

Augmentative and alternative communication for children with complex communication needs: the opinions of parents and caregivers

Comunicação suplementar e alternativa para crianças com necessidades complexas de comunicação: opinião de pais e cuidadores

Comunicación suplementaria y alternativa para niños con necesidades complejas de comunicación: opinión de los padres y cuidadores

Franciane da Silva Nascimento¹ 📵

Rivail Almeida Brandão Filho¹ 📵

Flávia Fialho Cronemberger¹ D

Natalie Argolo Pereira Ponte¹

Paula Taís Moreira² 🗓

Renata de Assis Fonseca Santos Brandão¹ 🗓

Abstract

Introduction: Assistive technologies include resources, practices, and services that aim to promote functionality, quality of life, and autonomy for people with disabilities. In the face of complex communication needs, assistive technology systems such as Augmentative and Alternative Communication

Authors' contributions:

FSN: study conception, methodology, data collection, coleta de dados, study design.

RABF: methodology, critical revision.

FFC, NAPP: critical revision.

PTM: data collection.

RAFSB: study colnception, methodology, critical revision, orientation.

Email for correspondence: fon of ranciane@gmail.com

Received: 14/04/2025 Accepted: 03/07/2025



¹ Universidade do Estado da Bahia - UNEB, Salvador, BA, Brazil.

² Centro Estadual de Prevenção e Reabilitação da Pessoa com Deficiência - CEPRED, Salvador, BA, Brazil.



may be indicated. **Objective:** To analyze the opinions of parents and caregivers of children with complex communication needs regarding the use and barriers to the implementation of augmentative and alternative communication. **Materials and method:** This is a descriptive cross-sectional study with a quantitative approach. The research was developed through the application of a questionnaire answered by parents and caregivers of children who use Augmentative and Alternative Communication and are treated at a reference center for the rehabilitation of people with disabilities located in Salvador-BA. **Results:** A total of 15 participants responded to the survey. Based on the analysis of the opinions of parents and caregivers, it was noted that communication skills were acquired and/or developed using Augmentative and Alternative Communication, with emphasis on intentionality, communicative initiative, and turntaking. The main barriers to its implementation in this study were environmental/social and material in nature. Parents and caregivers consider Augmentative and Alternative Communication important for the communication of their children/wards. **Conclusion:** Adherence by family members can contribute to the successful implementation of Augmentative and Alternative Communication. Understanding the perceptions that parents and caregivers have about assistive technologies for communication allows us to identify facilitating factors and barriers that impact the process.

Keywords: Augmentative and alternative communication systems; Communication disorders; Family; Caregivers.

Resumo

Introdução: Tecnologias assistivas incluem recursos, práticas e servicos que têm como objetivo promover a funcionalidade, a qualidade de vida e a autonomia da pessoa com deficiência. Diante de necessidades complexas de comunicação, sistemas de tecnologias assistivas como a Comunicação Suplementar e Alternativa podem ser indicados. Objetivo: Analisar a opinião de pais e cuidadores de crianças com necessidades complexas de comunicação, em relação ao uso e às barreiras à implementação da Comunicação Suplementar e Alternativa. Materiais e método: Trata-se de um estudo transversal descritivo, com abordagem quantitativa. A pesquisa foi desenvolvida por meio da aplicação de um questionário, respondido por pais e cuidadores de crianças usuárias de Comunicação Suplementar e Alternativa atendidas em um centro de referência em reabilitação da pessoa com deficiência, localizado em Salvador-BA. Resultados: Responderam à pesquisa, 15 participantes. A partir da análise da opinião de pais e cuidadores, percebeu-se aquisição e/ou desenvolvimento de habilidades comunicativas por meio do uso da Comunicação Suplementar e Alternativa, destacando-se a intencionalidade, a iniciativa comunicativa e a troca de turnos. As principais barreiras à sua implementação, nesta pesquisa, foram de natureza ambiental/social e material. Pais e cuidadores consideram a Comunicação Suplementar e Alternativa importante para a comunicação de seus filhos/tutelados. Conclusão: A adesão por parte dos interlocutores familiares pode contribuir para o sucesso na implementação da Comunicação Suplementar e Alternativa. Conhecer a percepção que pais e cuidadores têm a respeito das tecnologias assistivas voltadas à comunicação permite identificar fatores facilitadores e barreiras que impactam no processo.

Palavras-chave: Sistemas de comunicação alternativos e aumentativos; Transtornos da comunicação; Família; Cuidadores.

Resumen

Introducción: Las tecnologías de apoyo incluyen recursos, prácticas y servicios cuyo objetivo es promover la funcionalidad, la calidad de vida y la autonomía de las personas con discapacidad. Ante necesidades comunicativas complejas, pueden recomendarse sistemas de tecnologías de apoyo como la Comunicación Suplementaria y Alternativa. Objetivo: Analizar la opinión de padres y cuidadores de niños con necesidades comunicativas complejas en relación con el uso y las barreras para la implementación de la Comunicación Suplementaria y Alternativa. Materiales y método: Se trata de un estudio transversal descriptivo, con un enfoque cuantitativo. La investigación se llevó a cabo mediante la aplicación de un cuestionario, respondido por padres y cuidadores de niños usuarios de la Comunicación Suplementaria y Alternativa atendidos en un centro de referencia en rehabilitación de personas con discapacidad, ubicado



en Salvador-BA. **Resultados:** Respondieron a la encuesta 15 participantes. A partir del análisis de la opinión de padres y cuidadores, se observó la adquisición y/o el desarrollo de habilidades comunicativas mediante el uso de la Comunicación Suplementaria y Alternativa, destacando la intencionalidad, la iniciativa comunicativa y el intercambio de turnos. Las principales barreras para su implementación, en esta investigación, fueron de naturaleza ambiental/social y material. Los padres y cuidadores consideran que la Comunicación Suplementaria y Alternativa es importante para la comunicación de sus hijos/tutelados. **Conclusión:** La adhesión por parte de los interlocutores familiares puede contribuir al éxito en la implementación de la Comunicación Suplementaria y Alternativa. Conocer la percepción que tienen los padres y cuidadores sobre las tecnologías de apoyo orientadas a la comunicación permite identificar los factores facilitadores y las barreras que afectan al proceso.

Palabras clave: Sistemas de comunicación alternativos y aumentativos; Transtornos de la comunicación; Familia; Cuidadores.

Introduction

Communication is a process that involves both reception and expression of language, through which the individual is inserted into culture and society. It consists of verbal and nonverbal elements that convey the message intended by the sender to the interlocutor¹. When oral communication is restricted, it is necessary to expand the communicative possibilities so that the individual's dialogical autonomy is guaranteed².

Assistive Technologies (AT) encompass resources, products, practices, and services that promote functionality, quality of life, and social inclusion for people with disabilities³, such as Augmentative and Alternative Communication (AAC) being an example of AT. AAC is an interdisciplinary field of knowledge, with clinical, educational, and scientific interests, which uses verbal and nonverbal signs to support and mediate the dialogic relationships of individuals with complex communication needs^{4,5}.

AAC systems can use different channels for language expression, such as gestures, facial expressions, concrete symbols, and writing. They can be classified as low-tech, produced at low cost and with little complexity, such as printed pictographic and/or ideographic boards, objects, and photographs. Or classified as high-tech, which include electronic resources, such as digital communication boards, vocalizers, and smartphone applications^{1,6}. Through AAC, individuals can express everything from physiological needs to desires, opinions, feelings, exchange information, and other manifestations^{5,7}. AAC allows users to express what they are unable to communicate through natural means².

It is important to highlight that, in addition to promoting autonomy and social inclusion, AAC favors the acquisition, expansion, and development of receptive and expressive language⁸. It is incorrect to infer that, in the absence of spoken language, there is no individual, since the use of nonverbal communication (gestures, facial expressions, and the body as a whole), that is, forms of unmediated or unassisted communication, which do not require additional equipment, also enable language expression^{9,10}. However, some people need mediated solutions using external support systems, such as AAC resources. These resources support communication, allowing individuals who are unable to communicate through unmediated means to have communicative autonomy and express their subjectivity and uniqueness¹¹.

The AAC users can become authors of their own discourse, taking an active role in communicative interaction⁹. However, for functional communication to occur, it is necessary to train the user's dialogical partners so that they know how to use AAC tools and become able to attribute linguistic meaning to the user's forms of communication².

The literature points out that the implementation and success of AAC also depends on family members, caregivers, teachers, and therapists who, when properly equipped, act as facilitators, encouraging the use of AAC in the various social contexts in which users are inserted. On the other hand, the reverse is also true: even the closest interlocutors can represent barriers when they do not adhere to AAC or display attitudes that hinder the user's autonomy^{2,12,13}.

In view of the above, this study aims to analyze the opinions of parents and caregivers of children



with complex communication needs regarding the use and barriers to the implementation of Augmentative and Alternative Communication.

Material and method

This is a quantitative, cross-sectional, and descriptive study. The research was approved by the Research Ethics Committee (CEP, in Portuguese) of Bahia State University (Universidade do Estado da Bahia, in Portuguese) under opinion number 5.185.608, ensuring compliance with the requirements of current legislation. Consent to conduct the study was requested from the local research institution and granted by it.

The research was conducted with parents and caregivers of children with complex communication needs, treated in the neuropediatric department of a public institution that is a reference in the rehabilitation of people with disabilities, located in the city of Salvador-BA. After conducting an internal survey to verify which patients met the inclusion criteria for the research and consulting with and receiving authorization from those responsible for sharing the telephone number with the researchers, the institution provided the contact numbers of 16 parents or caregivers of children who use AAC.

The inclusion criteria were: having a child or ward aged between 3 and 17 years old, being a AAC user, being aged 18 years or older, and consenting to the research by signing the Informed Consent Form (ICF). The exclusion criteria included: parents and caregivers who did not experience the routine of the child/young AAC user or who had children or wards with visual impairments.

Those who met the selection criteria were then contacted via a messaging app and invited to participate in the study. All those who accepted the invitation received a link via the same messaging app. Clicking on the link directed them to read the ICF. After reading it, they were presented with two options: "I agree to participate" and "I do not agree to participate." All those who clicked on the first option were included as participants and had access to the research questionnaire, with a copy of the ICF sent to their personal email.

The questionnaire, the data collection instrument, was developed based on the adaptation of two scripts: the interview script for identifying children's communication skills and the script for analyzing mothers' perceptions of the implementation of Augmentative and/or Alternative Communication (AAC), both developed by Manzini (2013)¹⁴. The adaptations were made with the aim of adapting the language to the target audience and considering the specificities of the service where the research was conducted. Questions were included and excluded, resulting in a questionnaire consisting of 27 closed questions, with single and multiple answer options, organized into two sections: socioeconomic profile and the use of AAC. The questionnaire was made available in digital format through the Google Forms platform and sent to participants via a messaging app (WhatsApp). The estimated time to complete it was approximately 10 minutes. The researchers remained available for clarification, committing not to interfere with or influence the responses.

It should be noted that participation was voluntary, and participants were assured the right not to accept to respond to the survey or, once they had accepted, to withdraw from participation without compromising their relationship with the institution. The identity of all participants was kept confidential.

The data collected was stored in the cloud, tabulated in a spreadsheet program, and analyzed using descriptive quantitative analysis.

Results

The survey was answered by 15 participants, 13 of whom were female (86.7%) and 2 males (13.3%). Female participation was more significant, with 11 of the women who responded to the survey being parents (73.3%), 1 a sister (6.7%), and 1 a caregiver (6.7%). Regarding the socioeconomic profile of the participants, 13 lived in urban areas (86.7%) and 2 in rural areas (13.3%). When asked about their monthly income, 8 said they lived on less than the minimum wage (53.3%), and 7 had a monthly income of 1 to 3 minimum wages (46.7%).

None of the children/wards of the research participants were aged 12 to 17 at the time of data collection. Thus, although the research also sought to understand the opinions of parents and caregivers of young AAC users, the data collected only concern the perceptions of parents and caregivers of children aged 3 to 11 years.

In addition to complex communication needs, AAC users served by the institution have other impairments, notably motor impairment 11 (55%),



cognitive impairment 6 (30%), and neurodevelopmental disorders 2 (10%). When asked about the type of assistive technology system for communication used by their children/wards, 12 (80%) responded that they use low-tech AAC systems (paper boards, miniatures, or objects), and 3 (20%) stated that they use high-tech AAC systems (applications, computers, or vocalizers).

Regarding the frequency with which AAC users initiate communication turns, 4 (26.7%) responded always, 5 (33.3%) often, 5 (33.3%) sometimes, and 1 (6.7%) never. Regarding the means of communication used by children who use AAC: 9 (60%) use gestures, 8 (53.3%) use eye contact, 8 (53.3%) use body movements, 6 (40%) use facial expressions, 2 (13.3%) use vocalizations, and 1 (6.7%) use articulate speech.

The survey showed that the main interlocutors of children who use AAC are: family members 15 (44.1%), friends 8 (23.5%), teachers 7 (20.6%), and neighbors 4 (11.8%). Regarding the frequency of AAC use in the family environment, 8 (53.3%) said they use it often, 4 (26.7%) sometimes, and 3 (20%) always engage in AAC-mediated dialogue. In social environments outside the home, 9 (60%) responded that they use it sometimes, 4 (26.7%) rarely, 1 (6.7%) often, and 1 (6.7%) always. The types of information communicated through AAC as perceived by parents/caregivers: 14 (93.3%) happiness, 8 (53.3%) desires, 6 (40%) fear, 6 (40%) pain, and 4 (26.7%) sadness.

A comparison was made between functional communication skills before and after the implementation of AAC (Figures 1 and 2), according to what was perceived by parents/caregivers.

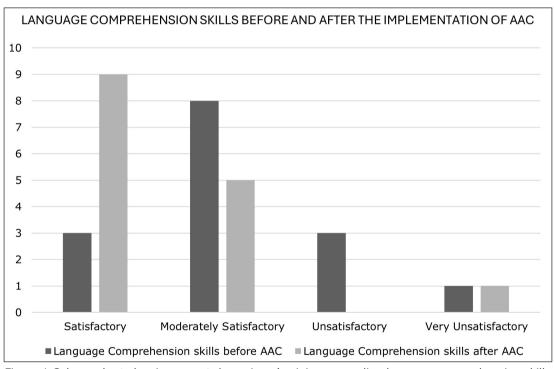


Figure 1 Column chart showing parents/caregivers' opinions regarding language comprehension skills before and after the implementation of Augmentative and Alternative Communication (AAC).



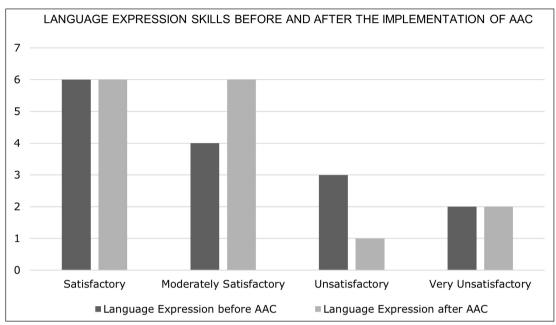


Figure 2 Column chart showing parents/caregivers' opinions regarding language expression skills before and after the implementation of Augmentative and Alternative Communication (AAC).

It was observed that most participants reported perceiving the acquisition or development of communication skills through the AAC system. Participants reported noticing: 10 (66.7%) communicative intentionality, 7 (46.7%) turn-taking, and 3 (20%) turn-initiation. Regarding the perception of the importance of AAC in dialogic relations with children who use AAC, 11 (73.3%) stated that it was extremely important, 3 (20%) stated that it was very important, and 1 (6.7%) stated that it was moderately important.

The barriers to implementing AAC relate to the knowledge and availability of others about this form of communication 8 (40%), difficulty in obtaining pictures/words and making boards 8 (40%), cost or difficulty in accessing applications 3 (15%), and difficulty in transporting the boards 1 (5%). Regarding the degree of difficulty or ease that parents/caregivers had in learning to communicate through AAC, 7 (46.7%) responded that it was easy and 8 (53.3%) responded that it was moderate. Regarding their perception of the degree of difficulty or ease for children to learn to communicate through AAC, 3 (20%) said it was easy, 10 (66.7%) said it was moderate, and 2 (13.3%) said it was very difficult.

Discussion

In addition to functional communication, the use of AAC systems also contributes to the development of motor, cognitive, and affective skills. This is due to the body organization and stimulation of higher mental functions such as attention, perception, and reasoning provided using these systems⁶.

In this sense, AAC can be recommended for people with a wide variety of diagnoses, ranging from syndromic cases and neurological conditions to acquired or developmental language disorders. It can be used in all social and therapeutic contexts¹⁵. The indication, selection, and adaptation of the type of AAC should be user-centered, considering their specific demands and potentialities¹⁶. Individualized assessment, in addition to being multidimensional, should also be collaborative, involving communication partners such as parents, teachers, and therapists¹⁷.

On the other hand, language with its nonverbal manifestations can often be overlooked in the face of severe oral communication disorders⁹. The results of this study, however, showed that most participating parents and caregivers can identify more than one means of nonverbal communication used by children to express language¹⁴.



This finding reinforces the importance of understanding the nonverbal dimensions of communication, which is essential for broadening the interlocutor's perspective during communicative interaction, favoring more functional dialogic exchanges¹⁴. When there is an excessive focus on organic speech alterations, the content of messages tends to be disregarded, which can generate frustration in the dialogic relationship¹⁸.

However, it was observed that the use of AAC in unfamiliar environments, as reported by parents and guardians, occurs less frequently when compared to its use within the home environment. This finding contradicts the literature, which points out that the use of AAC in all social contexts contributes to the individual assuming their role as author and protagonist of their own discourse, promoting their autonomy and inclusion¹. Thus, it is essential to understand the factors that hinder the use of AAC in broader social contexts¹⁹.

Considering this scenario and the central role of the family in the implementation of AAC, it is necessary to develop strategies that encourage the active participation of parents and caregivers. In addition to individual guidance, initiatives such as family involvement in clinical sessions, workshops to produce materials, and therapeutic groups enable productive exchanges between professionals and family members, which favors adherence to and expansion of the use of AAC in different environments².

However, regarding the frequency of AAC use in the family environment, the results of this study contrast with those of another study, which indicated that parents and caregivers reported less use of AAC at home, claiming to fully understand the messages transmitted by children without the need for mediation⁴.

Even so, although the interlocutor must attribute linguistic meaning to the utterances of individuals with severe communication disorders, it is essential to ensure that the sender is not placed in a passive position. Effective language acquisition and development depend on continuous dialogic exchanges between users and their peers⁴, ¹⁴.

Among the aspects observed, the following communication skills perceived by caregivers stand out: intentionality, communicative initiative, and turn-taking. There is evidence that the use of AAC favors the relationship between parents and children, promoting the recognition of children

with complex communication needs as active interlocutors with discursive intent⁴.

However, beyond the family nucleus, it is necessary to involve other interlocutors, such as friends, teachers, and neighbors. The inclusion of persons with Disabilities (PwD), as provided for in the Brazilian Inclusion Law, is the responsibility of both the State and society²⁰.

In the school context, for example, promoting inclusive education requires education professionals to have access to continuing education programs so that they are prepared to welcome children with disabilities and oral language impairments into their classrooms²¹. Communication difficulties represent significant barriers to the learning process, and AAC is an effective strategy for developing teaching resources that promote the development of these students²².

In addition, a study conducted with children with intellectual disabilities who use AAC examined the effects of interventions focused on phonological awareness and reading decoding, demonstrating that AAC favored communicative autonomy and the development of initial reading skills through strategies adapted to the cognitive, linguistic, and motor abilities of the participants²³.

Therefore, AAC should not be seen as an obstacle to teaching, but as an essential tool for its users' learning. Thus, effective inclusion requires adaptations in teaching practices and collaborative actions between the school, the family, and society²².

Still on the benefits observed, the use of AAC favors the acquisition of communication skills in children with complex communication needs, such as: improvement in message encoding, greater speech intelligibility, increased verbal and nonverbal expressions, as well as the development of aspects related to pragmatics⁶. Therefore, early AAC interventions can reduce the impact of the severity of language deficits²⁴.

It is also important to highlight the importance of paying special attention to family members, who constitute the child's main network of linguistic meaning. For this reason, they should also be the focus of intervention. For this to occur effectively, it is essential to understand the family's expectations regarding AAC, their level of acceptance of the new communication model, their socioeconomic conditions, and family structure²⁵. In this way, it is



possible to identify the barriers to the implementation of AAC systems.

According to the data from this research, the main barriers identified were: the difficulty in obtaining figures for the production of materials, the lack of knowledge of AAC by interlocutors outside the family nucleus and limited financial resources.

Material and environmental/social barriers stand out as limiting factors in the use of AAC. The cost of low- and high-tech resources was also cited by speech therapists as a significant barrier². And the relationship between family income and the effective use of AAC was considered directly proportional⁴.

Despite this, advances in mobile technology have expanded access to new resources. Even so, the implementation of AAC requires the support of professionals trained in the selection and adaptation of materials and the training of communication partners²⁵.

Other factors that should be considered regarding adherence to AAC applications relate to usability and internal flexibility with the ability to customize vocabulary. These factors impact the experience of the user and their communication partners and may even represent barriers to the effective implementation of AAC¹¹.

In general, most participants in this study consider the use of AAC to be extremely important for communication with their children/wards. The relevance and effectiveness of AAC in improving the quality of life and communication of users and family members has been widely discussed and proven^{1,15}.

Although the number of participants is a limitation, after an internal survey of the total number of families using AAC, it was found that, during the data collection period, only these families met the inclusion criteria.

In this regard, some factors that could justify the low adherence to AAC resources are: lack of knowledge among caregivers; insecurities and beliefs in myths about AAC (such as that its use hinders the process of speech acquisition and development); the lack of technical expertise in the area of AAC on the part of speech therapists and multidisciplinary teams, which may lead to resistance in recommending its use, or even late recommendation; in addition to the limited time available to professionals for preparing materials¹⁸.

Finally, the disproportionate participation between female and male participants reinforces the findings in the literature that women are primarily responsible for caring for children with disabilities^{26,27}.

Conclusion

The results of this study revealed that parents and caregivers consider AAC systems important for the communication of their children/wards, although they do not use AAC frequently in social settings. This fact can be justified by the environmental/social and material barriers identified in this study.

The findings of this study highlight the need to also focus intervention on the family of the AAC user. Adherence by family members can contribute to the successful implementation of AAC. In addition to analyzing the specific needs and potential of each individual, possible barriers should also be identified, and strategies developed to reduce them.

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