Original Article

https://doi.org/10.1590/2317-6431-2022-2642en

Audiology Communication Research
ISSN 2317-6431

Profile of speech-language pathology care focused on Augmentative and Alternative Communication

Perfil do atendimento fonoaudiológico voltado para a Comunicação Suplementar e Alternativa

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ABSTRACT

Purpose: The aim of this study is to identify the main aspects of the decision-making process indicating the use of Augmentative Alternative Communication (AAC), as well as characteristics of the interventions. **Methods:** This is a prospective study, which was submitted to and approved by the Ethics and Research Committee. An electronic questionnaire was created and sent to speech therapist professionals to collect data for this research, with a minimum of 5 years clinical experience in the AAC area. **Results:** We found a predominance in the clinic, of work with young children, especially in cases of ASD and CAS. There is a divergence in the reporting of the addressed technology and the example of the used resource. Most report difficulties in adherence to AAC, mainly due to lack of understanding what AAC is all about and barriers from family members and other professionals. **Conclusion:** There is a lack of research and professional training in the AAC area. Therefore, investing in these areas is necessary to expand the conscious use of AAC and to promote awareness of other professionals and family members.

Keywords: Communication aids for disabled; Communication disorders; Speech Language and Hearing Sciences; Language disorders; Language therapy

RESUMO

Objetivo: identificar os principais aspectos na tomada de decisão para indicar o uso da Comunicação Suplementar e Alternativa (CSA), bem como características de intervenção. **Métodos:** trata-se de um estudo prospectivo. Foi elaborado um questionário eletrônico para envio a fonoaudiólogos com experiência clínica na área de CSA há cinco anos ou mais, objetivando o levantamento dos dados para esta pesquisa. **Resultados:** verificou-se predomínio de atuação na clínica, com crianças pequenas, sobretudo para casos de transtorno do espectro do autismo e apraxia de fala na infância. Houve divergência de relato de tecnologia abordada e exemplificação de recurso utilizado. A maioria referiu dificuldades de adesão ao trabalho, atribuídas, principalmente, por dificuldades de compreensão do que é a CSA por parte dos familiares e de outros profissionais. **Conclusão:** há escassez de pesquisas e de capacitação profissional para a área de CSA. O investimento nessas fragilidades faz-se necessário para ampliar o uso consciente da CSA e favorecer ações de conscientização de outros profissionais e de familiares.

Palavras-chave: Sistemas de comunicação alternativos e aumentativos; Transtornos da comunicação; Fonoaudiologia; Transtornos da linguagem; Terapia de linguagem

Study carried out at Santa Casa de São Paulo School of Medical Sciences – FCMSCSP – São Paulo (SP), Brasil.
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Conflict of interests: No.
Authors' contribution: LSM and SCFP participated in the development of the study in the determination of the theme, bibliographic survey, research development, and writing.
Funding: None.
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Received: February 22, 2022; Accepted: June 24, 2022

INTRODUCTION

The condition of communication is inherent to the human being, developed from birth, and exercised in the most varied ways. To communicate is to transmit an emotion, an idea, a desire, to position oneself, to interact, to question, and to socialize. Speech is just one of the forms of communication and it hardly occurs in isolation, without the complement of another modality, whether gestures, facial expression, and/or body expression[1,2].

In the absence of access to effective communication, individuals with complex communication needs are conditioned to live their lives with minimal means to express their needs, and desires, develop social relationships, and exchange information with other people[3].

According to the American Speech and Hearing Association (ASHA)[4], Augmentative and Alternative Communication (AAC) encompasses different forms of alternative or augmentative communication to speech[5]. AAC has the potential to improve the communication, language, and literacy of children with complex communication needs. AAC systems include a spectrum of varying communication models, with or without assistance. Unassisted AAC systems include the use of gestures, body language, and signs, and assisted AAC systems include the use of tools or equipment other than the person's body, ranging from low to high-tech features[6].

The intervention encompasses a series of strategies and adjustments to the components of the AAC system, in order to enable the individual to communicate and interact in a variety of situations and environments[7].

Speech-Language Pathology practice in the area of language includes expertise concerning the linguistic aspects involved in the process of implementing an AAC system, but acting in this area involves technological issues of resource, accessibility, and portability, covering a multidisciplinary dimension[5]. It is necessary to know how to propose, adjust and develop the AAC system for each case, as well as to know the usual barriers to the development of this work, in order to better circumvent them and make the process viable[8,9]. There are many myths about this area, making the process difficult.

The population that needs AAC has a wide variety of characteristics, whether in terms of age or physical, cognitive, and language characteristics[1,3,7]. The target audience is vast, from children to the elderly, covering neurological and syndromic cases, among other language difficulties with temporary or permanent demand. In children's cases, the importance of early monitoring and the introduction of the AAC system with the maturation process and level of complexity of language development is highlighted[1].

As a result, AAC systems have also been developed over the years and present a diversity of possibilities for combinations and adjustments, to meet the varied demands of communication support[10-12].

The challenge is to develop evidence-based, culturally competent AAC interventions to support these individuals in fulfilling their communicative needs so that they can express their emotions and desires, develop social relationships, exchange information and participate in activities, have a routine at home, school, work, and society[3].

The AAC indication can cover three main groups, depending on the function that the alternative communication system fulfills, namely as a means of expression, as a support language, or as an alternative language[2].

In the brief survey of definitions and concepts, we could focus on some relevant points and describe the AAC as a set of instruments, tools, and techniques that brings together graphic material, such as systems of graphic signs, drawings, photos, and writings that allow dialogue in the absence or impairment of oral language[7].

Regarding terminology, the translation to Portuguese of Augmentative and Alternative Communication (AAC) at the national level is still a complex issue and without a single determination, since, specifically for the term Augmentative, there is no direct translation, generating variations[12]. Thus, mentions such as "Comunicação Suplementar e Alterantiva" (CSA), "Comunicação Amplicada e Alternativa" (CAA), and Comunicação Aumentativa e Alternativa (CAA)[12] are found in the literature.

The present study aimed to characterize the profile of speech-language pathologists who use AAC in their clinical practice, through the identification of the target audience, the instruments used for AAC indication and intervention, and the most adopted and indicated AAC systems. The specific objectives were, to identify parameters used for AAC indication and intervention, and to identify the AAC systems in relation to the user profile.

METHODS

This is a prospective study, approved by the Ethics Committee in Research on Human Beings of the Santa Casa de Sao Paulo School of Medical Sciences, under number 4,870,533. Participants in this study received a letter of invitation to participate and an Informed Consent Form (ICF) to be signed, as a prerequisite for their participation.

The authors developed an electronic questionnaire through the Google Forms platform, to be sent to speech-language pathologists, to collect data for this research. In the first contact with professionals duly selected by the authors, the first invitation was made and, with an agreement, the form was sent, aiming to obtain minimum participation of 50 professionals. The professionals to be invited to participate should follow the following inclusion criteria: being speech-language pathologists with clinical experience in AAC for five years or more; speech-language pathologists with recognition in the area, either scientific recognition, or by indication of the authors of this work, or, still, of other professionals.

The online questionnaire was used in the study, using the Google Forms platform, developed by the authors on a theoretical basis.

The elaboration of the questionnaire was based on the collection of data consulted in a literature review in the area of AAC. Topics related to the profile of care and patients, characteristics of the AAC systems usually indicated, indication criteria, principles, and intervention strategies were highlighted.

The questionnaire was structured with 26 questions in total, divided into three sections so these breaks favored completion and avoided giving up on the response route. As soon as the questionnaire began, the participant was informed that there would be three sessions and, at each of them, they were also informed of the purpose of the session. The first session, containing nine questions, was about the 'professional profile', to characterize the participants regarding the year of training,

gender with which they identified, Brazilian region, service profile (health plan, private or public), location profile (hospital, clinic, practice), if took any specific course on AAC and if were affiliated with the International Society for Augmentative and Alternative Communication – Brazil (ISAAC-BR).

The second section, containing nine questions, was about the 'profile of the public assisted by the participants to obtain information about the AAC user population they attended, what was the diagnostic hypothesis, age group, literacy status, how many patients used them, or not, of AAC, which were the main barriers the participants considered in the process of indication and use of AAC.

The third section, with ten questions, focused on 'AAC assessment/indication and intervention' and the questions were more focused on AAC systems, types of technology, protocols, and applications.

Each section was composed of closed questions, and in some, possibilities were offered for the participant to add an alternative if he so wished. For example, despite having listed several applications to indicate which of them were used, in one of the questions, the participant could add another that was not included in the list. At the end of the questionnaire, a single open question was asked about the barriers in the process of evaluation and intervention in the use of AAC.

For the application of the questionnaire, a survey of the professionals to be invited was carried out and, then, initial contact was established by WhatsApp or e-mail, for a brief presentation of the proposal of this research and an invitation to participate. For professionals who agreed, the link to the online form was sent for completion. The questionnaire begins with the presentation of the ICF so that it is only possible to access the content after signing the term. After sending the questionnaire to the professionals, the results obtained were monitored, keeping it open while the dissemination and sending were carried out, remaining like this for about a month, as verified by the increasing number of responses. Once the total number of responses was considered, the data were analyzed quantitatively and qualitatively.

RESULTS

The second stage of the work referred to the application of the questionnaire already described in the methods. Fifty-nine acceptance responses were obtained for participating in the research, but only 79.7% of professionals met the inclusion criteria, that is, 47, with a loss of 12 participants.

Regarding the first section - characterization of the participants' profile -, 100% reported identifying themselves as female. Only 4.3% had an undergraduate education level and the others ranged from specialization to post-doctorate, with a predominance of specialization level (44.7%), followed by master's degree (23.4%), doctorate (17%), and postdoctoral fellows (10.6%).

There was a wide variation regarding the time since graduation,, from 5 to 35 years of training. The main places of work of these professionals were speech-language pathology clinics (64%), multidisciplinary clinics (36%), and home care (34%), with less representation of hospitals and long-stay institutions for the elderly (both with 15%).

The profile of the public assisted was predominantly private - 91.5%. On the other hand, public service was 27.7% and health insurance was 25.5%. Most participants were from the Southeast Region of Brazil (68.1%), followed by the Northeast Region (14.9%), South (10.6%), North (4.3%), and Central-West (2.1%) and 68% of the participants were affiliated to ISAAC-BR. Regarding courses, 70.2% reported having already taken some type of specific AAC methodology or resource course, 27.7% a general course on AAC, and only 2.1% had no course at all.

Regarding the second section of the questionnaire - characteristics of the public served by the participating professionals - a distribution was identified in the answers referring to the diagnostic hypothesis of the patients, but with a predominance of cases of autism spectrum disorder (ASD) and speech motor disorder (apraxia). Only 1 participant, that is 2%, selected 'deaf blindness' and 'Covid and post Covid' (Figure 1).

Regarding the age group of the public assisted by the participants, we observed that there was a higher incidence of children, between 4 and 7 years old, followed by 8 to 10 years old, and less representation of children up to 3 years old, adolescents and adults.

Regarding the patients' literacy level, the alternatives for this question were separated by an area of mastery and understanding. Most of the public served did not master the alphabetic principle (68.1%), or only recognized the letters, but could not associate the meaning of the words (66%). Next, those who were able to write simple words (51.1%) and, to a lesser extent, those who understood and were able to write/spell sentences (27.7%).

Regarding the number of patients who were already using AAC, 63.8% of professionals answered that an average of 5 or more patients were using AAC and 36.2% had only 1 to 4 patients using AAC. Of those patients who used AAC, the contexts in which they were able to use them were, primarily, during speech-language therapy, at home, in other therapeutic activities, and then at school. A low number of its use in social contexts could be observed. (Figure 2)

About half of the participating speech-language pathologists reported having more than 5 patients with an indication for the use of AAC, but there was no adherence to the work. Only 14.9% of the participants reported having no cases of non-adherence.

Regarding the reasons for difficulties in adhering to work and using AAC, 80.8% reported problems with understanding and family acceptance, followed by a lack of understanding by

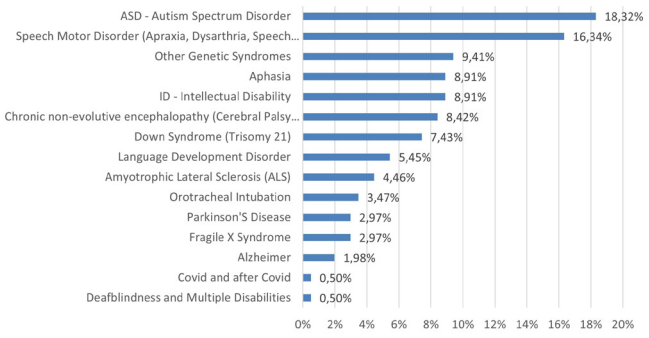

Figure 1. Profile of patients who used or had an indication of Augmentative and Alternative Communication in relation to the diagnostic hypothesis
Caption: % = percentage; Covid = coronavirus disease

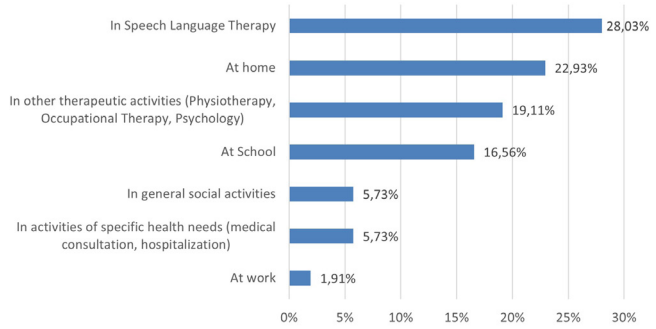

Figure 2. Social context in which patients using Augmentative and Alternative Communication/Extended and Alternative Communication were able to effectively use
Caption: % = percentage

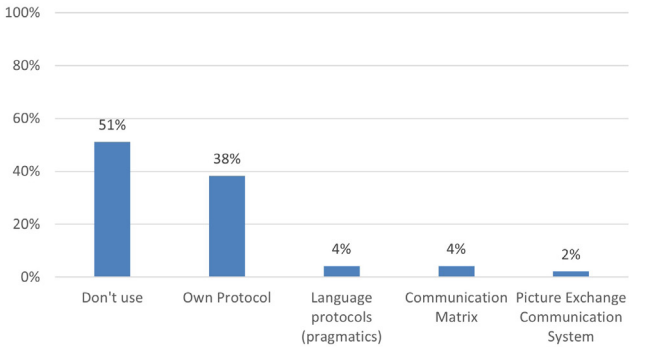

Figure 3. Protocols used for evaluation or intervention of Augmentative and Alternative Communication
Caption: % = percentage; PECS = Picture Exchange Communication System

the professional team (38.3%). Clinical and financial conditions had low representation as a cause of work adherence problems.

In the third and last section, aspects related to the AAC evaluation/indication and intervention process were verified. Regarding the use of protocols, more than half (55.3%) did not use protocols for AAC indication. Of those who answered to use it, there was a predominance of participants who used their protocol (36.2%) and the others, language protocols, especially pragmatic aspects, and the Communication Matrix, as shown in Figure 3.

Regarding the aspects considered important for an evaluation, 9 were listed: language comprehension, speech condition, global motor condition, auditory perceptual sensory condition, visual perceptual sensory condition, socioeconomic condition, family structure, diagnostic hypothesis, and personality. Of these 9 aspects, only socioeconomic status, family structure, diagnostic hypothesis, and personality were not considered in the assessment by some of the participants, but the other aspects were all considered important.

Concerning AAC systems, Figure 4 presents the most used symbol systems. There was a diversity of use, with less representation only for Bliss (Blissymbolics Communication International).

As for the use of technology, 89.4% reported using low technology, 66% using medium technology, and 48.9% using high technology. However, when asked about using apps, 90% reported using apps.

Regarding the use of these applications, 15 applications were listed, and the participants were able to add others that they used. There was an addition of 9 items. There was a predominance of the use of the LetMe Talk application, cited by 80% of the participants, followed by about 5 other applications that had 30% of indication, as shown in Figure 5.

Regarding the type of AAC use that the participants have already indicated in terms of time character (regardless of adherence), 6.4% indicated temporary use, 10.6% permanent use, and 83% both cases.

Regarding the types of use of AAC/CAA that the participants have already indicated and intervened in terms of proposed use (supplementary or alternative), only 2.1% reported having indicated only in a supplementary way, 6.4% in an alternative way, and 91.5% indicated both use proposals.

In the last question of the questionnaire, an open question was chosen so that the participants could answer in an essay

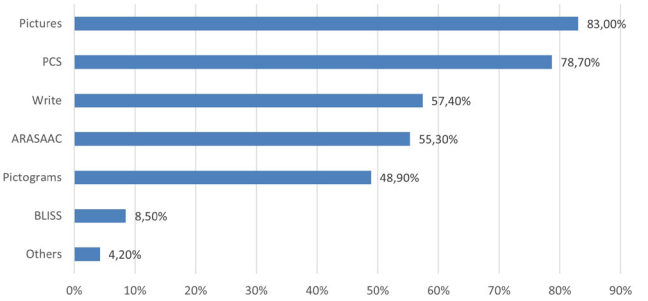

Figure 4. Symbol systems most used in Augmentative and Alternative Communication indications
Caption: % = percentage; PCS = Picture Communication Symbols; ARASAAC = Aragonese Portal of Augmentative and Alternative Communication; Bliss = Blissymbolics Communication International

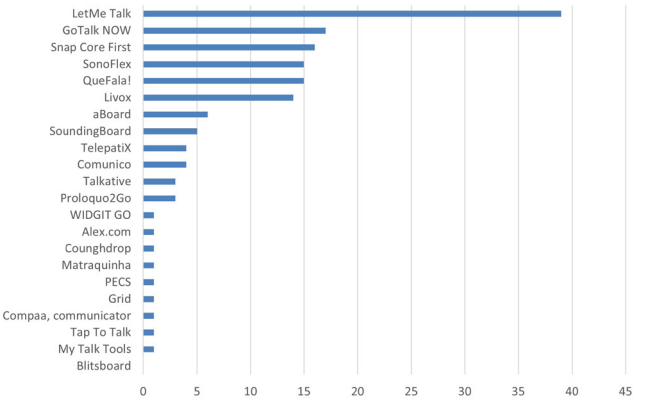

Figure 5. Applications used by professionals in the indication of Augmentative and Alternative Communication

about the barriers faced, as also mentioned in the closed question mentioned above. They mentioned barriers related to family and patient issues, staff, knowledge of the Speech-Language Pathology area, resources, and instruments for evaluation, among others.

Lack of family adherence was the most recurrent complaint. Most mentioned the caregivers' lack of knowledge, insecurity,

the belief of many that it can interfere with the speech process, difficulties in understanding by the patient, and myths about AAC.

Another aspect that was also frequently reported, in relation to the knowledge by the speech-language pathologist and the multidisciplinary team, was the lack of domain in the AAC area, providing for late indication or even resistance to this indication, some of the professionals highlighting the lack of training/specialization in the area. There was also mention, regarding the speech-language pathologists, of difficulty in time management for the preparation of boards.

Recurrently, there was a record of the lack of assessment instruments, protocols, and specific tests for the area. Few participants addressed the lack of communication partners and continuation of stimulation in settings other than therapy. To a lesser extent, financial issues and access to more varied resources were mentioned as barriers to the use of AAC.

DISCUSSION

As verified in the data collected from the application of the questionnaire, there was a predominance of participants who identified themselves as female. There was also a predominance of participants from the Southeast region, which is following the distribution of Speech-Language Pathology courses in the country. According to the Federal Council of Speech-Language Pathology[13], there are 29 courses in the Southeast Region, 21 in the Northeast Region, 19 in the South Region, 8 in the North Region, and 4 in the Center-West Region.

According to a study by Silva et al.[14] on speech-language pathology assistance in the Unified Health System (UHS), between 2010 and 2020, the Southeast Region concentrated more than half of the procedures registered in the country and had the highest percentage of speech-language therapists professionals. It was also observed the disparity between the quantity and the need for speech-language pathologists in the UHS, in the North and Northeast regions, which presented a deficit in the studied period, evidencing that the distribution of speech-language pathologists in the national territory seems to be related to social inequalities[14].

Considering the responses of the participants about the service profile and the workplace profile, the inequality between the areas of activity in the public system (with only 27.7%) and the private system (about 90%) was clear. The professional who works with AAC does not necessarily work in all sectors, which can generate this variety, but it leads to thinking about the population that uses the UHS that, consequently, will have more difficulty in accessing professionals who work with AAC, as shown by the result of the workplace profile, in which 64% were attended in clinics and private offices and no response was received in relation to attendance at the Psychosocial Care Centers (*Centros de Atenção Psicossocial* - CAPS).

Regarding courses, as mentioned in the last question about barriers to work, there is a lack of regular training courses in the AAC area, according to the answers analyzed, therefore, occasional courses and often method- or resource-specific training courses predominate..

Regarding the public assisted by the participating professionals, we found that the profile of care showed a prevalence of cases of ASD and apraxia of speech in childhood, among other cases, which ranged from adult neurological conditions (aphasia, Alzheimer's, Parkinson's disease, amyotrophic lateral), childhood neurological and genetic syndromes (T21, X-Fragile).

It is known that communication is one of the main skills that are altered in individuals with ASD. People with ASD express themselves and understand better through non-oral systems and, therefore, benefit from the use of AAC[15,16]. However, it is worth noting that AAC is an area of activity in language and is intended for any individual who has communication difficulties, either due to impaired expression or understanding, thus covering a wide target audience, of any age group, without restrictions[1,2,4].

Considering that the age group of patients was primarily children between 4 and 7 years old, it is consistent with the types of diagnoses most referred to in consultations by the participating professionals. It is worth mentioning that it was a convenience sample, there was no control number of a balanced sample, but, even so, it showed a portrait of greater use of AAC in the clinical and children's context.

The number of older patients (+18 years) is also related to the environment in which these professionals worked, for example, only 14.9% of professionals worked in hospital environments and long-stay institutions for the elderly (LSIE).

This data alerts to the need to investigate whether communication has due recognition in the hospital context. Speech-language pathology intervention for communication with patients in an intensive care unit (ICU) can promote significant gains, favoring conduct from other professional areas and even contributing to the reduction of the use of sedative drugs, and anxiety control, and have an impact, including, in the time of hospitalization[17]. There are a variety of low- and high-tech strategies that can be used in hospitalized patients. Evidence suggests that these tools intensify communicative acts, and improve quality of life and psycho-emotional issues, in addition to allowing communication exchanges between the patient care team[18].

There was a trend in the choice of low-tech tools, with the communication board being the most used, due to the availability of health services and ease of use[18]. Despite the low representation of professionals working in the hospital environment, it was observed that the AAC has great potential in this environment.

About 90% of the participating professionals reported that patients were able to make effective use of AAC in the speech therapy environment, at home, in other therapeutic activities, and at school. There was low adherence to using in other social contexts, which is consistent with one of the barriers mentioned in the open question, that is, the difficulty in encouraging use in environments other than therapy.

Added to this data is the verification of a large part referring to situations of low adherence and difficulty in making effective use of the AAC. Most of the complaints were related to the lack of information, dissemination, and awareness of AAC for the population, both for family members and the teams. Access to a variety of resources was not a predominant issue as a barrier, both in the closed question, as in the open question.

Myths about the use of AAC can impact and harm the AAC work process and impact both professionals from other areas and family members, generating resistance due to a lack of adequate understanding of the objectives and benefits of this language intervention approach[10-20].

As for the lack of citation of protocols, it is a finding that is following the lack of protocols aimed at the AAC area on a national basis, with general language protocols being often

used to identify communication difficulties and the need for intervention with AAC[15-21]. Specific protocols that direct or monitor the AAC approach itself are lacking.

According to the literature, various language protocols were cited. Also noteworthy is the reference to the Communication Matrix protocol, which is an assessment tool to trace the communicative profile of children up to 24 months of age and meets any form of communication, including AAC[22].

Of the items listed as important for the assessment, only socioeconomic status, family structure, diagnostic hypothesis, and personality were reported by some participants as not considered in the assessment. All items have, in some way, an impact on the decision-making of the type of AAC system to be indicated, varying the weight in the evaluation according to the characteristics of each case[1,2,14].

Regarding the type of symbol indicated in most cases, approximately 80% of speech-language pathologists highlighted the use of photos, as well as pictograms in general (either from the formal Picture Communication Symbols (PCS) and Aragonese Portal of Augmentative and Alternative Communication (ARASAAC) systems, or others. Since the largest target audience of patients reported was children, the use of iconicity symbols between transparent and translucent is seen as indicated[1,2] and, therefore, expected to have been of greater use in the sample of this study.

Regarding the type of resource of the AAC system, the majority reported using low technology and, to a lesser extent, high technology (49%), but 90% confirmed using applications, which suggests a divergence of understanding of what is a high technology, referring to the importance of training beyond instruments and resources, that is, also to the AAC's area of the approach. In the open question, the lack of more specific training for the speech-language pathologist in this area was reported as one of the barriers to the development of AAC work, with a shortage of improvement and specialization courses.

The results showed that there is a variety of applications, but that there is a trend towards greater use of an application, LetMe Talk, which is free and available for Android and IOS systems. Some other applications also have these characteristics, and the priority use may be related to personal disclosure, however, there is no more data to understand the preference.

It is worth noting that communication is multimodal; the fact of using low technology does not mean that high technology cannot be used. The AAC system strategy aims, precisely, at the diversified use of symbols, resources, and techniques, according to the contexts, communicative partners, and communicative demands[2].

This research had as a limitation the access and dissemination to a wider audience and acting in the area of AAC in the most diverse environments.

CONCLUSION

The results of this study suggest that AAC work has been carried out more comprehensively in the clinical context and with children. The literature highlights the importance in other contexts, including the ICU, and with different age groups, but more studies are needed to better understand this data.

Also noteworthy is the lack of specific AAC instruments, both for evaluating and indicating the AAC system and for monitoring the intervention, highlighting the importance of producing more national research in the area. The data also pointed to the need to train speech-language pathologists in the area of AAC, so that it is possible to count on more professionals with mastery of this approach, knowing that it is not covered uniformly in undergraduate courses. The variety in the use of resources and symbols, as well as the clarity of the type of technology, only occurs from an awareness of what AAC is and which area it belongs to. By improving science and professional training, awareness-raising actions, to reach other professionals, as well as family members, will be enabling to fight the myths that provoke resistance to action.

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