

Aphasia and social inclusion: a Brazilian Speech-Therapy overview

Afasia e inclusão social: panorama brasileiro na Fonoaudiologia

Afasia y inclusión social: un panorama brasileño en Fonoaudiología

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Abstract

Introduction: The impacts of aphasia are not restricted to changes in language or communication, and affect both quality of life and social participation. Therefore, it is essential that speech-language pathologists work within an interdisciplinary approach and their scope of action in aphasia therapy should not be restricted to correct language deficits. This study discusses the importance of social inclusion goals in aphasia therapy, suggesting ways to better meet the demands of this population. **Objective:** To discuss the role of speech-language pathologists in tackling the social impacts of aphasia. **Method:** This is a non-systematic literature review that addresses topics related to social inclusion, as well as current Brazilian initiatives that promote social participation for people with aphasia. **Results:** Despite remaining gaps, there are important signs of a change in perspective and scope of action of speech-language pathologists, such as increasing actions involving peer groups, the development of associations, as well as nation-wide awareness campaigns. **Conclusion:** There has been an increase in group interventions, as well as greater promotion of artistic activities for people with aphasia. Studies on these interventions report positive impacts on quality of life, social participation and functional communication for this population. Further combined efforts with family members and society as a whole are needed, as well as the promotion of policies and services that promote social inclusion for people with aphasia.

Keywords: Aphasia; Quality of Life; Social Participation.

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Authors' contributions:

EAA: Methodology, Data Collection, Paper Outline.

DMB: Data collection, Article outline.

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Received: 09/14/2020

Accepted: 23/11/2020

Resumo

Introdução: Os impactos da afasia vão além de alterações de linguagem ou comunicação, afetando a qualidade de vida e a participação social. Faz-se necessário, portanto, que o fonoaudiólogo atue de forma interdisciplinar e amplie seu escopo de atuação na terapia das afasias, indo além de uma perspectiva que foca majoritariamente na correção de déficits linguísticos. Esta comunicação discute a importância de metas de incentivo à inclusão social e aponta caminhos para melhor atender às demandas dessa população.

Objetivo: Discutir o trabalho do fonoaudiólogo no que tange a metas de enfrentamento dos impactos sociais da afasia. **Método:** Revisão não sistemática de literatura. São discutidos temas ligados à inclusão social e apresentadas iniciativas nacionais que promovem a participação social da pessoa com afasia.

Resultados: Apesar das lacunas ainda existentes, as ações crescentes de diversos grupos de convivência, a criação de associações e as campanhas de conscientização da população apontam para importantes sinais de mudança no escopo de atuação do fonoaudiólogo junto a essa população. **Conclusão:** Há um crescimento das intervenções em grupo e valorização de atividades artísticas oferecidas junto a pessoas que vivem com afasia. Os estudos sobre tais intervenções demonstram impactos positivos na qualidade de vida, participação social e funcionalidade da comunicação dessa população. São necessários esforços no sentido de trabalhar com a família e com a sociedade, bem como ampliar políticas públicas e oferecer serviços que promovam a inclusão social da pessoa com afasia.

Palavras-chave: Afasia; Qualidade de Vida; Participação Social.

Resumen

Introducción: los impactos de la afasia van más allá que las alteraciones de lenguaje o de comunicación, afectando la calidad de vida y la participación social. Sin embargo, es necesario que el logopeda trabaje de forma interdisciplinar y amplíe su alcance de atención a la terapia de afasia, más allá de una perspectiva centrada en la corrección de déficits lingüísticos. Esta comunicación analiza la importancia de metas de incentivo y de medidas de inclusión social para satisfacer mejor las demandas de esta población. **Objetivo:** Discutir el trabajo del logopeda en relación con las metas de enfrentamiento del impacto social de la afasia. **Métodos:** revisión no sistemática de literatura. Son discutidos temas relacionados con la inclusión social y la presentación de iniciativas brasileñas que promueven la participación social de la persona con afasia. **Resultados:** aún que existan faltas, las iniciativas crecientes de variados grupos de convivencia y la creación de asociaciones y de campañas de concientización indican haber cambios importantes en el ámbito de actuación del logopeda junto a esta población. **Conclusión:** Ha habido un aumento en las intervenciones en grupo y en las actividades artísticas ofrecidas a las personas que viven con afasia. Los estudios sobre estas intervenciones demuestran impactos positivos en la calidad de vida, la participación social y la funcionalidad de esta población. Son necesarios esfuerzos en el sentido de trabajar junto a familia y la sociedad, así como expandir las políticas públicas y el ofrecimiento de servicios que promuevan la inclusión social de la persona con afasia.

Palabras clave: Afasia; Calidad de Vida; Participación Social.

Introduction

The high incidence of depression and disability among stroke survivors in Brazil has been known for more than a decade. Stroke is the main cause of aphasia and the data have already shown that stroke survivors who have communication deficits are the ones who most face depression and low levels of quality of life. Among stroke survivors, the impact of communication on quality of life makes

people living with aphasia to be among those who suffer most from depression and reduced social participation.¹

Regarding the guidelines for care for stroke survivors, the publication of the National Guidelines for Stroke Rehabilitation Care was a significant milestone in Brazil. The guidelines guide multiprofessional health teams regarding rehabilitation care, according to the physical, hearing, visual, intellectual and emotional dysfunctions of



individuals who have suffered a stroke.² Despite its undeniable importance for advancing care for people with stroke, the low emphasis on aphasia in the guidelines and the predominance of rehabilitation goals should be questioned, as there is no clear focus on social inclusion.

The psychosocial vulnerability of the person with aphasia is a strong reason for the speech-language-hearing pathologist to seek to promote changes in daily life related to communication with this population and the promotion of their well-being.³ A broad work on social inclusion in aphasia requires a broad discussion that involves rethinking the role offered to individuals with aphasia in making decisions about their life priorities.

In the scope of the evaluation, the speech-language-hearing pathologist should use tools that inform about the perception of the aphasic and their family about how the patient feels in communicative situations and how much they participate in social situations.⁴

The literature shows a mismatch between holistic perspectives of care for people with aphasia, understanding of the social impacts of aphasia and the reality of the care provided. Reports by speech-language-hearing pathologists who work in health services in six countries show that the aphasia approach tends to have an almost exclusive focus on treating the individual's deficits and providing interventions with strict time limits. The devaluation of communication was also reported due to choices to focus on the treatment of dysphagia, either due to the pressure of overwork or the impact of discharge guidelines during hospitalization periods and the duration of services. This data reflects a common understanding that the speech-language-hearing pathology work should focus exclusively on the acute phase, disregarding the often chronic nature of aphasia.⁵

Speech-language-hearing pathologists also raise concerns about the limited time for therapeutic follow-up and highlight the need for further research to strengthen the evidence in favor of long-term management of aphasia. Having the skills and abilities necessary to offer a holistic model of rehabilitation is seen as the main factor that influences the implementation of services to promote the social inclusion of the person with aphasia.⁶

This study aimed to discuss the work of the speech-language-hearing pathologist with regard to the goals when facing the social impacts of aphasia.

Initially, the study addresses three crucial questions to support the role of the speech-language-hearing pathologist in achieving social inclusion goals: (1) greater focus on communication functionality; (2) empowerment of the person living with aphasia; (3) awareness of society about the changes required to include the person with aphasia and the development of public policies for social inclusion of the person living with aphasia. Then, the study conducts a non-systematic literature review tracing a broad and non-exhaustive overview of Brazilian initiatives that have been seeking to promote the achievement of these goals. These initiatives consist mainly of promoting coexistence in social and cultural spaces, as well as the practice of art by people with aphasia.

Functionality of communication

There is nothing new in the idea that speech-language-hearing pathology intervention in aphasia should not be restricted to isolated linguistic components. The concept of functionality of communication, or functional communication, is quite common in the literature, although there is still no consensus on its definition. This study understands it as a complex concept composed of multiple variables: (1) interaction; (2) multimodality; (3) based on what is shared between participants in the communication, such as knowledge shared or different between speakers, physical and communicational environment.⁷

Non-verbal aspects are not excluded from speech-language-hearing therapy from the perspective of the functionality of communication; on the contrary, they are important partners. Thus, communicative skills are considered preserved in overcoming linguistic difficulties. In this context, complementary and alternative communication is an important tool, especially when oral expression is severely impaired in a chronic way. Complementary and alternative communication is understood as any resource that uses gestures, images, reading and writing, when possible.⁸

The person living with aphasia, their family members and society must realize that aphasia does not exclude discursive capacity, since there are different coexisting or compensatory non-verbal communicative strategies in relation to speech and writing, such as gestures, looking and body posture. Preserved linguistic processes also allow adjustments and reformulations in the conversation, as

well as strategies for checking the communicative intention, paraphrases and explanations. The conversation of the person with aphasia is a construction that involves oral and gestural help from the interlocutor and these aspects should have greater attention from the therapeutic models.⁹

Communication Partner Training (CPT) is one of the intervention models that focus on orientation to the interlocutor, which aims to prepare the interlocutors of the individual with aphasia, such as family members, caregivers, friends and health professionals, in order to promote functional communication. The appreciation of this type of approach shows an important change in therapeutic focus, showing an awareness of the joint effort required for communication.¹⁰

Empowerment

The concept of empowerment in the health field may be an important reference, aiming at the centrality of individuals in the decisions that concern them and that impact their health. Empowerment refers to processes and results related to issues of control, critical awareness and participation.¹¹ It can also be understood in combination with the social model of disability, which promotes goals to fight stigmas. Therefore, the empowerment of this population in the defense of their rights becomes a goal involving the elimination of stigmas, respect for individuality and autonomy, and participation in different social and cultural spaces.¹²

The concept of empowerment is seen on the international stage as a guide for initiatives aimed at people with aphasia. The approach proposed by the Life Participation Approach to Aphasia is a significant example of this concept, as it promotes listening to personal goals and objectives, considering the needs and interests of the individual with aphasia in the decisions and direction of their own rehabilitation.¹

A systematic review¹³ investigated the perspective of people with aphasia about their own recovery and post-stroke quality of life. The study highlighted factors such as: social support through relationships and wider community structures and attitudes; a collective understanding of aphasia; social inclusion of individuals so that they feel they are active members of the community; centralized support for the individual; and the presence of prepared professionals, as well as access to information.

These reports include a clear conception that the needs and interests of the individual and their family must be at the center of therapeutic decisions, providing horizontality to the therapist-patient relationships and promoting autonomy. In addition, these reports show the importance of involving society as a whole, which is central when discussing inclusion goals. In practice, these goals include awareness of aphasia and structural changes that allow greater support for this population.

Social awareness and public policies

There is an urgent need for awareness about aphasia in Brazil. A study carried out in 2013 interviewed 120 people between 18 and 72 years of age and found that only 20% of people had 'heard about aphasia'. The participants were not clear about the causes of aphasia, nor did they know how to describe its characteristics. Most of the interviewees reported that they knew about aphasia through personal contact with affected people, which shows the restriction of other sources of information.¹⁴

In addition to public awareness campaigns, it is necessary to advance the development of public policies to guarantee rights. The lack of accessibility to different community spaces is one of the greatest social challenges for people with aphasia, which is a gap not only in physical conditions but also in attitudinal environments. In addition, there are significant barriers to services, systems and policies for reintegration into work and employment. Therefore, it is essential that public policy planning addresses the identification of these flaws and aims at a project that is able to contemplate the singularity of individuals.¹⁵

Bill 311/2018 is a significant example of seeking political advancement, which proposes the inclusion of communication disorders in the list of impediments that characterize disability.¹⁶

Ensuring the rights of people with communication disorders deserves special attention in terms of providing guidance and support to the family and fighting stigma in society. Intervention policies focusing exclusively on the individual, requiring effort and overcoming to adapt to expectations of normality represent a perspective focused on capacity and that understands communicative differences as incapacity. The immediate result of this perspective is the demand for attitudes of heroism from those who live and live with aphasia and who

see themselves as the only ones responsible for overcoming obstacles.¹⁷

Description

This is a non-systematic literature review that searched the following databases: Google Scholar, Lilacs, Scielo, Pubmed, Periódicos CAPES and Brazilian Digital Library of Theses and Dissertations. The research sought studies carried out to date on aphasia and the following topics in the Brazilian scenario: empowerment, social coexistence, artistic practices and social inclusion.

Due to the multiple topics, multiple combinations of terms in Brazilian Portuguese were used: aphasia and art; aphasia and social inclusion; aphasia and empowerment; aphasia and theater; aphasia and social groups. Given the social relevance of non-academic initiatives through web portals, searches were also carried out outside indexed databases.

The study chose to use broad inclusion criteria: relationship with at least one of the topics and the presence of critical reflection. The exclusion criteria used were: production not related to the Brazilian scenario. In turn, criteria of type or date of publication were not used. Due to the limited scope of this review, it was not possible to include all the findings. Publications that addressed initiatives already presented were excluded, prioritizing publications with greater detail and discussion of the proposal.

These broad criteria reflect the more general scope of this review, and aim to make a national overview feasible, although not exhaustive. This overview was subdivided into two types of initiatives: social groups and associations and groups that promote contact with art for people with aphasia.

Social Groups and Associations

The search found a trend in the literature to involve social groups, which has been shown to be very rich and well accepted in different theoretical and practical contexts, with publications from different regions of the country and including a wide scope of activities.

Due to the social and discursive factors involved, group interventions in aphasia have great potential for promoting inclusion.¹⁸ In addition to international studies, there are national publica-

tions providing evidence that group intervention in aphasia leads to improved communication skills and quality of life.¹⁹

As a core, there is the objective of expanding the possibilities of expression and interaction of the participants, understanding communication from a functional perspective and including other modalities, in addition to language.²⁰ There are also activities in different spaces, which is relevant from the perspective of social inclusion as a way not only to provide interaction in new contexts, but also to raise awareness of the wider community about aphasia. The interventions address cultural visits, artistic activities, resumption of hobbies, discussion of news, among other activities, with great openness for interdisciplinary action.^{16,21}

Another type of action can be observed in associations and independent organizations in the context of a broader relationship with society. These institutions are extremely significant in achieving empowerment goals, since they provide information and direct support for people with aphasia and their families; and its social function of awareness can and must reach participation in health and rights councils for people with disabilities. In turn, given the undeniable impact of ignorance about aphasia on the part of society, the development of political articulation is essential to discuss inclusion of aphasics.^{22,23}

With regard to direct communication with society, it is essential to emphasize the importance of platforms and websites on the Internet due to their potential to expand the reach of campaigns and access to information, which should not be ignored. These platforms can also be a bridge for more direct contact and support, and are instrumental in promoting a greater understanding of society about the experience of living with aphasia.^{24,25}

The role of art in the expression of the person with aphasia

In addition to publications aimed at social groups and associations, the search found initiatives based on artistic expression in aphasia. The arts have great potential as a means to achieve the goals of empowerment and quality of life for people with aphasia. Artistic expressiveness provides a space for strengthening autonomy and resignification of living with aphasia, assuming active social roles. Furthermore, art values expression through multiple means of communication, which is especially



relevant in a concept of speech-language-hearing pathology intervention that goes beyond the recovery of lost linguistic functions.

Some initiatives use art as an instrument to empower people with aphasia to promote social transformation. Initial evidence suggests that expression through art may increase the psychosocial well-being of stroke survivors.²⁶ In particular, group interventions provide benefits for individual expression, confidence to achieve goals, and a safe means to express communicative diversity. There is also evidence that participation in art groups significantly reduces depression and has a positive impact on the concentration, motivation, functionality and quality of life of this population.²⁷

Although several artistic modalities may be suitable for the purpose of intervention, the Performing Arts have been prominent in Brazil.^{28,29} There is a wide context and paradigm shift in this performance that transcends the clinical and academic space to include cultural spaces. In addition, there is an emphasis on exploring different modes of expression, based on the interdisciplinary exchange with the Performing Arts. Finally, the person with aphasia also plays another role, leaving the exclusive position of a patient in rehabilitation to participate in a group, and also as an agent in cultural productions, such as in theatrical performances.

The practice of clownesque art by people with aphasia is a promising modality with regard to the promotion of subjective well-being and quality of life. The social rules are quite different in the interaction between apprentice clowns. Clowns are successful in sharing their failure with humor, in a revolutionary aspect that may have major changes in the perception of themselves and society as a spectator. In addition, the form of communication employed by the clown is not attached to the concept of right or wrong, thus favoring the widespread use of multimodal functional strategies and the enhancement of personal communication styles.³⁰

Discussion

The brief review carried out shows important trends in the field of speech-language pathology and audiology practice associated with aphasias in Brazil, with the growing development of social groups, associations and artistic projects. These types of interventions have shown benefits in the

quality of life of people living with aphasia, and the advance in the dissemination of these practices is shown to be a strong partner of speech-hearing pathologists in the struggle for an approach that addresses the social impacts of aphasia.

As reported in the initial sections of this study, setting goals that address the social impact of aphasia is a complex task and includes issues of functionality in communication, empowerment, social awareness and public policies. The work of associations, social groups and artistic groups is instrumental in all of these areas.

On the one hand, social and artistic groups broaden the perspective of communication, often working in a paradigm of discursive co-construction and the use of different strategies and humor. At the same time, they place the person with aphasia in an active and central position in the decision-making process, contributing to their empowerment. In addition, these contexts provide possibilities to instrumentalize and provide support to the interlocutors of people living with aphasia, promoting necessary adaptations to the functionality of communication in a perspective of empathy and respect for diversity.

Associations and awareness initiatives act at the same time, in addition to immediate interlocutors, in the relationship of society with aphasia, also enabling this population to articulate to fight for rights, which implies attention to public policy issues. This performance in the macrosocial context is within the scope of the speech-language-hearing pathologist: the general lack of knowledge about the difficulties faced by aphasics has direct impacts on their daily lives. In fact, the growing attention provided by the Brazilian Society of Speech-Language Pathology and Audiology to Awareness Month campaigns about Aphasia is a clear indication of the importance of this topic in Speech-Language Pathology.

There is a long way to go in terms of advances in public policies that promote social inclusion and communicative accessibility for people living with aphasia and support for their families. The inclusion of communication disorders among the characteristics that may be part of the disability conditions may foster an articulation with the search for rights already disseminated to other groups. In turn, this may generate important developments in the empowerment of people with aphasia and assist in the development of a different paradigm for dealing



with the changes caused by an acquired condition. It is essential to rethink the perception about the deficiency that prevails in most social media in order to generate constructive repercussions for this issue.

The provision of services such as therapeutic follow-up can be essential in this sense. The guarantee of rights could enable the support to caregivers and the participation of people who are not independent, either due to the severity of the motor condition, or due to cognitive difficulties. To this end, there is again a need for inter and transdisciplinary advances, which implies training that includes not only hospital contexts, but also decentralization of care both in health centers from the perspective of family and community care, as well as in non-healthcare settings, such as associations, cultural centers and other means that, in fact, directly favor social inclusion.

The university has an essential role in the training of qualified health professionals to work in a biopsychosocial and interdisciplinary perspective, in addition to being an important driver of discussions and projects that promote social transformation. Projects developed at universities should be increasingly extended to the Unified Health System in order to reach a larger portion of the population. From this perspective, it is necessary to expand and continue the attention to the care of the stroke survivor in order to include practices aligned with the principles of comprehensiveness, transcending the care exclusively focused on overcoming cognitive deficits.

In general, and still regarding the principle of universality and accessibility to services, this review found that living programs tend to be provided in large centers that do not offer specialized transport, which implies accessibility problems. As a result, socialization is almost exclusively relegated to the care of family members who often do not have any support. At the same time, social groups and associations that implement group interventions provide a significant model to be developed. Similarly, online platforms may be instrumental in supporting and accessing information.

Currently, the pressing need to use these media to mitigate the impact of social isolation from at groups during the COVID-19 pandemic suggests the growing need for digital inclusion. Of course, advances are required for policies that enable low-income population access to technology, and this

new interactional context is likely to have perennial repercussions.

Final considerations

This study aimed to present an overview of the possibilities in the performance of the speech-language-hearing pathologist with regard to coping with the social impacts of aphasia. Due to the often chronic character of aphasia, it is not possible to ignore the importance of empowerment for the quality of life of this population. Speech-language pathologists must move towards extending their performance beyond the clinical and biomedical contexts, reaching cultural and community spaces. Participation in political discussions on the rights of persons with disabilities should also receive greater attention.

There is a growing awareness of the need to strengthen understanding in Collective Health and to engage Speech-language pathology and more in the struggle for the social inclusion of aphasic patients. Important advances can be achieved through the adoption of strategies that meet the needs of aphasics in an interdisciplinary way, particularly in interaction with areas such as Psychology and the Arts. It is necessary to value proposals for assessment, intervention, formulation of public policies and research that encourage the restructuring of services, covering the psychosocial impacts of aphasia.

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