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CASE REPORT

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Evaluation of augmentative and alternative communication in patients with amyotrophic lateral sclerosis, based on the international classification of functionality

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ABSTRACT
Background: The alternative and augmentative communication (CAA) is a tool that seeks to provide efficient functional communication in patients with difficulties in communicative ability. **Objective:** To evaluate the use of CAA in patients with Amyotrophic Lateral Sclerosis (ALS) according to the International Classification of Functioning (ICF). **Methods:** Patients with a diagnosis of ALS who had a CAA indication or who had already used some resource, but who presented complaints regarding their use underwent an evaluation process. They received a questionnaire based on the ICF, and subsequently, they received a new CAA resource along with postural adjustments necessary for the use of the resource; they received training and support for use; used the new feature for about two months and returned to the revaluation. **Results:** It was evaluated five patients, ages between 43 and 76 years, of both sexes. The findings indicate a positive impact of CAA on the difficulty of communication when transmitting a message using the new available CAA resource. **Conclusion:** Even with the progression of ALS, all patients presented a reduction in communicative difficulty, confirming the communicative benefits in relation to their use.

Keywords: Nonverbal communication, motor neuron disease, quality of life.

BACKGROUND

Amyotrophic Lateral Sclerosis (ALS) is a generic term for motor neuron syndromes(1). It is characterized by widespread motor impairment; In the more advanced stages of the disease, there is a decrease in respiratory muscle strength, dysphagia, progressive loss of body weight and muscle mass, and difficulties in communication(1, 2).

In ALS communicative difficulties appear from the early stages of the disease. Initially, the individual has only hoarseness; however, as the disease progresses, it becomes difficult to vocalize, progressing to total loss of verbal communication(3).

Alternative and augmentative communication (CAA) seeks effective communication, promoting social participation, which considered an efficient tool for improving the quality of life (QOL) of patients with ALS. The AAC developed to solve or reduce the difficulty in communicative ability, such as speech loss, language disorders and cognitive and intellectual development deficit(4-6). The augmentative tool has complementary function in communication, without substitution of speech. The alternative completely replaces and more indicated when there is insufficiency of verbal function, by either speech deficit or inability to understand the spoken message(7).

AAC can divide into three categories:

I. Without technology, when the body is used to transmit and communicate, such as sign language(8);
II. Low-tech, by means of simple resources, including images, drawings and letters, used alone or by means of communication cards and / or communication boards(7, 9);
III. High technology, generally indicated for those who have severe motor impairment associated with communication disorders(10) such as software, vocalizers, system that allows control of the computer through a sensor that interprets eye movement or movements of the head and facial expressions(9, 11).

The main purpose of these features is to provide efficient functional communication and the International Classification of Functioning and Disability (ICF) is a tool that played a key role in this perception of functionality in communication. His collaboration was present in the concept changes and interventions aimed at broadening communication. The ICF pointed out the relationship between communicative needs and the individual's involvement in different demands and environments showed that interventions have to focuse on the effectiveness and functionality of communication, according to their demands, and not on the limitation of communication presented by the individual, showing the communicative participation. Therefore, the ICF established the functional communication approach with effective participation(12).

Brazil has a lack of studies that present information related to the process of intervention and

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access to CAA, in addition to urgent needs such as training and continuing education for professionals who are in contact with people who present challenges (13). There is also little information about the use of the various resources used to improve the QOL of people with ALS, including CAA. This information is essential to contribute to the improvement of intervention, prescribing process, use and development of future technologies that meet real demands(14). The objective of this research was to evaluate the use of CAA in patients with ALS according to the ICF.

METHODS

This clinical quantitative, longitudinal study seeks to evaluate the use of CAA in patients diagnosed with ALS. The research was conducted in Goiânia-GO, following the Resolution No. 466/2012 of the National Health Council, and approved by the Research Ethics Committee of the UniEVANGÉLICA University Center (Opinion No. 1,789,435).

Selection of research participants

The participants were ALS patients followed by the outpatient neuromuscular disease outpatient clinic of the Dr. Henrique Santillo Rehabilitation and Rehabilitation Center (CRER), Goiânia (GO), who signed their collaboration with this research after signing the declaration of co-participant institution. Patients referred to participate in the research by speech therapists, occupational therapists and physiotherapists of the institution's team, according to the inclusion criteria and level of need for the indication of CAA.

Patients, under follow-up, were included in the referred rehabilitation institution; of both sexes; 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; and who agreed to participate in the research by signing the Informed Consent Form (ICF) or signing by their legal guardian.

Individuals whose caregivers or caregivers did not have sufficient cognitive conditions to understand the study and individuals at an advanced stage of the disease with severe physical and respiratory impairment left the study.

It was chosen fourteen patients, seven patients did not meet the inclusion criteria; one of them had a cognitive problem associated with memory loss, and the others because they were at an advanced stage of the disease.

However, 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 gave up participating during the evaluation process, because according to the family, he developed sociophobe. The complete process: evaluation; indication of CAA; postural adjustments necessary for the use of CAA; use; and reassessment allowed the evaluation of five participants.

Data collection instrument: communication evaluation questionnaire

The communication evaluation questionnaire (Figure 1) was according to the ICF. 11 categories of analysis were selected that involve the activity and participation components, environmental factors described by the World Health Organization(15), as well as the personal factors, listed in Table 1.

Table 1. Communication evaluation questionnaire in patients with Amyotrophic Lateral Sclerosis (ALS) of the Dr. Henrique Santillo Rehabilitation and Rehabilitation Center (CRER), Goiânia-GO.

Components	Domain
Activities and participation	• d335 Produce nonverbal messages • d350 Conversation • d360 Use of communication devices and techniques • d710 Basic Interpersonal Interactions • d9205 Socialization • d940 Human Rights
Environmental factors	• 1251 Communication Assistive Products and Technologies • e310 Close Family • e355 Health Professionals • e460 Social attitudes • e575 Services, systems and policies related to social support in general
Personal Factors	• Age, gender, background, marital status, income, color or race, education, housing, access to technology, physical

	condition, time since diagnosis, personal experiences lived.

Note: * We did not classify personal factors in the ICF.

The ICF classifies body-related components (anatomy and physiological function), activities (task the individual performs), participation (the individual's actual performance in a given situation) and environmental factors (they are the external influences of the physical, social and attitudinal environment that influence functionality).

Nevertheless, addressing personal factors, the ICF does not classify them, because it refers to the profile, history and individual lifestyle, which is positively or negatively interfere with the functionality of each person. According to the World Health Organization.

Personal factors were obtained through a sociodemographic survey and observation of patients by the researcher throughout the development process of this research. From the 11 selected categories (table 1) twelve questions based on the ICF were developed. Questions Q1 to Q6 based on the category of activities and participation were assessed on a 4-point measure: 1 = Yes, no difficulty; 2 = Yes, with difficulty; 3 = Yes, with great difficulty; 4 = I do not / do not perform. The questions developed with the categories of environmental factors from Q7 to Q11 measured as barrier, facilitator or neutral in the individual's life. Question Q12 assessed by multiple choice (Chart 1).

Chart 1. Communication evaluation questionnaire in patients with Amyotrophic Lateral Sclerosis (ALS) of the Dr. Henrique Santillo Rehabilitation and Rehabilitation Center (CRER), Goiânia-GO.

Q1	When it is 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?
Q2	When do you want to talk to someone, or join a group conversation, whether in a familiar or strange environment, can you start, maintain and end this conversation?
Q3	Does the communication feature you use to communicate now meet your communication needs?
Q4	By interacting with others, can you express and express your feelings (showing affection, appreciation, reacting to criticism)?
Q5	Do you participate in informal or occasional meetings with others, such as visiting friends or relatives and having informal meetings in public places?
Q6	Do you consider that you enjoy all your human rights (equality, social, freedom, expression)?
Q7	Is the communication resource (CAA) you use to communicate a facilitator, barrier, or neutral in your life?
Q8	Is the support you receive from your family (spouse, parents, siblings, children, grandparents) a facilitator, barrier, or neutral in your life?
Q9	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?
Q10	Are the attitudes that society in general have towards your communication limitations a facilitator, barrier, or neutral in your life?
Q11	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?
Q12	What items do you consider to have improved your communication after you start using the feature you purchased? Communication with family members ( ); community life ( ); friends ( ); with strangers ( ); with health professionals ( ).

Data collection procedures

The electronic medical records of the patients collected information on anamnesis and clinical evolution of all specialties, in which each followed: physical therapy, occupational therapy, speech therapy, neurology, pneumology.

With the data from the assessment instrument, the discussions of each case began together with the occupational therapists and speech therapists of each research participant. In order to select and define the CAA resources to compose the test phase of each participant, considering the expectations and communicative demands of each one, as well as the motor alterations and disease progression (Figure 2).

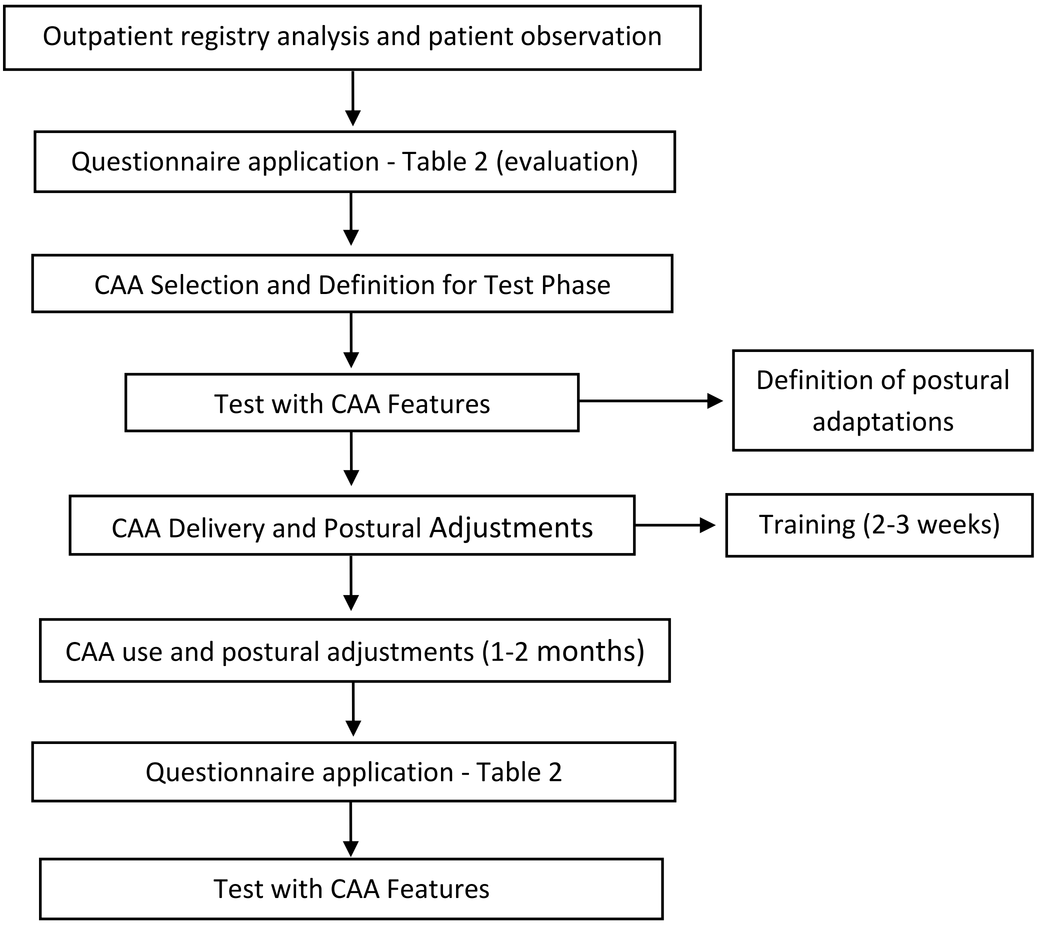

Figure 2. Schematic presentation of the data collection procedure.

Each patient went through the test phase individually to choose the CAA feature that best suited his or her reality, communicative requirement, usability, and operationalization of the feature, in addition to the patient's perspective. One of the requirements presented by all participants was the need to provide a postural adjustment for the use of CAA, given the physical impairment presented by all, due to the evolution of ALS. After defining the CAA of each case, the postural adjustments necessary for the functional use of resources with the occupational therapy team had created together. The orthopedic workshop of the Dr. Henrique Santilo Rehabilitation and Rehabilitation Center (CRER), Goiânia-GO was responsible for making the wheelchair support tables, known as trays, to position the indicated resource. The other adaptations (tablet cover with support, adapted keyboard, support pad, slate) provided by the researcher. These postural adjustments were established and made within five to eight weeks.

Upon delivery of the resource, each participant received training and support to use it, on the day of attendance at CRER and / or at home, from those who eventually missed outpatient therapy and agreed to receive training visits. The follow-up of the use during the research period performed by telephone and if there was any doubt, from the participant and / or family, regarding the use of the resource, the patient received support and maintenance in person.

Upon receiving CAA with postural adjustments, patients used the resource for one to two months before returning for reevaluation. The difference in time of use was due to hospitalization, due to aggravation of the disease, or absence of the participant in the city for personal reasons. After fulfilling the minimum time established for use (1 month), they returned for reevaluation of communication through the application of the questionnaire (Figure 1).

Each patient assumed responsibility for making use of the resource for as long as necessary, while taking care to preserve the integrity of the device during its use. When they were no longer useful, they pledged to return it to the researcher to be returned to the CAA laboratory of the University Center of Anapolis - UniEVANGÉLICA, and thus passed on to other patients with communication disorder.

The CAA laboratory of the University Center of Anápolis - UniEVANGÉLICA had created from the approval of the Project "Consolidation of multi and interdisciplinary team. For the use of Alternative and Augmentative Communication technologies in the state of Goiás'', inserted in the Postgraduate Support Program and the Scientific and Technological Research in Assistive Technology in Brazil (PGPTA), launched by the Coordination for the Improvement of Higher Education Personnel) Announcement Assistive Technology in Brazil and Disability Studies (CAPES No. 59/2014).

Data analysis

The data obtained through the questionnaire (Table 2), in the evaluation and reassessment based on activity and participation (Q1 to Q6) had organized in an Excel spreadsheet, and then treated and analyzed quantitatively in isolation, using the Statistical Package software, for Social Science (SPSS) 22

The Results presented in table form. Regarding the variables that made up the personal factors (gender, age, time since diagnosis, personal and family income, information about the history and clinical evolution of each participant), environmental factors (Q7 to Q11) were obtained through observation. The researcher and annotated in free text and presented descriptively.

RESULTS

The personal factors related to the sociodemographic profile had compiled and presented in Table 2. Of the five patients evaluated, two were male and three female, aged between 43 and 76 years. Three patients reported self-reported white color and two brown color patients. Only one patient declared himself single, the others have been married. All had more than five years of schooling and reported receiving retirement as a source of personal income, four for disability and one for time of contribution.

As for household income in minimum wage, only one patient reported receiving the maximum income questioned (5 to 10 household income wages). All live in an urban area, four in their own residence and one in rented residence, with the number of residents between two to nine people

All patients reported having access to Information and Communication Technology (ICT) such as internet and mobile phones for personal use, even those with low family incomes.

Table 2. Personal aspects analyzed through sociodemographic data of patients with Amyotrophic Lateral Sclerosis of the Dr. Henrique Santillo Rehabilitation and Rehabilitation Center (CRER), Goiânia (GO), Brazil.

Personal Aspects	Case 1	Case 2	Case 3	Case 4	Case 5
Gender	M	M	F	F	F
Age	43	64	65	76	63
Skin color	Brown	Brown	White	White	White
From	MS	MT	GO	SP	CE
Marital Status	Married	Single	Married	Married	Married
School level	> 12 old	9 a 11 old	9 a 11 old	5 a 8 old	>12 old
Personal in come	Retired (invalidity)	Retired (invalidity)	Retired (invalidity)	Retired (invalidity)	Retired (tax payer)
Household in come	5 to 10	2 to 3	1 to 2	1	2 to 3
ICT acess	yes	yes	yes	yes	yes
Housing	Urban and rental owner	Urban and owner	Urban and rental house	Urban and rental house	Urban and rental house
Residents	9	3	5	2	2

Workers	2	1	2	1	0

Note: MS= Mato Grosso do Sul; MT= Mato grosso; GO= Goiás; SP= São Paulo; CE= Ceará.

Case by case description

All patients had a total decrease in communication difficulty when transmitting a message using the new available AAC feature (Q1), using them without difficulty (Table 3).

One patient (Case 2) did not present alteration to start, maintain and end a group conversation (Q2), but the others presented decreased difficulty.

No patient presented alteration when asked about the AAC to meet their communicative needs (Q3), all maintained the same evaluation results, with results ranging from: without difficulty and with difficulty.

Table 3. Aspects of social life of patients with Amyotrophic Lateral Sclerosis of the Dr. Henrique Santillo Rehabilitation and Rehabilitation Center of Goiânia (GO), before and after the use of alternative and augmentative communication provided by the researcher.

		Q1	Q2	Q3	Q4	Q5	Q6
Case 1	Evaluation	2	4	1	1	1	1
	Revaluation	1	2	1	1	4	1
Case 2	Evaluation	2	2	2	1	1	2
	Reavaluation	1	2	2	1	1	1
Case 3	Evaluation	3	3	1	1	1	1
	Reavaluation	1	1	1	1	1	1
Case 4	Evaluation	3	4	1	3	1	1
	Reavaluation	1	3	1	1	1	1
Case 5	Evaluation	2	3	2	4	3	4
	Reavaluation	1	1	2	1	4	1

Note: 1 = Yes, without difficulty; 2 = Yes, with difficulty; 3 = Yes, with great difficulty; 4 = I do not / do not perform.

Three patients (Cases 1, 2 and 3) showed no changes to express and express their feelings when interacting with others (Q4), being able to demonstrate their feelings without difficulties. Cases 4 and 5 showed a total decrease in difficulty. Cases 2, 3 and 4 did not present alterations in the difficulty to participate in informal meetings (Q5), remaining without difficulty. Already Cases 1 and 5 stopped participating in such activity. Cases 1, 3 and 4 showed no change in the difficulty of enjoying their rights (Q6), claiming to enjoy it without difficulty. Cases 2 and 5 showed a total decrease in the difficulty in enjoying their rights (table 1).

Case 1

When asked about the use of another resource to convey the message (Q1), the patient reported difficulty in performing the activity. After using the CAA, along with postural changes, presented an improvement to convey the message, informing perform without difficulty.

Another positive result was regarding participation in conversation (Q2). The patient who previously did not perform this activity began to do so through the new communication feature, although he reported that before the new resource could express his feelings through facial expressions and some gestures. A negative factor was socialization, before the patient participated in informal or occasional meetings without difficulty (Q5), but in the reevaluation reported no longer performing the activity, justifying that the reason would be the difficulty of locomotion. Question Q3, Q4 and Q6 did not change.

The environmental factors (Q7 to Q11) did not differ from the evaluation to the reevaluation. The CAA resource, family, health professionals, and services, systems, and policies were rated as facilitators in the patient's life. Already social attitudes were classified as neutral. The areas that improved communication after starting to use CAA were: communication with family, friends, strangers, and health professionals (Q12).

Table 4. Presentation of the profile and clinical history of Case 1.

Year of diagnosis	**2013**
Medical history	• Clinical history • Dysphagia • Dysarthria with severe speech loss • Deficit muscle strength in upper limbs • Upper limb atrophy • Poor postural control • Use of motorized wheelchair • Use of noninvasive mechanical ventilation • Dependent on Daily Life Activities (ADL's)
CAA used before assessment	• Notepad phone
CAA provided	• 9.6 "tablet with free board and notepad
Postural adaptations	• Tablet case with keyboard stand • Making a wheelchair table for tablet positioning.

Case 2

When asked about the use of another resource to convey the message (Q1), the patient reported performing the activity with difficulty, after CAA and postural adequacy began to perform without difficulty. In the evaluation, the patient reported enjoying the rights (Q6) with difficulty, while in the reevaluation stated enjoying without difficulty. Questions Q2, Q3, Q4, Q5 did not change. Even though he was a patient who presented a worsening clinical condition during the research, he is a very communicative patient, a personal characteristic that can influence the stabilization of the results of social aspects.

The environmental factors (Q7 to Q11) did not differ from the evaluation to the revaluation. The CAA resource, family, health professionals had classified as facilitators in the patient's life. Social attitudes, services, systems and policies had classified as neutral. Regarding social attitudes follow the following comment “are more positive attitudes, I am very communicative’’. The areas that improved communication after starting the use of CAA: communication with family, friends, community life, strangers, and health professionals, characterizing improvement in all areas questioned (Q12).

Table 5. Presentation of the profile and case history of Case 2.

Year of diagnosis	**2016**
Medical history	• Dysphagia • Dysarthrophony • Phonation and breathing incoordination • Total loss of speech, • Upper and lower limb motor deficit • Global muscle weakness • global atrophy • Postural instability • Use of non-motorized wheelchair • Use of noninvasive mechanical ventilation • Dependent on ADLs.
CAA used before assessment	• Writing in notebook and chalkboard

CAA provided	10.1 "tablet with free notepad and surfboard apps
Postural adaptations	Tip Tablet stand without keyboard Making a wheelchair table for tablet positioning.

Case 3

When asked about the use of another resource to transmit the message (Q1), the patient reported that she performed the activity with difficulty, after using the new device of CAA began to perform without difficulty.

Regarding participation in a conversation with a person or group, whether in a known or strange environment (Q2), the patient reported during the evaluation to perform the activity with great difficulty accomplish without difficulty, thus starting, maintaining and ending this conversation. Questions Q3, Q4, Q5 and Q6 did not change. This patient with a stabilized clinical picture maintained the same functionality in relation to aspects of social life from the evaluation to the reevaluation, presenting difference only in the communicative aspects with the new feature and in the use of this feature in a conversation.

The environmental factors (Q7 to Q11) did not differ from the evaluation to the reevaluation. The CAA resource, family, health professionals, and services, systems, and policies rated as facilitators in the patient's life. Already social attitudes had classified as neutral. The areas that improved communication after starting the use of CAA: communication with family, community life, friends, strangers and health professionals, characterizing improvement in all questioned areas (Q12).

Table 6. Presentation of the profile and clinical history of Case 3.

Year of diagnosis	**2013**
Medical history	Dysphonia Dysphagia Dysarthrophony Severe dysarthria Severely impaired speech Global motor deficit with moderate trunk function loss Mild upper limb weakness and preserved manual strength Dependent for locomotion Semi-dependent on ADL's Non-motorized wheelchair use.
CAA used before assessment	Notepad phone
CAA fornecida	Tablet 7.0 "with notepad, freeboard and voice recorder apps.
Adequações posturais	Tablet case Tablet support pad

Case 4

When we asked the patient about the use of another resource to convey the message (Q1), he reported performing the activity with great difficulty. After the use of CAA and postural adjustments, he started to perform without difficulty. When asked about participating in a conversation with a person or group (Q2), the patient reported not performing such activity.

Regarding interacting with other people and being able to express and demonstrate their feelings (Q4), the patient previously performed with great difficulty, in the reevaluation said to perform without difficulty. Questions Q3, Q5 and Q6 did not change.

The environmental factors (Q7 to Q11) did not differ from the evaluation to the reevaluation, except for social attitudes, which in the evaluation presented itself as a facilitator and in the reevaluation as neutral, followed by the following comment: '' the attitudes are more negative and that makes me shy ''. Both in the evaluation and in the reevaluation, the CAA resource, the family, the health professionals presented themselves as facilitators, while the services, systems and policies had classified as a barrier in the patient's life, followed by the comment '' poor accessibility, laws that help and guarantee access to medicines and retirement are not fulfilled ''. Areas that improved communication after starting to use CAA: communication with family, friends, community life, and health professionals (Q12).

Table 7. Presentation of the profile and clinical history of Case 4.

Year of diagnosis	**2017**
Medical history	• Alteration of orofacial complex • Phonation and breathing incoordination • Dysphagia • Total loss of speech • Global muscle weakness • Upper limb motor deficit with preserved hand skills and handgrip. Performs supervised AVD's, semi-dependent for walking, ambulance with human assistance and wheelchair request in progress.
CAA feature used before assessment	• Writing with notebook and pen
CAA feature provided	• Whiteboard accompanied by brush and eraser
Postural adaptations	• Decrease the width of the board to 30cm x 20cm in order to facilitate its use and positioning. • Support pad for the feature.

Case 5

When asked about the use of another resource to convey the message (Q1), the patient reported performing the activity with difficulty and after using the CAA began to perform without difficulty. When we asked them about talking to a person or group (Q2), the patient reported performing the activity with great difficulty, and the reevaluation began to perform without difficulty. However, in the comments raised a limitation as to the feature: the difficulty to draw attention of people, who are not in the same environment, whether in a room of the house or even outdoors. Thus, the patient had suggested using an audio amplifier with a Bluetooth connection.

When asked if the CAA feature met her communication needs (Q3), both in the assessment and reassessment the patient reported that she was having difficulty supplying, but in the reevaluation made the following comment '' provides 80% because I am losing the movement of the hands, without the table to support (the CAA) I could not type ''.

Regarding interacting with other people and being able to express and demonstrate their feelings (Q4), in the evaluation to the patient reported not performing the activity, after the intervention reported performing without difficulty (Table 1).

In the evaluation, the patient reported participating in informal or occasional meetings with great difficulty (Q5), while in the reevaluation reported no longer performing the activity followed by the comment ''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 that".

When asked if the patient enjoys all her human rights (Q6), in the assessment the patient reported not enjoying followed by the comment '' I feel prevented from enjoying my rights because it is bureaucratic and difficult to achieve, without lawyer I could not '. In the reevaluation, the patient stated that she enjoyed all her rights without difficulty, but declined to comment. Question Q3 did not change. This patient has depression with great emotional demotivation.

The environmental factors (Q7 to Q11) did not differ from the evaluation to the reevaluation. The CAA resource, family and health professionals had classified as facilitators by the patient. Social attitudes were classified as a barrier, with the following comment ''society still cannot handle it (communication limitation)''. Services, systems and policies have also been classified as a barrier ''it is difficult to get access to what is right''. The areas that improved communication after starting CAA were communication with family, friends, strangers, and health professionals (Q12).

Table 8. Presentation of the profile and clinical history of Case 5.

Year of diagnosis	2009
Medical History	• Dysphagia • Difficulty in voice with voice alteration • Alteration of orofacial complex • respiratory distress • Poor postural control • Dependent on ADL's • Moderate loss of manual function • Dependent for locomotion • Use of motorized wheelchair • Emotionally unstable
CAA used before assessment	• Notepad phone
CAA feature provided	• 7.0 "tablet with notepad and free board apps
Postural adaptations	• Tablet stand without keyboard • Wheelchair table manufacturing for tablet positioning

DISCUSSION

The CAA resources made available to the participants in this study had positively accepted in all cases, as they all complained about the use of previously used communication resources. Only one patient received the low-tech slate feature; the appeal had chosen by her according to her demands and demands.

The patient explained that she was not a high-tech fan and had no interest in learning to use any of the other features presented. The decision had respected, since the patient was successful in usability with the board, and that the CAA must be in accordance with the user's wishes and daily demands. All patients had as their main caregivers the spouse, followed by close relatives such as in-laws and children. Only one patient declared himself single, the caregivers were his sister and brother-in-law, both elderly, without assistance from other relatives.

When compare the results, it had observed that, even with the progression of the disease, all remained without complaints of difficulties to communicate using the new AAC resources, meeting their communicative needs.

During the intervention, the case 1 patient underwent hospitalization due to respiratory injury followed by worsening of motor control, overall muscle strength, and total loss of speech. Case 2 similarly showed respiratory and motor problems, during this period, discharged from the outpatient neuromuscular therapies, but continued with the follow-up of CRER.

The patient in Case 5 also presented respiratory injury, was discharged from outpatient therapies and began receiving private health care from home care. He showed great emotional lability as a differential factor of other patients, being the most evident case of depressive symptoms, as well as lack of motivation and self-acceptance of her health condition. This factor may possibly have influenced the results of this case, since the depressive condition negatively affects the interaction and participation of the person with ALS(16).

Patients in Cases 3 and 4 had a temporarily stabilized clinical picture, but with greater speech impairment. In contrast, they had better breathing conditions, better upper limb, and trunk motor controls. The health condition may have contributed to the stability and reduction of the communication difficulties presented.

Two patients (Cases 1 and 5) reported no changes in communication in community life (neighbors, church, clubs, ceremonies), but both improved communication with family, friends, strangers and health professionals. These patients did not have difficulties in interpersonal interaction (Q4), but for different reasons, both reported in the reevaluation, no longer participating in informal or occasional meetings with other people, such as visiting friends or relatives (Q5).

Case 1, due to mobility and accessibility problems - ''I don't do it because of mobility'', and Case 5 because of poor self-acceptance and low self-esteem - ''I have been more at home because of emotional problems, but I have all the support to go out, adapted car. I feel bad that they see me like that'' - and possibly facing barriers to social attitudes ''society still can't handle it''.

Even though they did not improve communication in relation to community life, they had reduced difficulty in conveying a message, starting and ending a group conversation, and showing their feelings when interacting with others (Table 1).

Only one patient (Case 4) reported no improvement in communication with strangers. Although there was no difficulty in personal interaction and socialization (Q4 and Q5), there was worsening in relation to social attitudes. The factor that was once a facilitator, in the reevaluation was classified as neutral followed by the comment "Attitudes are more negative and this makes me shy'', a situation that can disrupt the approach with strangers.

CONCLUSION

Even with the progression of ALS all patients had reduced communicative difficulty when using available CAA resources, confirming the communicative benefits in relation to its use. The participation of the patient and family during the prescribing process, as well as the utilization training, assistance and follow up of the use were fundamental in the acceptance and utilization of these resources. All patients had good acceptance and use of resources, as well as improved communication with family, friends and health professionals. The loss of communication skills can generate emotional instability, which hinders the ability to cope with barriers that arise during this new condition, such as the difficulty of socialization. It is extremely important to train health professionals and managers in the prescription and use of CAA to support equipment maintenance and information for people with loss of communicative skills. This study presented results that allow assisting in the clinical practice of professionals who accompany people with ALS or other health conditions that compromise communication.

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