

Utilization of alternative and augmentative communication resources by patients with amyotrophic lateral sclerosis.

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ABSTRACT

Introduction: Amyotrophic Lateral Sclerosis (ALS) is a multisystemic impairment disease, among them, the total loss of communicative abilities. Augmentative and Alternative Communication (CAA) seeks to provide effective communication through specific resources. **Objective:** To verify the influence of ALS on aspects of personal, social and environmental life in patients who use the CAA. **Methods:** This is a qualitative, exploratory, longitudinal research of a series of cases. The patients with ALS were invited to participate of an evaluation with a sociodemographic and semi-structured questionnaire. Each participant obtained a CAA resource offered by the present research and returned for a reevaluation. **Results:** The analysis based on the reports that emerged from the spontaneous comments and generated five categories (socialization, social attitudes, communication and rights, services, systems and policies, and family interaction). **Conclusion:** Even with the use of CAA, ELA generates negative impacts on socialization and social participation due to social and environmental factors.

Keywords: Nonverbal Communication; Frailty; Neuromuscular Diseases; Amyotrophic Lateral Sclerosis.

INTRODUCTION

The communication is part of the human essence and as part of which essence becomes primordial for its development from the beginning to the end of life. There is communication when there is understanding of the exchanged information between the parties; otherwise, there is only the attempt to communicate¹. Communication may be understood as a necessity, being a legal and basic right to live. Through it, you can express yourself, share ideas, establish social relationships, and develop skills and competencies. Thus, individuals facing the communication barrier are less likely to satisfactorily develop many fields of life^{1,2}. Therefore, depriving alternative conditions of communication for someone with loss of communicative skills would be like imprisoning them in social and emotional isolation, with no chance of developing their potential³. Some health conditions cause loss of communication skills, including Amyotrophic Lateral Sclerosis (ALS). ALS is a disease that causes multiple impairments and affects speech, progressing to total loss in an irreversible way, thus hindering social interaction. It is clinically degenerative, with progressive and extremely destructive development^{4,5}. The incidence of ALS in the world population is in the range of 1.5 and 2.5 cases per year per 100,000 inhabitants. It is more common in males

after age 40⁶. Survival is around 3 to 5 years^{7,8}, with the main cause of death being respiratory failure^{9,10}. Some cases have a survival of more than 10 years¹⁰. It is estimated about fifteen thousand people are diagnosed with ALS¹¹ in Brazil. Due to the severe global impairment, patients suffering from this disease daily need various AT products to maintain autonomy and quality of life. Among these AT resources, CAA stands as a tool capable of increasing communicative skills since the beginning of its commitment⁵. In the advanced phase, in addition to being unable to express itself without alternative means, progression progresses to quadriplegia and respiratory failure, leading to severe disability^{7,10,12}. For these reasons, ALS patients need various assistive technology (AT) products, such as communication and mobility devices, breathing apparatus, architectural accessibility, professional services), to maintain dignity, social participation and quality of life^{5,13}. Augmentative and Alternative Communication (CAA) is a category of AT that seeks to provide effective communication and social participation through tools, methods, facial expression, symbols, simple computer programs to the most advanced. It is aimed at solving or amplifying any loss of communicative ability such as speech difficulty, language disorders, and

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developmental and / or intellectual deficit^{2,14}. The objective of this study was to verify the influence of the use of CAA on the personal, social and environmental aspects of ALS patients in a series of cases.

METHODS

This is a qualitative, exploratory, longitudinal study of a series of cases conducted with patients diagnosed with ALS. The research took place from September 2015 to July 2017 in the city of Anápolis (GO), Brazil. The qualitative analysis of the present study is based on the investigative method described by Bardin¹⁵ characterized as content analysis. It is an empirical method and understood as a set of communication analysis techniques. Content analysis includes verification techniques that seek to systematize and clarify the message content through logical and justified inductions. In quantitative research, content analysis verifies the presence or absence of a particular characteristic or set of characteristics of the message content.

Survey participants and patient selection

The study included patients with ALS followed by Centro de Reabilitação e Readaptação Dr Henrique Santillo (CRER), who signed their collaboration with this research after signing the Declaration of co-participation institution. Currently, the institution follows about 30 patients with ALS. Initially, the proposal was to include all patients who met the inclusion criteria, but due to the time and availability of the staff of the neuromuscular disease outpatient clinic and the orthopedic workshop of the institution involved in the study, it was stipulated the composition of up to six participants. The patients were included in the rehabilitation center after were diagnosed with ALS in accordance with the International Statistical Classification of Diseases and Health Related Problems (ICD-10) - G12.2 - motor neuron disease; loss or impairment of speech ability; without presenting cognitive impairment that would compromise the assessment; with indication of CAA or who were already using CAA; and who agreed to participate in the research by signing the Informed Consent Form (ICF) or signing by their legal guardian. The study excluded individuals whose caregiver or companion did not have sufficient cognitive conditions to understand the study and individuals at an advanced stage of the disease.

During the development of the research, participants were completely free to stop participating in it. During the observation period of the patients, the therapists in the areas of speech therapy, occupational therapy and physiotherapy indicated fourteen patients who attended weekly outpatient therapies, had indication of CAA or who used some resource, but had complaints regarding their use. Of these indicated, seven patients did not meet the inclusion criteria, one due to cognitive problems associated with memory loss, and the other due to being in advanced stage of the disease, leaving seven

patients. There were invited patients, who met the inclusion criteria, together with family members and / or caregivers, to participate in the research after a detailed presentation of the study. Before the start of data collection, one patient presented worsening health status, undergoing long hospitalization due to respiratory complications, and it was not possible to follow up on her participation in the research. Another patient developed sociophobia, according to information provided by the family, and it was not possible to complete his participation in the present research. Therefore, this research presents a sample of five participants.

Description of the data collection process

After the observation process that occurred during outpatient visits, it was performed a documentary analysis of records and reports of each participant's medical records, investigating information pertinent to the history and clinical evolution. Then, it was invited each patient along with their companion to participate in an assessment with a sociodemographic questionnaire to investigate personal aspects, as well as the researcher's observation regarding the clinical condition, and another semi-structured questionnaire to analyze social and environmental aspects, which presented the following questions:

- a) When is it not possible to speak and you need to communicate using other forms such as mime (smile, frown), symbols, drawings or the other means of communication, can you convey what you mean?
- b) When you want to talk to a person, or join a group conversation, whether in a familiar or strange environment, can you start, maintain and end that conversation?
- c) Does the communication resource you use to communicate now meet your communication needs?
- d) When interacting with others, can you express and express your feelings (showing affection, appreciation, reacting to criticism)?
- e) Do you participate in informal or occasional meetings with others, such as visiting friends or relatives and having informal meetings in public places?
- f) Do you consider that you enjoy all your human rights (equality, social, freedom, expression)?
- g) Is the communication resource (CAA) you use to communicate a facilitator, barrier, or neutral in your life?
- h) Is the support you receive from your family (spouse, parents, siblings, children, grandparents) a facilitator, barrier, or neutral in your life?
- i) Is the support you receive from health professionals (doctors, nurses, physiotherapists, occupational therapists,



speech therapists, technicians, social workers, nutritionists, psychologists) a facilitator, barrier, or neutral in your life?

- j) Is the attitude that society in general has to its communication limitations a facilitator, barrier, or neutral in its life?
- l) Services (social support generally due to their health condition), systems (regulation that ensures social support), policies (laws, regulations and governing rules guiding and ensuring social support and right of access) are characterized as a facilitator, barrier, or neutral in your life?

Each assessment with the above questions lasted about two hours, due to the participants' difficulty in communication and respiratory fatigue, requiring two to three meetings to complete the assessment. Only one person, the researcher, collected the data from this evaluation. In the case of patients who were already using CAA resources, only those were inserted who had the need for experimentation to change the resource.

Subsequently, in the presence of the researcher, a physical therapist and two occupational therapists of Rehabilitation Center, each participant experimented with different CAA resources offered by this research. After experimenting with different CAA features and analyzing which feature best suited each patient's needs, each participant was evaluated and selected, if necessary, for a wheelchair postural fitness feature (for users) and conventional chair (non-users) required for the use of the selected communication device, in order to better use and functionality of the CAA feature.

These participants received the selected CAA resource with the respective postural adjustments defined by the occupational therapy team, prepared by the orthopedic factory, one to two months, and returned to answer the same assessment questions listed above. During this evaluation process, CAA prescription and reassessment, patients were

free to express each other according to their potential, whether by writing, expressions and / or family help. During the conversation, the researcher certified with the patient the message, if confirmed, and registered on each patient's follow-up form. If not confirmed, dialogue continued until an understanding was established. The qualitative analysis presented in this article corresponds to the analysis of all spontaneous comments that emerged during the application of these questions and because of this process of data collection. The research respected Resolution no. 466/2012 of the National Health Council and approved by the Research Ethics Committee from where? (Protocol No. 1,789,435).

Data analysis

Personal aspects were analyzed through sociodemographic data (age, gender, birth, marital status, income, color or race, education, housing, access to technology, time since diagnosis and observation of the researcher regarding physical condition and analysis of reports. of lived personal experiences). Personal aspects obtained through the semi-structured questionnaire and the researcher's observation noted in free text as directed by the World Health Organization (16), and presented descriptively. It was analyzed the social aspects (communication, mobility, interpersonal interactions and relationships, community life) and environmental aspects (products and technology, support and relationships, attitudes, services, systems and policies) through spontaneous comments. The analysis of the respective comments followed the precepts of Campos (17), divided into three phases. a) sequential readings for message comprehension; b) selection of units of analysis divided by the frequency of common content; c) relevance of isolated content associated with the objectives and non-a priori categorization, ie, according to the context of spontaneous reports followed by discussion of the analyzed content (Figure 1).

Phase 1: Material pre-exploration

- Full speech transcript followed by sequential readings

Phase 2: Selection of Analysis Units

- Divided by frequency of common content, relevance of isolated content associated with objectives

Phase 3: Categorization Process

- Emerging categories according to the context of spontaneous reports:
- Socialization - Social Attitudes - Communication - Rights, Services, Systems and Policies - Family Interaction

Figure 1. Schematic presentation of qualitative analysis



RESULTS

It was evaluated five patients, and analyzed the patient's personal aspects, using the sociodemographic data presented in Figure 2, and described the reports of each case with the spontaneous comments of the participants.

All patients reported having access to information and communication technology with internet and mobile phones for personal use, even those with a low family income. According to the International Classification of Functioning (ICF), personal factors provide an empirical basis, but through them it is possible to verify the profile of each patient and the influence of these factors on the functionality of these patients^{16,17}.

Case 1

Patient HT M, male, 43 years old, self-reported brown, born in Mato Grosso do Sul, married, retired for disability, has more than 12 years of study, living in the urban area, in his own home with nine residents, where two work. Household income is between

Personal aspects	Case 1	Case 2	Case 3	Case 4	Case 5
Age	Male	Male	Female	Female	Female
Age	43	64	65	76	63
skin color and race	Brown	Brown	White	White	White
From	MS	MT	GO	SP	CE
Marital status	Married	Single	Married	Married	Married
Years of study	> 12 years	9 to 11 years	9 to 11 years	5 to 8 years	>12 years
Retirement	Disablement				Contribution
Household income in minimum wage	5 to 10	2 to 3	1 to 2	1	2 to 3
Access ICT	Yes	Yes	Yes	Yes	Yes
Housing	Urban Own home	Urban Own home	Urban For rent	Urban For rent	Urban Own home
Residents by residence	9	3	5	2	2
Worker by residence	2	1	2	1	0

Figure 2. Personal aspects of patients with Amyotrophic Lateral Sclerosis analyzed through sociodemographic data.

5 and 10 minimum wages. The patient has access to the internet and mobile phone for personal use. Diagnosed with ALS six years ago, has dysphagia, dysarthria, severe speech loss, marked upper limb muscle strength, upper limb atrophy, severe postural control (tetraparesis), dependent on mobility, uses motorized wheelchair and noninvasive mechanical ventilation, and is dependent on Daily Life Activities (ADLs). The patient received as a CAA feature the 9.6 "tablet with free board and notepad and the following postural adaptations: tablet support cover with keyboard, and wheelchair support table for tablet positioning.

Case 2

Patient J. N. S, male, 64 years old, self-reported brown color, born in Mato Grosso, single, retired for disability, has 9 to 11 years of study, living in an urban area in his own house, with three residents, in which one works. The household income is 2 to 3 minimum wages. The participant has internet access and mobile cell phone for personal use. Diagnosed with ALS three years ago, presents dysphagia, dysarthria, phonation and breathing incoordination, total loss of speech, upper and lower limb motor deficit with global muscle weakness, global atrophy and postural instability, dependent on mobility motorized and noninvasive mechanical ventilation, being dependent on ADLs. The patient received as a CAA feature the 10.1 "tablet with the notepad and freeboard applications and the following postural adjustments: tip, tablet-free tablet cover, and wheelchair table making for positioning the tablet.

Case 3

Patient M. R. C. P, female, 65 years old, self-reported white, born in Goiás, married, disability retired, with 9 to 11 years of study, resident in the urban area in a rented house, with five residents, in which two work. Household income is 1-2 minimum wages. The patient has access to the internet and mobile phone for personal use. Diagnosed with ALS six years ago, it has dysphonia, dysphagia, dysarthrititis, severe dysarthria, and severely impaired speech, overall motor deficit with moderate loss of trunk function, mild upper limb weakness, and preserved hand-dependent, non-dependent hand force. AVD's, uses non-motorized wheelchair. It also has visual impairment, depressive symptoms, emotional fragility and anxiety. The patient received as a CAA feature the 7.0 "tablet with notepad, free board and voice recorder applications, while undergoing orthopedic workshop evaluation was identified the need for a new wheelchair prescription due to weight gain. Consequently, the occupational therapy team prescribes the new chair. The SUS/CRER will provide the new wheelchair, and approximately, it will delivery within 8 to 12 months, the making of an adapted table if necessary. In the current wheelchair, the patient satisfactorily supports the CAA on the tablet-mounted cover on a support pad, but he preferred to use a pillow to support the device while awaiting the new chair with its adaptations.



Case 4

Patient C. S. S, female, 76 years old, self-reported white, born in São Paulo, married, retired for disability, has 5 to 8 years of study, living in the urban area in a rented house, with two residents, in which one works. Household income is 1 minimum wage. The patient has a mobile phone for personal use. Diagnosed with ALS two years ago, it presents alteration of the orofacial complex and phonation and breathing incoordination, dysphagia to solid and liquid, total speech loss, global muscle weakness, upper limb motor deficit with preserved handgrip and palmar grip. Performs supervised AVD's without dependent for walking, walks with human assistance and has wheelchair request in progress. The patient received as a CAA resource a whiteboard accompanied by a brush and eraser. During the testing phase, the patient suggested reducing the size of the dishes from 50cm x 20cm to 30cm x 20cm in order to facilitate its use and positioning. The following postural adjustments provided decreased board width and support pad for the resource.

Case 5

Patient MLF F, female, 63 years old, self-reported white, born in Ceará, married, retired for contribution time, has more than 12 years of study, living in an urban area in her own home, with two residents, in which none works. The household income is 2 to 3 minimum wages. The patient has access to the internet and mobile phone for personal use. Diagnosed with ALS nine years ago, has dysphagia, difficulty in verbalizing with voice alteration, alteration of the orofacial complex, respiratory discomfort, mild tetraparesis, dependent on ADL's, moderate loss of manual function, dependent on mobility, uses motorized wheelchair, presents yourself emotionally unstable. The patient received as a CAA feature the 7.0 "tablet, with notepad and free board applications, and the following postural adaptations: tablet-free tablet cover and wheelchair table for tablet placement.

Analysis of spontaneous comments during data collection

The analysis was based on the reports that emerged from the spontaneous comments and generated five categories, four divided by the common content of the reports (socialization, social attitudes, communication and rights, services, systems and policies) and one by content relevance (interaction family). These categories named in light of the ICF.

Socialization

The patient in Case 1 reported not having adequate access conditions for locomotion, as he has no adapted car or motorized wheelchair. In this patient's residence, nine residents reside, during the follow-up time, and the in-laws there were people who accompanied him the most in the therapies. The patient commented that because the

elderly in-laws were the ones who were most available to accompany him in the commitments related to his treatment, it was difficult to find time and physical willingness to accompany them during leisure time. For this reason, in his view, it was more feasible to stay at home to avoid any family overload. The patient in Case 5 has all the necessary structure to leave home, but does not perform because of emotional fragility to deal with the progress of the disease, and the patient also reported not being comfortable when receiving visits. This patient suffered from the rapid advance of the disease in the months of her participation in this research. In the process, there were several times when she commented on her former autonomy, independence and professional success. The patient referred to herself as a woman who had always been "hyperactive," both in her former teaching and family careers, and after ALS she felt unable, as if trapped in herself, outside her own world. According to her, at many times, she was embarrassed by the painful glances of friends, acquaintances and even strangers in the face of their physical and communicative worsening, and therefore prefers to avoid social contact. Regarding socialization, only two participants commented, and reported being inmates at home:

[...] I do not perform due to locomotion. (Case 1)

[...] I have been more at home due to emotional problems, but I have all the support to leave, adapted car. I feel bad that they see me like this (Case 5).

Social attitudes

The patient in Case 2 reported that the attitudes are positive, but he is an extremely communicative patient, with no problems related to low self-esteem or acceptance. This particular patient would daily enter in a folder in his notebook a report about his diagnostic process and personal feelings. The purpose was to present his diary to friends and family who visited him. Case 4 reported feeling coaxed to communicate due to negative attitudes toward her limitations. Although she was able to interact using CAA, during follow-up, she reported better interaction in a family environment. The patient in Case 5 pointed to society's lack of knowledge about ALS and its communication difficulties, as a negative factor for its social interaction, and commented that society does not know how to deal with communication difficulties. During follow-up, the patient reported that society's level of information about ALS is low, and this makes it difficult for people to understand when they see its limitations. Three patients commented on the attitudes that society has towards communication limitations, and regarding being able to express and express feelings (showing affection, appreciation, reacting to criticism) when interacting socially. Following are the comments:



[...] they attitudes are more positive, I am very communicative. (Case 2)

Attitudes are more negative and this makes me shy [...]. (Case 4)

[...] society still does not know how to deal with it (communication limitation) [...] due to the (communication) difficulty, I prefer not to react to criticism. (Case 5).

Communication

Case 4 reported no difficulty communicating using the whiteboard as an AAC feature. Her caregiver reported that the patient communicates more with family members, writing phrases and loving statements on the board to their children and grandchildren. The caregiver photographs and sends in the family group on a social network, and the patient receives the answers from family members by audio. The caregiver mentioned that the family bond is strengthened by frequent coexistence with most children and grandchildren. The patient lives in Goiânia to perform her treatment, but every two months she travels to the home of one of the children, and thus, intersperses her visits keeping in touch with all of them. Case 5 patient also reported communicating well using the new AAC feature, but reported difficulty with communicating by text message when the person she wanted to communicate with was in another home setting. Another factor mentioned was regarding the progress of the disease and the difficulties for the use of AAC, because according to the patient, without postural adaptation in the wheelchair would not be possible to use tablet with the applications. During follow-up, the patient reported that the only environment that she does not use the table is in therapy, because it has done outside the chair and the break time is short, not worth it to take the table to set it up on the chair. Following are comments regarding the use of CAA:

[...] with the blackboard, I have no difficulty. (Case 4)

[...] with you as long as the person gets close to read.

[...] supplies 80% because I am losing my hands movement [...] without the table to support (the CAA) I could not type. (Case 5).

Rights, services, systems and policies

Case 4, the patient reported many difficulties regarding accessibility, she still walks without human assistance, but she complains about the lack of handrails to assist her when walking in most environments. Another negative point relates to the bureaucracy to reach some services, due to the long waiting time, in which, in the Most of the time, it is required to purchase with its own resources, as in the case of medicines. Case 5, the patient understands that in this case access is still a barrier. During the follow-up, the patient commented that she found several barriers and bureaucracies to get services that improve her quality of life, such as financial aid, health services, and medicines. The patient believes that if there were no lawyer in the family, she would not have been able to break

through the barriers she encountered in fighting for her rights. Two patients commented on rights, services (social support to improve functionality in society), systems (regulation that ensures social support), and policies (laws, regulations and standards governing, guiding and ensuring social support).

[...] poor accessibility. It was not find in the law help and ensure access to medicines and retirement. (Case 4)

I feel prevented from enjoying my rights because it is bureaucratic and difficult to achieve [...] without a lawyer, I could not. [...] it is difficult to gain access to what is right '. (Case 5).

Family interaction

Despite referring to family support as a facilitator, the patient claims not to have much participation in decision-making at home because of her health condition. During the follow-up, the patient reported receiving much support and family assistance, but complained of impatience in some moments of dependence to do simple things, such as asking the accompanying family member to give a message to someone, to move around in the environment in order to get her some information. During follow-up, many participants reported some complaints (desire to visit a friend, desire to share some anguish, desire to try to crochet but not have material at home) and when asked about family knowledge about these complaints, these patients justified that family members already had a lot of responsibilities with them, as well as personal responsibilities. Regarding family support, only one patient commented on the subject:

[...] my husband says that I should not opine due to my condition. (Case 3)

DISCUSSION

Overall, all participants in this research showed good acceptance and use of CAA during the development of this study, though, according to the evolution and worsening of the disease, it is known that these resources will no longer be used by these participants. One of the biggest difficulties in the field of AT is the abandonment of these technologies and one of the factors related to the abandonment of CAA is related to the severe physical limitations that increase the difficulty of the user to use a simpler resource, leading to the need to adhere to it. CAA increasingly sophisticated in high technology¹⁸. Due to the physical limitations developed by the evolution of the disease, it was essential for all participants to develop postural adaptations in wheelchair (for users) and conventional chair (for non-users) to enable the operationalization of CAA. The weakening of the muscles responsible for breathing generates progressive respiratory disability, causing fatigue and shortness of breath with little effort, especially in lying position. Fatigue makes speech difficult, which in turn becomes increasingly tiring, paused and incomprehensible. Another contributing factor to the



acceleration of speech misunderstanding is the involvement of the face muscles, as the speech function depends on the good and coordinated motor performance of the tongue, lips, and maxillomandibular⁹.

Other factors are related to speech recovery, insufficient family support, little incentive to use, poor professional motivation to indicate AAC, and features that do not meet the user's communicative requirements or have complex operationalization that make it difficult to use¹⁸. All patients still are been followed by telephone by the researcher. To date, according to family members, three patients have abandoned CAA because they are in the final stage of the disease, in which they undergo recurrent hospitalizations due to respiratory complications. Two patients continue to use CAA, but they have a stable clinical picture. Communication is known to be one of the worst compromises caused by ALS, and it interferes with social participation, which is becoming increasingly restricted, causing weak decisions, poor quality of life and the development of emotional problems^{8,12}. However, with increasing dependence some patients begin to show less their wants and desires, not only for communicative difficulty, but also for fear of generating family overload. One situation that drew attention was the condition of home restriction. During the observation was observed that the main reasons for restriction of these patients were related to the difficulties that arise according to the progression of the disease, such as breathing difficulty and physical limitations, dislocation or locomotion difficulty, as well as emotional fragility. According to Yorkston¹⁹, may be the reasons that lead to restriction in the participation of people with ALS relate to the evolution of the disease, but may also have other factors involved, such as education, communicative demands in living environments, emotional factor, and cognition, among others. Nevertheless, it determines that the level of speech impairment is one of the most determining factors in this process. Van Groenestijn²⁰ reports the respiratory condition, fatigue caused by impaired functional mobility and depressive symptoms as factors related to restriction of participation. These results are similar to those found by Sandstedt²¹ who out of 51 people with ALS found that 61% had fatigue, 9% had anxiety disorder, 16% had possible anxiety disorders, 4% had depression and 18% presented possible depressive symptoms. These participants had low participation and social interaction and low ability to face barriers. Two patients, cases 1 and 4, portray the difficulty of accessibility, " I don't do it (visiting friends, family, etc.) due to locomotion" (Case1), in this case, for not having adapted car and to have the help of the elderly to get around – "poor accessibility ..." (Case 4), for not having adequate accessibility in public and private places to assist her in walking. When investigating the main accessibility difficulties faced by people with disabilities, Silva²² found in a sample of 112 participants that the three major accessibility difficulties encountered were the absence of handrail ramps, elevators and others (64%),

followed by the lack adapted toilets (21%) and parking spaces (7%). Among the assistive technology resources most used by these participants are communication resources (13%). When asked about the origin of these resources, 66% reported having purchased from institutions and associations supporting the disabled and only 1% reported having used funding programs to acquire their resources.

Two patients had longer time in years of study (Cases 1 and 5). The patient in case 1, in addition to the high study time, also had the highest family income among the respondents and the largest number of residents in the house. Despite having a high income, during the observation the patient reported not having AT support for mobility, for example: adapted car, car access ramp. According to the patient, the reason for not having these resources would be not to cause some family overload in their in-laws / caregivers, since they had no goal of leaving home often. The patient in case 5 did not have high family income, however, in the observation reported having full support in AT for locomotion, but did not perform due to self-acceptance problems. This patient is with high intellectual level and high knowledge about the progression of the disease, a factor that may eventually interfere with the non-acceptance of her health condition.

CONCLUSION

CAA had a positive result in resource usability performance, presenting effective communication mainly in a family environment. A contributing factor is the effort to prioritize the individual need and willingness of each patient at all stages of the prescription process to use CAA, in addition to the training, support and follow-up provided, as the patient needs it. The use of CAA, ALS generates negative impacts on socialization and social participation due not only to the difficulty in managing communication caused by the limitations arising from the disease. But also due to the inability of the patient's social cycle, in particular, to develop effective interaction and communication with the person with this condition and the inability of some patients to cope emotionally with the barriers encountered in their social cycles. Emotional fragility may be relate to one's own health condition, social, family and environmental barriers, such as the difficulty in obtaining their rights to a decent and quality life.

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STUDY LIMITATIONS

It was reduced the number of research participants due to the difficulty of prolonged follow-up of these patients due to clinical complications resulting from the evolution and characteristic progression of the disease. Another reason was the availability of the orthopedic workshop to meet a demand of less than six participants to make postural adaptations, and postural adequacy is a fundamental factor for the development for the development of research.

AUTHORS CONTRIBUTIONS

MKRM- performed data collection; VRS - prepared the study design; FMF - carried out the critical intellectual revision of the manuscript; ASBO carried out the critical intellectual revision of the manuscript; LPR - performed the critical intellectual revision of the manuscript; KCBT - conducted the critical intellectual review of the manuscript; VLSF- carried out the critical intellectual revision of the manuscript; SLSP- prepared the study design; All authors read and approved the final manuscript.

CONFLICT OF INTEREST

Nothing to declare.

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