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## **Impact on occupations and social participation derived from communication processes in people with Amyotrophic Lateral Sclerosis**

*Introduction:* Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease that in its evolution affects the occupational performance of the person. This may require the use of different assistive technology in order to improve the communication possibilities and, by extension, personal autonomy. *Objective:* to identify the perspective of people with ALS in relation to the influence of communication processes in their occupations and to explore possible Augmentative and Alternative Communication (AAC) in the occupational therapy intervention process. *Methods:* A descriptive and observational quantitative study of a series of cases with a transversal temporal perspective. The ALS-FRS-R, ACIS, ATD PA and PIADS instruments have been used. The sample consisted of 10 people with ALS. *Results:* The level to which the person normally incorporates the device into his life does not depend on the functional health situation derived from ALS. The AAC that has had the greatest impact on the participants has been the APP voice assistant. An informative guide on AAC has been developed for people with ALS and families. *Conclusions:* The functions of the occupational therapist in the intervention with support products for communication (assessment, planning, intervention and monitoring) are transcendental for the promotion of personal autonomy of people with ALS because thanks to the incorporation of the communication device they can continue to develop, participate and make their own decisions in freedom.

**Keywords:** Amyotrophic Lateral Sclerosis (ALS), Augmentative and Alternative Communication (AAC), Occupational Therapy, Autonomy, Quality of life (Qol)

## **Introduction**

Amyotrophic Lateral Sclerosis (ALS) is a neuromuscular disease of unknown origin, characterized by the involvement of upper and lower motor neurons that progressively degenerate in the central nervous system. (Ministerio de Sanidad y Política Social, 2009).

About 120,000 new cases are diagnosed worldwide each year, with an approximate incidence of 1-2 cases per 100,000 inhabitants per year (Mitchell and Borasio, 2007).

ALS manifests itself heterogeneously in each person; initially, the first symptoms may go unnoticed. (American Lateral Sclerosis Association [ALSA], 2017a). Its evolution causes an impact on occupations, especially in the performance of Activities of Daily Living (ADL) and in social participation, derived from difficulties in communication processes. Due to this, people begin to use different assistive technology (AT) in order to improve their communication possibilities and, by extension, their personal autonomy and quality of life. (Xunta de Galicia. Consellería de Sanidade. Servizo Galego de Saúde, 2018).

“Augmentative and Alternative Communication (AAC) is a set of tools and strategies that an individual uses to solve the everyday communicative challenges. Communication can take many forms such as speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc.” (Burkhart, 2010). Both systems "allow people with communication difficulties to relate and interact with others, expressing their opinions, feelings and making personal decisions to face and control their own lives" (Abril, Delgado & Vigar, 2010).

Assistive technology should be understood as resources available to help a person with ALS continue to participate and make their own decisions in freedom. The AACs that are most commonly used in advanced stages of the disease are those that allow control or access by looking, that is, eye readers in combination with other non-technological alternatives and other non-technological alternatives exist, such as communication boards (Delgado & Vigar, 2021; American Lateral Sclerosis Association [ALSA], 2017b).

The general objectives of the study were: (1) to identify the perspective of people with ALS on the characteristics and impact of communicative processes on their occupations and (2) to determine the functions of the occupational therapist for the promotion of the autonomy of people with ALS, through intervention with assistive technology.

## Methods

### *Study design and participants*

That is a quantitative study of a descriptive and observational nature, of a series of cases with a transversal temporal perspective. This design has made it possible to obtain objective data on the perspective of people with ALS, in relation to the influence of communication processes in their occupations.

The scope of the study is limited to the entire autonomous community of Galicia, through the Galician Association of Amyotrophic Lateral Sclerosis (AGAELA). The field work has been carried out from November 2020 to February 2021, with a duration of 5 months.

The selection of the participants was carried out through an intentional sampling, in which were invited to participate all people with ALS belonging to the AGAELA entity and who, in turn, needed the use of an AAC for their communication processes and would like to enhance their opportunities for participation through the use of communication supports.

Once these criteria have been applied for the selection of the participants, Table I shows the characteristics of the final sample made up of 10 people:

**Table I:** Characteristics of participants

Code	Sex	Age	ALS type	Years since diagnosis	Assistive technology <sup>1</sup>
AG01	Man	63	Bulbar	7	Talk Irisbond Duo Etran Board
AG02	Man	42	Spinal	1	Tobii Eye Tracker 4C
AG03	Man	54	Bulbar	2	Tobi PCEye 5
AG04	Woman	80	Spinal	1	Talk Irisbond Duo
AG05	Man	72	Bulbar	1	Talk Voice Assistant

AG06	Man	69	Bulbar	2	Talk Voice Assistant
AG07	Woman	68	Bulbar	2	Voice Assistant CAA Etran Board
AG08	Man	40	Bulbar	6,5	Irisbond Duo
AG09	Woman	62	Spinal	2,5	Talk Tobii Eye Tracker 5
AG10	Man	45	Spinal	2	Tobii Eye Tracker 5

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<sup>1</sup> The same person can use several different devices

### ***Data collection instruments***

Quantitative instruments have been applied to people prior to the transfer of the support device, and after its use:

- Questionnaire of sociodemographic variables: participant code, sex, age, type of ALS, by whom the questionnaire was completed, time (in years) that has elapsed since the diagnosis of the disease until the present moment, and what is the type of borrowed device
- ALS Functional Rating Scale Revised (ALS-FRS-R) is a standardized scale specifically designed to assess 12 aspects of physical function, grouped into four functional domains (bulbar, fine motor, gross motor, and respiratory) of people with ALS during carrying out their activities of daily living (Campos, et al. 2010).
- Assessment of Communication and Interaction Skills (ACIS) is a scale for evaluating communication and interaction skills in three domains: physical, information exchange and relationships (Kielhofner, 2011).
- Assistive Technology Device Predisposition Assessment (ATD PA) allows for identifying the level of motivation of the person and how the devices could be adapted to it as a whole (Scherer, 2005).
- Psychosocial Impact of Assistive Devices Scale (PIADS) is a questionnaire that assesses a person's perceptions of how PAs, specifically communication devices, affect their quality of life and their impact on psychosocial factors of life. person (Jutai & Day, 2002).

## ***Procedures***

An individualized evaluation of each person was carried out, at home or virtual, in which sociodemographic data were collected through a survey and the evaluation scales were applied: ALS-FRS-R and ACIS.

Next, the clinical reasoning phase was addressed, subsequently designing an intervention plan with different AACs.

The next step focused on the assessment phase, installation and commissioning of the communication device. Although eight different devices were used, when analyzing their impact and matching with the person, they have been grouped into five categories, according to the type of device and their homologous characteristics, to facilitate the interpretation of the results: Tobii, Irisbond, Voice Assistant APP, Etran y Talkk App.

After this phase, a follow-up was carried out during the following three weeks in case any type of doubt or need related to the AAC delivered arose.

Then, the results of the intervention carried out with each participant during a face-to-face interview were collected and the scales were applied: ATD PA and PIADS.

Finally, the results obtained from the intervention were analyzed and, in 6 cases, the need to carry out a new intervention using a new communication device was determined.

## ***Statistical analysis***

A statistical analysis derived from the application of the scales has been used: ALS-FRS-R, ACIS, ATD PA and PIADS.

Numerical variables are expressed as mean (M) and standard deviation (SD), while categorical variables are shown with their absolute frequency and valid percentage. With the Kolmogorov-Smirnov and Shapiro Wilk normality test, the normality condition for the age variable is verified, parametric tests have been applied.

The association of quantitative variables was analyzed through the Pearson test; with quantitative and qualitative variables, T Student or ANOVA, as appropriate; and for categorical variables, likelihood ratio and the chi-square test.

The statistical treatment of the data has been executed with the program SPSS version 27.



<b>Turning in bed and adjusting bed clothes</b>	,00	,00	1,67	,00	1,00	,91	,00
<b>Walking</b>	,50	,33	2,00	0,50	1,40	1,55	,00
<b>Climbing Stairs</b>	,00	,00	1,67	,00	1,00	,91	,00
<b>Dyspnea</b>	1,50	1,33	,67	2,00	1,60	1,82	,67
<b>Orthopnea</b>	2,00	1,33	1,33	1,00	2,40	1,64	2,00
<b>Respiratory insufficiency</b>	1,00	1,67	1,00	1,00	2,00	1,27	1,67

Regarding communication skills and according to the descriptive data obtained from the ACIS scale, items that obtained the highest score are "Orients" and "Gazes", both belonging to physicality. In contrast, the items with the lowest score are "Articulates", "Speaks" and "Sustains" from the Information Exchange module.

### ***Relationship of the person with the AACs***

This section offers a summary of the results on the impact and degree of matching of AAC in the person, indicating the scores obtained on the ATD PA and PIADS scales (with their three domains of competence, adaptability and self-esteem) according to sex and type of support product. received, in Table IV.

**Table IV:** Results of the variables of the ATD PA matching scale and the PIADS scale according to the type of AAC and sex.

	<b>ATD PA</b>		<b>PIADS</b>		
	<b>Sum</b>	<b>Mean</b>	<b>Competence</b>	<b>Adaptability</b>	<b>Self-Esteem</b>
<b>Type of AACs</b>					
<b>Tobii</b>					
M	40,00	3,48	,84	1,00	,66
SD	4,55	,32	,12	,30	,48
<b>Irisbond</b>					
M	31,33	2,80	,14	,11	-,29
SD	23,44	1,76	1,81	1,71	1,75
<b>Voice Assistant APP</b>					
M	47,00	3,92	1,33	1,78	1,25
SD	2,00	,17	,58	,25	,70
<b>Etran</b>					
M	34,00	3,10	,50	,83	,19
SD	2,83	,14	,00	,71	,27
<b>Talk APP</b>					
M	34,60	3,65	-,72	,40	-,97
SD	8,68	,73	,38	,52	,45
<b>Sex</b>					
<b>Male</b>					

M	40,09	3,69	,43	,91	,20
SD	10,89	,80	1,02	,70	1,04
<b>Female</b>					
M	32,50	2,99	,07	,56	-,21
SD	10,45	,73	1,14	1,24	1,31

To determine whether the type of AAC has a different impact on people's lives, the difference in means obtained in the scores for the domains of competence and self-esteem on the PIADS scale was analyzed (Figures 1 and 2).

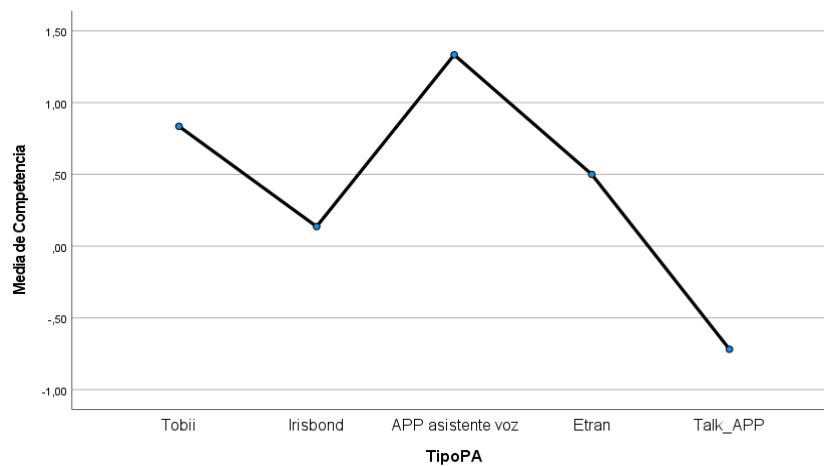


Figure 1: Mean difference analysis between the types of assistive technology with the PIADS competence scores.

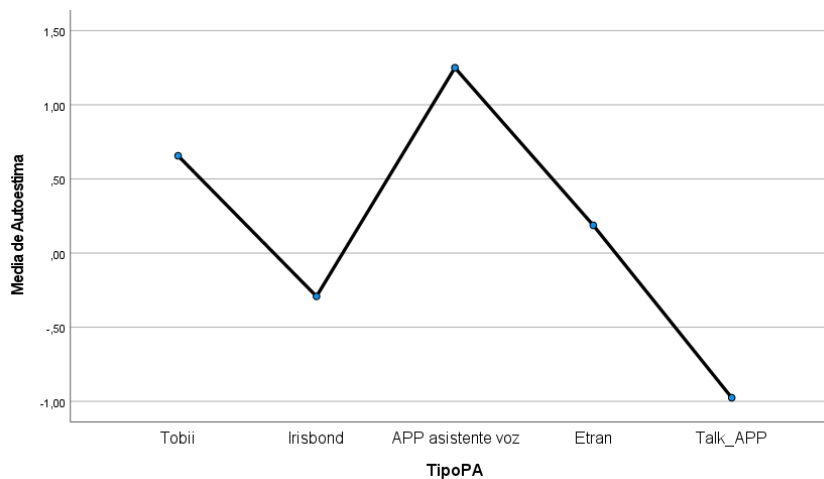


Figure 2: Mean difference analysis between the types of assistive technology with the PIADS self-esteem scores.

Thus, a significant difference is observed in the means obtained for the competence and adaptability subscales of the PIADS scale in relation to the devices delivered. In this case, the AACs that has had the greatest impact on the competence and adaptability of users has been the voice assistant APP, while the Talk APP for Samsung devices has been the



one that obtained the lowest score. Irisbond's eye reader, also considered a high-tech, high-priced device, scored low on all PIADS dimensions.

On the other hand, it is necessary to highlight that the 3 dimensions of the psychosocial impact of the AAC correlate with the total score of the matching scale. That is, there is a concordance between the impact of the AT and the degree of matching between the person and AT. Very significant correlation in the case of competence and adaptability with the degree of matching.

However, despite the fact that the devices have a clear influence on the impact on the person's quality of life, this does not seem to be the case when the pairing between the person with ALS and the AAC used is assessed

Regarding the analysis of the relationship between the sociodemographic variables and the scores obtained on the applied scales, no correspondence was seen with sex, type of ALS or the years elapsed since diagnosis.

In the case of the age variable, a significant and inversely proportional relationship was detected with the dimensions of competence and adaptability of the PIADS scale ( $p < 0.019$ ) and with the mean score of the matching scale ( $p < 0.085$ ). That is, the older, the less impact of AAC and the less degree of matching between the person and their AT.

Continuing with the analysis of the score obtained on the ALS-FRS-R scale and its relationship with the person's communication skills, it has been detected that the speech function (ALS-FRS-R) is directly proportionally related ( $p < 0.05$ ) with the items "Contacts" / "Shares" / "Engages" of the ACIS scale, and that the gait function is also directly related to the "Articulates" / "speaks" / "Sustains" / "Modulates".

Despite what might be thought, and regarding the relationship between the function of the person with ALS (assessed through the ALS-FRS-R scale) and the degree of matching between it and the AACs used, it has been detected that there is a remarkable relationship

On the other hand, and specifically for the functional characteristics derived from orthopnea, respiratory insufficiency and swallowing are inversely proportionally and significantly related to the dimensions of PIADS. In other words, the lower the score obtained in these functions (through the ALS-FRS-R scale), the greater the impact that the AACs has had on their life.

Additionally, it should be noted that communication skills, evaluated with the ACIS scale, have a little notable relationship with the impact that the AACs may have had on the person's life (PIADS) and with the degree of matching between this and the device (ATD PA).

Finally, Cronbach's  $\alpha$  test has been applied to determine the consistency and internal reliability of the PIADS tool and an  $\alpha$  level of 0.945 has been obtained, which demonstrates its excellent internal consistency.

Once the field work has been carried out and their results have been analysed, an informative dossier has been prepared: "Augmentative and Alternative Communication Systems Guide". The main objective of this document is to provide useful, practical and valid information for those people with ALS who may require an AAC, so that they have the knowledge about different useful resources to enhance their communication and participation. This guide presents different communication support devices (hardware/software) that favor people's occupational performance, as well as their characteristics.

## **Discussion**

The development of this research has allowed to obtain a general perspective of the participating people with ALS about the characteristics and the impact of the communicative processes on their occupations. Also, it has been possible to develop and to consolidate different functions of the occupational therapist for the promotion of the autonomy of people with ALS, through the intervention with support products for communication.

### ***AACs as a means of intervention***

After analyzing the data obtained, it can be stated that there is a "technological or digital gap", related to the age of the person. In other words, the older person is, the less impact a technology-based communication support device has on their life. This may be due to two factors, the first is that young people tend to be more versatile when it comes to incorporating a technological product into their daily routines than older people (Grande et al., 2008). The second refers to the impact of other non-technological factors such as economic, social or educational contexts (Wu et al., 2015).

Wu et al. (2015) refer that the economic context is an incident factor in the "digital divide", which can be related to the high cost of the support devices that will be used for the advanced stages of the disease, where the use is recommended. of an eye reader. This device was not available to the entire population until 2019, in which a regulatory text was established for said product to be included in the portfolio of common services (Orden SCB/480/2019, of April 26). Despite this, the associations themselves, such as AGAELA, continued to manage PA loan banks, in order to meet the occupational needs of the people associated with these entities (AGAELA, 2019).

However, communication devices have a clear influence on the impact on the person's quality of life. Although in this study it was not possible to detect a strong and significant relationship in the pairing between the person and the AACs due to the reduced time of device use. This reality agrees with the results of the study by Londral et al. (2015), who have shown this positive impact on quality of life, as well as a positive impact of communication support not only on the person who uses it but also on their environment and on caregivers. Other studies such as the one by Ball et al. (2004) and Caligari et al. (2015) state that this change in the quality of life, as well as in autonomy and participation is given by the good recommendation, by professionals, of the implementation of AAC in their lives.

Authors such as Pousada et al. (2021) have carried out a study to determine the benefits of the assistive device received from a loan bank and to analyze the correct match between the person and the technology, which derives from the advice of an OT. That research shows that the main influencing factor in this impact of the device is the adequate pairing between the person and the technology. Therefore, it is important that a correct prescription and advice of the support product is carried out by a professional so that the person has an optimal benefit from it.

In 2016, the Association for Persons with Severe Handicaps (TASH) published its statement of purposes which show that "the right to communicate is both a basic human right and the means by which all other rights are realized." (TASH, 2016). For people who cannot communicate effectively, AACs are assistive devices that facilitate communication and not only this, but also the rest of the occupations that they may carry out in their daily lives. Consequently, they may suffer from occupational alienation, that is, the fact of not being able to communicate occupational needs with their environment,

as well as not having autonomy or social participation, has a negative impact on the quality of life of the population with ALS (Townsend & Wilcock, 2004).

Communication devices should be understood as available, necessary, useful and facilitating resources to help a person with ALS to continue developing in their day-to-day life, participating in the community and making their own decisions freely.

On the other hand, no relationships have been found between the type of ALS and the person's communication skills. This may show that all people with ALS are going to need, throughout the disease, AACs to be able to communicate, regardless of the type of onset. In the case of, if it is bulbar-onset ALS, AACs will be required earlier compared to Spinal-onset ALS due to voice loss occurring later in the disease.

### ***Implications for the practice of Occupational Therapy (OT)***

Through this study, we have also tried to defend the role of occupational therapy in advising on AAC, its use in interdisciplinary interventions and the visibility of different assistive technology for the communication of people with ALS as a way to promote their social participation activities.

Occupational therapists must have basic training on communication AT, AAC, since it is a resource that not only refers to the person's communication but also to their decision-making capacity, maintaining their autonomy, and improving their occupational performance. This reality will have a positive impact on the level of quality of life perceived by the person.

The treatment that is implemented must be interdisciplinary, made up of professionals from various disciplines such as speech therapy, occupational therapy, physiotherapy or neurology. Specifically, the intervention focused on the use of AAC must be approached from speech therapy, since it includes communication processes, as well as their disorders, and from Occupational Therapy itself, which offers an intervention based on and directed towards important occupations for the person.

On the other hand, the World Health Organization (2016) published the "List of priority technical aids" as a guide that includes the 50 priority support products, which must be guaranteed in a public welfare system. In this way, it is intended to improve and universalize access to these devices, under equal conditions, since only 1 in 10 people can

have them. This document includes several AACs such as communication boards, communication software or keyboard and mouse emulator software (WHO, 2016)

### ***Study limitations***

Several limitations have been found, mainly, the scarce scientific evidence existing from occupational therapy on AAC and ALS.

On the other hand, the small size of the sample has been conditioned by the people who wanted to participate in the study and, in turn, by the number of communication devices available for loan.

Another relevant limitation has been the intervention time (three weeks) with the communication device. This period has been insufficient and has been able to affect the results obtained with the application of the results measurement scales.

In the same way, it would be interesting to carry out a new evaluation of the functional situation of the person (with the ALS-FRS-R scale) and of their communication skills after the incorporation of the AAC in their life, in order to be able to a comparison, through a longitudinal approach.

The results that emerged in this research could guide their transferability to another health status, with a similar level of impact on activities and participation and with the component of neurodegenerative disease. So, conditions such as muscular dystrophy or Spinal Muscular Atrophy can lead the affected person to use some specific and high-tech AAC, like the ones presented in this research. Nevertheless, and with the focus on the person and the specific needs, priorities, environments and context of each one, for occupational therapists is always important to carry on a complete process. It has to include the complete assessment and the determination of the occupational profile. The impact of any ACC and its match with the person's needs will depend mainly on this process of good assessment and counseling.***Future lines of research***

Some of the future lines of action that can be carried out are presented, such as promoting other research studies that focus and delve into the advice of support devices (AAC) from OT to obtain evidence on its effectiveness in other pathologies; explore the experiences of people with ALS who use AAC for their participation and communication; and investigate the perspective of socio-health professionals in relation to the approach and application of AAC in their interventions.

## **Conclusions**

The conclusions derived from the realization of this research study are:

- AACs are a tool to facilitate the relationship with the different environments and contexts that surround the person; the younger she/he is, the more impact the communication device will have on her/his life.
- People with ALS likely to benefit from an ACAS are those who, due to muscle atrophy, impaired phonation (speech) ability, and lingual fasciculations; their participation with their environment is compromised.
- Voice Assistant APP is the AAC that has best adapted to the needs of people with ALS, on the contrary, the Talk APP has been the one that has obtained the worst result.
- Although the devices have a clear influence on the psychosocial impact on people's quality of life, this fact is not evident when the match between the person and the AACs used is assessed.
- The functions of the occupational therapist in the intervention with assistive technology (assessment, planning, intervention and monitoring of these) are transcendental for the promotion of the personal autonomy of people with ALS. Thanks to the use of the AAC they can continue to develop, participate and make their own decisions in freedom.

## **Disclosure statement**

The authors report there are no competing interests to declare.

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