivers of aphasic patients<sup>15,16</sup>. It can be observed, with these studies, that the family was benefited from the exposure of the content and exchange experience with other participants.

Some studies in this area have been proposed, mainly under the name of Psychological-educational intervention<sup>17,18</sup>. The groups with caregivers have the main objective to improve the effectiveness of care, the welfare of caregivers and increase the use of coping strategies<sup>17</sup>.

Researchers assessed the efficacy of a speech-language orientation program with four sessions of an hour and-a-half each, focusing on communication strategies for caregivers of patients with Alzheimer's disease in the moderate phase. It was concluded that the program has promoted changes in the communicative behavior of caregivers, with increased use of communication strategies<sup>19</sup>.

It was observed, in the cited studies, the lack of information and preparation of caregivers facing the difficulties encountered, but on the other hand benefits were observed with the orientation programs, promoting clarification and guidance, contributing to the reduction of emotional overload and the possibility of improvement of the quality of life. The present study aimed to develop and evaluate the speech therapy and counseling program for

caregivers of adult brain injured patients treated at the Clinic of Speech Therapy at FOB-USP.

## Methods

This research was characterized as cross in quantitative and qualitative mode. This study was approved by the Ethics Committee for Human Beings Research, respecting the resolution 196/96, as n° 0103/2010, developed at the Clinic of Speech Therapy at FOB-USP for the period from September to December 2010.

Family members were invited to participate in this study by an invitation letter, delivered to them at the Clinic of Speech Therapy during the speech therapy sessions, informing them about the purpose of the proposed orientation program. Interested parties were invited to a meeting to explicit goals, justification, relevance, collection procedures, risks and benefits; it was affirmed that the participation was voluntary and speech therapy treatment was assurance to the patient, regardless of acceptance or refusal to participate and give the schedule of the subjects addressed.

For the sample, the inclusion criteria was established: to have daily contact with the patient, be a member of the family, adults and the elderly with no restriction of age, education and gender level who agreed to participate signed the consent form.

The sample consisted of 21 relatives of people with aphasia, two males and 19 females, aged 38-79 years. Three of them who participated the meetings, did not answer the final questionnaire.

The family members attended the orientation program which consisted of nine weekly meetings lasting 50 minutes each meeting; they were all led by a speech therapist and a psychologist. The program was designed in 9 meetings, considering a speech guidance program for brain injured adults' family members<sup>16</sup> which used themes of the speech therapy area addressed in this study, and also presented a supplementation with psychology matters crossed with the selected themes.

The first three meetings were coordinated by the speech therapist addressing the following topics: diseases (stroke, Alzheimer's disease and Parkinson's disease), speech pathology and communication strategies. Other meetings were conducted by the psychologist and addressed the following issues: behavior changes, the role of family in a multidisciplinary team and stress. At

each meeting, it was made a negotiated statement of the issues described and it was developed a newsletter. The support materials addressed the following topics: Pathologies; Speech-Language disorders resulting from acquired neurological damage; communication strategies; emotional and behavior of adults and elderly brain injury changes; Dealing with behavioral problems associated with Alzheimer's disease; Controlling stress; The multidisciplinary team and family in the rehabilitation process.

The structure of the meetings was justified considering the need for the family to know and understand the disorders, language disorders and behavior to better relate to the patient, as well as having a support to manage the overload on the caregiver position. Although the meetings have been coordinated by the two areas at different times, the issues addressed were interrelated.

At the end of the nine meetings, it was applied a final questionnaire containing ten questions, the last one asked for suggestions and comments in order to assess the importance of the orientation program, if it reached the initial expectations, understanding of the topics covered, the possible transfer of knowledge to other family members and the applicability of facilitating strategies of communication. It is emphasized that this questionnaire was designed and used in a group of speech guidance with families of brain injured patients<sup>16</sup>. No modification was made, because the issues presented met the initial objective to evaluate the current orientation program.

Data were organized in tables using the Excel program and submitted to descriptive statistical analysis. It was also used participants quotations to illustrate the results based on meaning core, analysis procedure based qualitative material in the socio-historical psychology.

## Results

The results showed that only questions six and seven did not obtain 100% positive response (Figure 1).

**Figure 1.** Absolute value and percentage of responses from 1 to 9 of the final questionnaire

Questions	Yes	No
	n (%)	n (%)
1. Have you judged important to conduct meetings with the participation of the family group?	18 (100%)	—
2. The meetings provided a connection between the family?	18 (100%)	—
3. During the meeting there was support and / or exchanges of experiences among family members?	18 (100%)	—
4. Did the guidelines help a better understanding of brain injury and its consequences?	18 (100%)	—
5. As facilitate communication strategies discussed at the meetings were the restaurant, as the way to proceed with the patient?	18 (100%)	—
6. Was there a possibility of you participate with frequency of meetings?	15 (83%)	3 (7%)
7. Did you have the opportunity to convey the issues discussed in the meetings with other family members?	16 (89%)	2 (11%)
8. The preparation of informative botetins was complementary to the issues discussed?	18 (100%)	—
9. The issues discussed in the meetings corresponded to their needs?	18 (100%)	—

Table 2 shows a summary of the responses provided by the family in question 10 related to comments and suggestions. It is important that all the participants suggested further guidance program in following semesters.

**Figure 2.** Description of the suggestions and comments made by the family in question 10 of

10. Comments and suggestions	Answers
	<ul style="list-style-type: none"> <li>- Address with the group what they cannot talk to their own family</li> <li>- The importance of the exchange of experiences among participants</li> <li>- Importance of the information received by professionals and materials available</li> <li>- Approach to other topics such as sexuality</li> <li>- Host Feeling</li> <li>- Self control</li> <li>- Orientation program continued in other semesters</li> </ul>

## Discussion

Although some studies related to the orientation programs are developed in four to six sections<sup>13, 15, 16</sup> with a duration from 50 minutes to four hours, the format of this orientation program was developed in nine meetings lasting 50 minutes, to meet the proposed schedule. It was chosen to be 50 minutes considering the time family members were waiting for their relatives in speech therapy session, it would not be necessary to come on another day.

It was noted that in all meetings the support of both professionals was necessary at the time of exchanging experience, regardless of the topic discussed was of Speech Therapy or Psychology approach, demonstrating the importance of interdisciplinary work, encouraging the full view of both caregiver and patient, since caregiver's quality of life interferes in the rehabilitation process such as the patient's quality of life and the reverse is also made true<sup>10</sup>.

The results of this study show that the proposed orientation program was effective because all participants reported the importance of meetings, experience exchanging and closeness between family members, also having a greater knowledge about the patient and the consequences of the injury, benefits regarding communication with the use of the offered strategies as well as the issues addressed and supplement the information with newsletter, according to the literature<sup>16</sup>.

Some speeches of family members reaffirmed the above data: "Everybody in the group understands the side of the people. We can unburden. Just hearing the other telling his/her experience we've learned". "It was great to meet and hear other people and they listen to me. Until then no one knew of my problem". "We have changed a lot. It was good to hear the woman talking about her mother. I began to understand better what I was going through".

A minority of participants reported difficulties in participating in all the meetings because of the difficulty of transport<sup>15</sup> and / or for health reasons both of the caregiver and the patient, and transmitting the information to other family members not interested<sup>16</sup>.

With regard to comments and suggestions, all participants reported that the orientation program should continue in all semesters<sup>16</sup>, and that they felt welcomed and developed self-control in the face of difficulties of being a caregiver<sup>14</sup>, illustrated the following statement: "Ah! When we have the

guidance you learn to control yourself. You believe that it is a part of the treatment."

The support material was used in several programs<sup>13, 15, 16, 20</sup>, aiding in the understanding of the information developed during the meetings, consistent data in this study, according to the testimony of one of the participants: "When we show the handout, people believe in what we are talking about. They understand that it is part of the treatment and want to follow the written rules".

During the process of the orientation program as they felt welcomed, the family realized the importance of self-care and self-control, reducing the overload, stress and fatigue resulting from the role of caregiver,<sup>3, 11</sup> reflecting positively in the rehabilitation process and relationship with the patient. These findings are in line with the study that analyzed the quality of life of family members of aphasic people, pointing out that the least affected areas were personal relationships and psychological issues. It is important that the group analyzed in this study was already participating in a multidisciplinary orientation program, reaffirming the importance and necessity of involving the family in the rehabilitation process<sup>10</sup>.

The lack of studies about this theme in the scientific literature specifically in multidisciplinary orientation programs for adult patients with neurological injury was a limitation of this study, since there were found only two studies that have developed multidisciplinary orientation programs<sup>13, 14</sup>, but without relation with the areas of Speech Therapy and Psychology.

However, caregivers appear to be at work burden conditions and experience conflict situations in their family environment that contribute to the loss of quality of life, then it is important for health professionals to propose policies and suggest to implement social support programs for family orientation about the reality of these caregivers<sup>6</sup>.

## Conclusion

The format of the program in nine meetings with the presence of speech therapy and psychology was well accepted by the families' members, to the extent that they could understand better the communication changes and patients behavior, assisting in situations of everyday life. The program was assessed positively by family members, who emphasized the importance of the speech pathologists

work with psychologists, reinforcing the need and effectiveness of multidisciplinary orientation programs. This study suggests the development of future research with multidisciplinary orientation programs, encouraging the interrelation of speech therapy and psychology with other areas of health.

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