Case Report

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Adherence to speech-language therapy by people with aphasia referred after hospital discharge: study of two cases

Adesão ao tratamento fonoaudiológico por pessoas com afasia encaminhadas após alta hospitalar: estudo de dois casos

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ABSTRACT

Given the perceived impact on communication and quality of life of aphasia, the importance of adherence to speech therapy treatment is clear. However, there are cases in which this treatment is not sought, for reasons that have not been fully investigated. The aim of this study was to analyze adherence to speech therapy by people with aphasia referred after hospital discharge. A qualitative case study of two cases was carried out. Two elderly women with aphasia after stroke treated at a micro-regional public referral hospital participated in this study. Sociodemographic and clinical data were collected from patient medical records and drawn from an interview with a family member during hospitalization. After about two months, a second interview was conducted to investigate whether speech therapy had been sought. The presence of post-stroke physical sequelae affecting lower limbs, its severity, and the post-stroke recovery phase were all factors contributing to non-adherence to public outpatient speech-therapy treatment by these individuals with aphasia. The interaction between sociodemographic factors, clinical aspects and characteristics of the public health network (such as non-availability of speech therapists in the home-care service) can influence the seeking of private home-based treatment in these cases. Results revealed that multiple clinical and sociodemographic factors influence nonadherence to speech therapy in this population. In addition, these factors indicate difficulties accessing public health services as a result of shortcomings in the regional health care network.

Keywords: Rehabilitation; Speech therapy; Aphasia; Referral and consultation; Access to health services

RESUMO

Diante da percepção do impacto na comunicação e na qualidade de vida ocasionado por um quadro de afasia, compreende-se a relevância da adesão ao tratamento fonoaudiológico. Porém, há casos em que a procura por tal tratamento não ocorre, por motivos que ainda não foram investigados de modo aprofundado. O objetivo deste estudo foi analisar a adesão ao tratamento fonoaudiológico de pessoas com afasia, encaminhadas após alta hospitalar. Foi realizado um estudo qualitativo de dois casos. Participaram deste estudo duas idosas com afasia após acidente vascular cerebral (AVC), acompanhadas em um hospital municipal de referência microrregional. Foi realizada a coleta de dados sociodemográficos e clínicos em prontuário e por meio de entrevista com um familiar de cada participante, durante a internação. Após dois meses, aproximadamente, foi realizada nova entrevista para investigar a procura por atendimento fonoaudiológico. A instalação de sequelas físicas pós-AVC, que afetam membro inferior, sua gravidade e a fase de recuperação contribuem para a não adesão ao tratamento fonoaudiológico público em nível ambulatorial, por pessoas com afasia. A interação entre fatores sociodemográficos, aspectos clínicos e características da rede pública de saúde (como a inexistência de fonoaudiólogo no serviço de atenção domiciliar) pode influenciar a procura por tratamento domiciliar particular nesses casos. É possível afirmar que múltiplos fatores, clínicos e sociodemográficos, influenciam a não procura por tratamento fonoaudiológico por essa população. Além disso, tais fatores indicam a existência de dificuldades no acesso a serviços de saúde públicos, por limitações na rede de atenção à saúde regional.

Palavras-chave: Reabilitação; Fonoaudiologia; Afasia; Encaminhamento e consulta; Acesso aos serviços de saúde

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INTRODUCTION

Aphasia is an acquired disorder, resulting from a focal brain lesion in the dominant hemisphere for language, which affects the individual's communicative and social functioning, their quality of life, and also impacts those around them[1]. The main cause of aphasia is cerebrovascular disease, particularly stroke[2].

In cases of aphasia secondary to stroke, the impairment in communication not only impacts the person's life, but also that of their family and society at large[1], who encounter difficulties conversing with and understanding the individual. Communication is essential in life, being constantly present and needed for expressing ourselves and understanding the dialogue of others. According to Happ[3], absence of oral communication poses problems in conveying thoughts, feelings, desires and needs, thus representing a communication barrier.

The aim of speech-language therapy in aphasia cases is to recuperate the patient's communication abilities, taking into account their limitations, and both mental and physical status[4]. Given the perceived impact of aphasia on communication and quality of life, the importance of adherence to speech therapy treatment is clear. In some cases, however, patients fail to seek this treatment, for reasons not yet fully investigated.

Given that each subject should be regarded from a biopsychosocial perspective in a multidimensional and holistic fashion, all aspects which might be associated with non-adherence to speech therapy treatment in these cases should be explored. Rates of adherence to long-term therapy for chronic disease generally reach 50% in developed countries. It is therefore reasonable to assume that rates are even lower in developing countries, due to a lack of resources and poorer access to healthcare facilities[5].

Although studies addressing various aspects of adherence to speech therapy are available in the literature[6-8], no Brazilian studies focusing specifically on adherence to speech therapy in aphasia were found. Investigations on this issue are pivotal to help identify the potential factors favoring or detracting from adherence. This knowledge can contribute to the improvement of those healthcare networks catering for this population, including health services and/or practices provided.

Therefore, the objective of the present study was to analyze the factors associated with non-adherence to speech-language therapy by individuals with aphasia referred after hospital discharge.

PRESENTATION OF CASES

The study was approved by the Research Ethics Committee of the National Board of Research Ethics, under permit nº 2.636.562/2018. A qualitative study of two cases was carried out at a microregional public referral hospital. The hospital is a large facility offering 195 beds (7 dedicated to the neurology ward), until 2018. It constitutes a medium-to-high complexity referral center, serving nine cities within its microregion. Since 2017, this unit has comprised part of the Urgent and Emergency Care Network (UEN).

Potential participants were recruited by identifying eligible adult or elderly patients from medical records. Individuals of both genders, whose native language was Brazilian Portuguese, who were clinically diagnosed with stroke and consequent aphasia, and hospitalized in the neurology ward of the hospital between June and September 2018 were included. Subjects whose language disorder was caused by other neurological diseases or who had a history of prior brain lesion were excluded.

Since the hospital did not have an in-house speech-language therapist, aphasia was diagnosed in another study investigating the frequency of aphasia in users admitted to the neurology ward of the same hospital due to stroke[9]. In the study, an active search was carried out for individuals with aphasia who were hospitalized during the study period by performing a brief language assessment. The diagnosis based on the test results was recorded in patient medical charts. Data was collected at the hospital by the research team once or twice a week. All users diagnosed with aphasia, or other associated speech-language disorders, were referred for outpatient speech-language treatment at the institution conducting the present study after hospital discharge.

Given that people with aphasia exhibit varying degrees of impairment in language comprehension (written or spoken), permission from both the patient's guardian was obtained by signing of the Free and Informed Consent Form, and from the patient by signing of the Free and Informed Agreement Form, depending on their level of comprehension.

After obtaining consent/agreement for participation in the study, data collection took place in two stages. In view of patients' language impairment, data were collected through an interview with a family member and/or collected from the user's medical record. In the first stage, the Clinical and Sociodemographic Questionnaire was applied, whose sociodemographic items were based on the study by Drummond and Alves[10] (Appendix 1). No other specific instruments for collecting sociodemographic and clinical characteristics of aphasia patients pursuant to the objectives of this study were found.

In addition, the Brazilian Economic Classification Criteria (2008) – Economic Classes were applied in full[11]. The questionnaire was applied to the informant during the patient's hospital stay in the neurology ward. The following data were extracted from the medical records: type of stroke, lesion location (as per latest structural neuroimaging report available), time elapsed since stroke (days) and type of aphasia.

The second stage took place approximately 2 months after application of the first questionnaire (at 64-68 days later), and entailed application of the Speech Therapy Adherence Questionnaire, devised especially for this study (Appendix 2). The interview was carried out with same family member by telephone, their preferred method for this stage of data collection, as indicated by the informants.

Three users of the service diagnosed with aphasia met the established inclusion criteria during the study period. However, one these eligible participants refused to take part in the study, giving a total of two participants. The sociodemographic data for the study participants are given in Chart 1.

With regard to the patients' economic class, participant 1 was classified into Class 4-C1, while participant 2 was Class 5-C2. Participant 1 had a higher average family income than participant 2.

The clinical data for the study participants are given in Chart 2.

Neither of the participants had other stroke sequelae and had not needed assistance for activities of daily living prior to the stroke event.

Chart 1. Sociodemographic data for study participants

Variable/Participant	PARTICIPANT 1	PARTICIPANT 2
Age	70	64
Sex	Female	Female
Education	5	3
Occupation/Working Status	Other forms of informal work (domestic chores)/retired	Seamstress/retired
Marital status	Married	Widowed
Household composition	Spouse, son, brother-in-law and two grandchildren	Grandson
Living abode status – property	Family member	Own

*Number of years of formal education completed

Chart 2. Clinical data for study participants

Variable/Participant	PARTICIPANT 1	PARTICIPANT 2
Stroke type	Ischemic	Ischemic
Lesion location	Internal capsule, frontal lobes and left temporal region	Internal capsule, corona radiata and left frontal lobe
Time since stroke – 1st interview*/2nd interview	19 / 83 days	8 / 76 days
Aphasia type	Global aphasia	Global aphasia
Post-stroke physical sequelae	-sensorimotor deficits in right lower limb (unable to walk) - dysphagia	-sensorimotor deficits in lower limbs (unable to walk) and right upper limb
Previous chronic diseases	- systemic arterial hypertension - peripheral vascular disease	- systemic arterial hypertension

*Corresponds to length of hospital stay in days

The results of the questionnaire on therapy adherence after hospital discharge showed that one of the participants (Participant 2) had sought private home-based speech-language therapy. The patient had been receiving treatment for 61 days and had not sought treatment at any other service apart from the one cited. Participant 1 had not sought speech-therapy, or treatment at the outpatient service to which they were referred, nor at any other care service in the public or private health network. The reasons why Participant 1 had not sought speech therapy were investigated. The explanation given was classified under the response category "related to stroke or other diseases", with the patient citing the presence of physical sequelae post-stroke (sensorimotor deficit in lower limb), resulting in the inability to walk.

DISCUSSION

The sociodemographic data for the study participants (Chart 1) reveals that both patients were older women. According to Engelter et al.[12] aphasia is considerably more common in older stroke patients and gender is not a predictor of the condition. By contrast, findings of other studies have shown a higher prevalence of aphasia in women[2]. Both cases reported in the present study were female patients.

These two patients also had low educational level, characteristics which might explain the lower communicative and rehabilitation needs associated with the aphasia, particularly for use of written language. The occupational status of the participants was another aspect which may have contributed to the lower communication demand and expectations of the rehabilitation process on the part of patients and family members alike.

Comparison of the participants' socioeconomic class, and analysis of the factors "household composition" and "living abode status", revealed that Participant 1 resided with more family members, in a property owned by one of these relatives, possibly indicating greater financial dependence. Participant 2 lived with one family member only, probably her dependent, in a home which she owned.

With regard to the clinical data (Chart 2), ischemic stroke was the cause of aphasia in both cases, representing the most common stroke subtype. Systemic arterial hypertension is an important risk factor for stroke and was associated with the condition in both cases reported.

Imaging results confirmed cortical lesions in the left hemisphere, an area typically associated with aphasia and physical sequelae involving the side of the body contralateral to the lesion, as seen in the cases reported. Both patients became dependent for basic activities of daily living following the stroke event.

At the initial stage of the study, the two participants had acute global aphasia. In general, during the acute phase of stroke, 32% of individuals have global aphasia[13]. The two cases reported exhibited severe aphasia. Participant 2, however, had worse oral comprehension impairment. Participant 1 had associated dysphagia, although the severity of the condition was not determined.

With regard to adherence to the outpatient speech therapy treatment indicated, during the study period neither participant accessed the service to which they were referred after hospital discharge. This outcome may be partially attributed to the physical sequelae of the stroke in both cases, with resultant limitations for walking, thereby constituting a physical barrier to accessing the service.

It is noteworthy that the speech therapy treatment adherence questionnaire was applied during the third month post stroke, i.e. in the subacute phase. Estimates suggest that over half of stroke patients are unable to walk independently in the acute phase, where this dependence persists in 25% of patients 3 months after the stroke event[14].

The physical barrier to accessing the service was exemplified for participant 2, who sought treatment after discharge via private home-based speech therapy. This option was possibly more viable for the patient, given that sensory and/or motor deficits in a lower limb post stroke rendered her unable to walk. In a recent national study, stroke cases accounted for 35.2% of requests for home-based treatment in the city of Maceió, comprising 41.8% public sector and 28.2% private sector requests[15].

The city where the study was carried out has had a public homecare service as part of the HealthCare Network (HCN) since 1992. This service is currently affiliated to the HomeCare Service (HCS) – Programa Melhor em Casa (Better at Home Program) provided by the Ministry of Health, and boasts a multiprofessional homecare team and multiprofessional support team (MST). Although the MST is supposed to have a speech therapist, the team in the city does not include this professional, revealing a shortcoming in the HCN. Consequently, when users need home speech therapy they are obliged to resort to a private service.

Participant 1, who did not access speech therapy treatment, also had physical sequelae, including sensory and/or motor deficits in a lower limb plus dysphagia. The explanation given for not seeking speech therapy was the patient's inability to walk. However, shortcomings in the municipal SAD network, which had no speech therapist available in the MST, should also be regarded as one of the factors negatively impacting access to speech therapy for this user.

Examining participants' respective socioeconomic classification, the participant who sought private homecare (Participant 2) had a lower family income than the participant not seeking treatment (Participant 1), but had a smaller household composition. Notwithstanding the inter-relationships that may be in play between these variables, it is reasonable to assume that fewer members sharing the household and thus promoting greater disposable income, coupled with the financial independence of the patient, may have favored access to a private care service.

Participant 2 accessed private home care treatment, had greater physical impairment (involving both upper and lower limbs) and linguistic impairment, while presenting more severe oral comprehension deficit than Participant 1. Therefore, greater sequelae severity may have been a factor associated with the patient seeking speech therapy treatment, although further investigation is needed to confirm this theory. On the other hand, the level of awareness of users and their family members about the possibility of treating aphasia, their expectations of the treatment, and the relationship with other sociodemographic variables, also warrant further investigation.

No previous studies exploring the process of adherence to speech therapy, or search for and access to treatment, in post-stroke aphasia patients were found. Most national and international studies on the topic involve people with dysphonia[6,7]. The cited studies, along with another investigation on people with dysphagia[8], explored aspects of adherence related to non-attendance of sessions[6], and observance of recommendations[8].

In the present study, it was decided to also include aphasic individuals who did not commence speech therapy, as was the case for one of the patients assessed. In the setting investigated, another notable weakness identified in the HCN of the microregion was the lack of a speech therapist within the referral hospital unit of the UEN. Given the hospital requests Intensive Care Unit beds for Acute Stroke (U-Acute Stroke), in accordance with the Line of Care in Stroke under the ambit of the National Health System, it should provide a multiprofessional service that includes a speech therapist. The absence of this professional significantly limits the access, integrity and continuity of care delivered to service users, where these aspects are directives of the National Hospital Healthcare Policy.

Access to speech therapy assessment and intervention with respect to the needs that involve communication and swallowing post stroke, while in the hospital setting, are fundamental for user rehabilitation, contributing to a better prognosis. Additionally, this serves to refer other elements of the HCN after hospital discharge and ensure continuity of care for these patients. However, this continuity is also compromised if the speech therapist is also absent in other components of the UEN, such as in home care, as observed in the present study.

Although this study encourages further investigation on the topic, the small number of participants characterizes it as exploratory in nature. The impact of the shortcomings identified in the UEN of the region, which lacks a speech therapist among its components (hospital and home care), not only limits integral treatment of stroke patients, but also stymies the scientific output elucidating the issue. The lack of a speech therapist in the service likely prevented identification of all possible cases of aphasia among the users hospitalized during the study period, explaining, in part, the small casuistic and limiting the scope of the study.

FINAL CONSIDERATIONS

The study results revealed an association between sociodemographic and clinical factors in determining adherence to speech therapy treatment by post-stroke aphasia patients. Moreover, weaknesses in the regional HCN were exposed, which hamper access to public health services catering for post-stroke aphasia patients during the subacute stage.

Different strategies should be combined to improve the HCN, through agreements in local regional decision-making bodies that involve different actors, such as managers, health professionals and users, besides social control allied with awareness about the possibility of treating aphasia, to effectively reduce the barriers to accessing care encountered by this patient group.

Future studies should incorporate effective designs that overcome the barriers imposed by the shortcomings in the network and by research funding, such as the involvement of other health professionals in the service to identify users with speech-language sequelae, drawing on the components in the network which provide treatment in the area, and monitoring of users who access these services. Such studies are important to inform proposed changes aimed at meeting the needs of aphasia patients in the local regional health network.

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Appendix 1. Sociodemographic and clinical questionnaire

Date: ___/___/____ Participant code: _____

City of residence:

Preferred contact method: ( ) telephone ( ) e-mail _____

SOCIODEMOGRAPHIC DATA

Sex: ( ) M ( ) F Age: _____

Education (years): ____ Profession/Occupation: _____

Marital status: ( ) single ( ) married ( ) separated ( ) widowed

Household composition: ( ) spouse only ( ) spouse and children ( ) spouse, children and grandchildren ( ) spouse and grandchildren ( ) children and grandchildren ( ) grandchildren ( ) lives alone ( ) other: _____

Living abode status - property: ( ) own ( ) belongs to spouse/children ( ) rented ( ) other _____

CLINICAL DATA

Stroke type*:

Lesion location*:

Length of hospital stay (days)*:

Time elapsed since stroke (days)*:

Aphasia type*:

Post-stroke motor sequelae (physical deficits): ( ) no
( ) yes / Unable to walk? ( ) no ( ) yes
Difficulty walking? ( ) no ( ) yes
Other(s)? _____

Other post-stroke sequelae? (cognitive and emotional impairments)
( ) no ( ) yes / Which? _____

Previous chronic diseases: ( ) no
( ) yes / Which? _____

Previously needed help to perform an activity? ( ) no ( ) yes Which? _____

*Data collected from patient medical records

Appendix 2. Speech therapy treatment adherence questionnaire

Date: ___/___/____ Participant code: _____

Speech therapy sought?
( ) no
( ) yes / At which service? _____

If answering yes:
Treatment duration (days): _____
Treatment sought at other* service? ( ) no
( ) yes / Which? ( ) public ( ) private
*Besides the service cited in preceding question, received at same or different times

If answering no, what reason(s) do you attribute to the patient not seeking speech therapy?**
( ) related to the stroke or other diseases- severity of the disease, presence of other sequelae or occurrence of other health problems.
( ) related to aphasia – severity of the condition or impact on quality of life.
( ) related to sociodemographic aspects – age, educational level, marital status, family composition; living abode status or socioeconomic status.
( ) related to health services - location of service(s) (far from home), architectural and/or geographical barriers to service access, bureaucracy, lack of human resources and materials or cost.
( ) related to patient experience/perception – no faith in health service or treatment, little knowledge on condition or treatment, demotivation, denial about condition, or indication for treatment/referral unclear.
( ) other(s) _____

**Free-text response, with classification by interviewer of possible alternatives