

Augmentative and alternative communication users and their interlocutors' impressions on using graphic symbol systems

Percepção do usuário de comunicação suplementar e alternativa e de seus interlocutores sobre o uso dos sistemas gráficos

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ABSTRACT: Graphic symbol systems used in Augmentative and Alternative Communication (AAC) are priority tools to expand communication possibilities. Objective: Describe the use of AAC by a female user, characterizing her and her interlocutors impressions on the means of communication used. Methods: Single case study, analyzing data obtained from AAC user history in occupational therapy interventions; two interviews with the user and nine interviews with her interlocutors. Results: We recognized AAC importance to facilitate user communication; the necessity of constantly rearranging symbols due to user motor skills; and the relationship between the established communication and activities demand, suggesting that limited communication with her interlocutors would be related to lack of social interaction. Conclusion: It was necessary to rearrange the boards, include greater vocabulary content to make communication faster; interventions in her routine to expand her relationship with her interlocutors.

KEYWORDS: Special education; Cerebral palsy; Disabled individuals; Occupational therapy.

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Resumo: Sistemas gráficos inseridos nos recursos de Comunicação Suplementar Alternativa (CSA) são ferramentas prioritárias para ampliar as possibilidades de comunicação. Objetivo: Descrever o histórico de uso da CSA de uma usuária, identificando a sua percepção e de seus interlocutores sobre os meios de comunicação utilizados. Procedimentos Metodológicos: Estudo de caso único, realizado por meio da análise dos dados obtidos do histórico da usuária de CSA nas intervenções de terapia ocupacional; duas entrevistas com a usuária e nove entrevistas com seus interlocutores. Resultados: Foram identificadas a importância da CSA para a facilitação da comunicação da usuária; a necessidade de reorganização constante dos símbolos em função da habilidade motora da usuária, bem como a relação entre a comunicação estabelecida e a demanda de suas atividades, sugerindo que a comunicação restrita com os interlocutores relacionar-se-ia com a pouca vivência de atividades sociais. Conclusões: Necessidade de uma reorganização das pranchas, envolvendo maior conteúdo de vocabulário, tornando a comunicação mais rápida; intervenções em sua rotina a fim de ampliar suas relações com seus interlocutores.

DESCRITORES: Educação especial; Paralisia cerebral; Pessoas com deficiência; Terapia ocupacional.

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INTRODUCTION

Human communication sustains human relations and depends on the availability of communication partners to share wishes, opinions, and desires, including people with disabilities who have severe motor difficulties and use a graphic symbol system to communicate¹.

People with disabilities and with speech problems may use Augmentative and Alternative Communication (AAC) different resources to communicate and build their interpersonal network².

AAC comprises resources, systems, techniques and services to help people with communication difficulties talk and have autonomy in their daily life activities. The boards with pictures, symbols, letters, words and the computer are considered the most frequent resources among AAC users³.

The American Speech-Language-Hearing Association (ASHA) determined that AAC comprises the clinic, education and research, focusing on expressive, gestural, oral or written communication disorders and/or comprehension deficit⁴.

In Brazil, AAC was introduced in the late 1970s, through systems based on graphic symbols and with some professionals' efforts together with parents in São Paulo, Rio de Janeiro, Minas Gerais and Rio Grande do Sul. Blissymbols were the most used then^{5,6,7}.

Propose an AAC language is to not only use graphic symbols, but also make sure that it is developed and applied in all social contexts. The occupational therapist goal thus is to expand its use in their clinical procedures together with the team involved and the user's family^{8,9}.

In a single case study conducted with parents of children with communication difficulties the authors showed interlocutors problems in using the communication systems and the urgent need of educating society to allow users to communicate in their daily lives¹⁰.

Thus, this case study described the use of AAC by a female user, describing her and her interlocutors' impressions on AAC methods of communication used in their daily activities.

METHODS

Case study of a young female AAC user. The case experimental design has two essential elements: repeated assessments and design of phase. It was part of a bigger project on the "Implementation of augmentative and

alternative communication resources in school and family contexts", approved by the Ethics Committee under report No. 1202/2006.

Participants

Young female diagnosed with cerebral palsy identified as Maria, 26 years old, AAC user since she was six years old, and nine people considered their main interlocutors.

Informed about the study objectives, all participants signed the informed consent form.

Data collection

We used multiple sources of evidence and data triangulation, organizing a database of progress reports and clinical evaluations selected among notes of occupational therapy interventions with the user, audio and audiovisual records of interviews with the user and her interlocutors¹².

We used external observers' participation to complement data, i.e., people who read the case, to broaden evidences from the study results and conclusion. We collected data using a semi-structured interview with two pre-elaborated scripts: user and interlocutors. Semi-structured interviews identify data and information, with the necessity of a pre-elaborated script¹³. The scripts were sent to a committee of three judges, AAC experts.

We carried out the reliability test to maintain questions reliability. After the judges had returned it to us, we elaborated a new version and sent it back to the committee. After approval, we elaborated its final version.

The 11 questions interview with the AAC user was held at her home, recorded and filmed:

1. What means of communication you use to be understood by people?
2. Do you remember how you started using the board to communicate?
3. The Board has always been more or less like this or has undergone many changes? Which ones?
4. With whom do you communicate using the board?
5. With whom do you communicate easier and what do you usually talk about?
6. Do you have any activity outside the house? Which is it?
7. How do you communicate with people there?
8. What do you talk about?

9. Do you think people in those places have difficulty talking to you?
10. Do you think the board of communication that you use is good enough to help talking to people?
11. Do you think it could be improved?

We transcribed the interview correcting grammar errors. After the content analysis¹⁴, we identified three categories of interlocutors: weekly, biweekly and sporadic. A new contact was made with the user (filmed and recorded), to confirm who were her interlocutors and how often they got in touch.

Her weekly interlocutors were her maternal grandmother, mother, cousin, sister and maid of honor; her brother-in-law was her biweekly interlocutor; and the user occasionally communicated with her godfather, her friend, her mother's cousin and her father.

We interviewed nine of ten identified interlocutors. Among them, eight talked to Maria using the board and the computer. Interviews with the interlocutors were recorded and carried out using a five-question script:

1. How do you communicate with Maria and how often?
2. What do you usually talk about?
3. What do you think about this method to communicate with Maria?
4. Do you perform some social activity together? How often? How does she communicate in that place?
5. Do you have any suggestions that could help her to communicate better?

After these interviews, the audio material was transcribed, correcting grammar errors.

Data analysis

Using data from the AAC user's history in occupational therapy and in interviews with the user and with the interlocutors, we did data triangulation¹², organizing a single temporal document with Arial font.

After the document was prepared, content analysis was carried out¹⁴, identifying two categories: Maria's trajectory and impressions on using AAC and her interlocutors' impressions on using AAC in her daily activities.

RESULTS AND DISCUSSIONS

Maria was born in 2/28/1989 with dyskinetic or athetoid cerebral palsy, which compromised the right side. She uses a manual wheelchair conducted by another person. The Gross Motor Function Measure Classification System¹⁵ (GMFCS) was determined as level V when she was 18 years old, i.e., all her motor function areas were limited and assistive technology use was restricted, remaining until today with the same motor characteristics. She uses a board with alphabets, numbers and words to communicate.

She started special school in 1991; in 1993, she attended regular school with room dedicated to students with special needs; in 1994, at the age of four, she attended normal classes of childhood education and after this she attended regular school accompanied by a tutor, graduating from high school when she was 17 years old, interrupting then her studies.

In 1992, an occupational therapist and a speech therapist organized the pictures that Maria used, selecting by theme 20 relevant symbols to her routine. They elaborated a board to her for school use with these symbols. When Maria wanted to communicate, she indicated the symbols with her left hand little finger.

Then, in 1994, she started using Picture Communication Symbols (PCS)¹⁶ and Blissymbols⁷. Information on these systems were scarce in Brazil, making it hard to use them, both for professionals and for families.

She continued using PCS color pattern¹⁶ with a board shaped like a folder that had representative symbols (me, mom, daughter, go, home, school) and facilitated her communication with her interlocutors, which was complemented with "yes" and "no" expressed with a gesture of her head.

Initially, we decided to encourage Maria to answer questions like "Who took you to school?" and, at the age of six, she pointed to the mother symbol; the verb *to take* corresponded to the school symbol. She always pointed with her left hand little finger. Following formal standards, the first board was made with 162 symbols in the period of 6 to 10 years old (Chart 1).

A second board was created in the same format for adolescence and youth periods, with 398 symbols (Chart 2), from the need of boards for specific issues. Three models were built and used according to the environment, one specific for music class, another for social activities and one for school (Charts 3, 4 and 5).

Chart 1 – Description of the first board symbols

Categories	The symbols background color	Number of symbols
People	Yellow	19
Verbs	Green	35
Nouns	Light orange	48
Adjectives	Blue	8
Ways to greet people	Pink	7
Vowels, numbers, alphabet, dates, questions	White	45
Total of symbols		162

Source: Prepared by the authors.

Chart 2 – Description of the second board symbols

Categories	The symbols background color	Number of symbols
Verbs	Green	36
Nouns	Light orange	145
Adjectives	Blue	46
Greetings	Pink	15
Vowels, numbers, alphabet, colors, days of the week, names	White	156
Total of symbols		398

Source: Prepared by the authors.

Chart 3 – Board used in music class

Categories	The symbols background color	Number of symbols
Alphabet	White	27
Numbers	White	10
Orthographic signs	White	14
Photograph	Colored	1
Notes and musical scale	White	19
Total of symbols		71

Source: Prepared by the authors.

Maria had at the same time on her wheelchair desk a board with 365 symbols, with the same category structure, in which the number of elements decreased as she mastered reading and writing.

We noticed that she preferred to use the alphabet to create sentences and structure dialogues. The board was reduced to 37 symbols with the alphabet, the numbers and

48 words (verbs, nouns, people, prepositions, with white background color).

Chart 4 – Board used in social activities and in school

Categories	The symbols background color	Number of symbols
Orders and compliments	Pink	20
Prepositions, calendar and dates	White	54
People	Yellow	24
Verbs	Green	68
Nouns	Orange	39
Adjectives	Light blue	76
Total of symbols		281

Source: Prepared by the authors.

Chart 5 – Board used in school

Categories	The symbols background color	Number of symbols
Alphabet	White	26
Number	White	10
Orthographic signs	White	11
Total of symbols		47

Source: Prepared by the authors.

In 1997, when she was eight years old, Maria was in the second year of junior high and used a Voxtable with quick messages for a short period. Maria did not like the synthesized male voice, one of the reasons why she stopped using it. With the Intellikeys keyboard with adapted honeycomb and mouse, in 15 minutes she typed sentences like “I will visit the doctor’s office to play”.

She starts using in 2014 the Ipad fixed on the desk, handling it with a few fingers of her left upper limb. The portable board made of paper has 85 symbols that enable communication with family members and close friends. Yes and no are represented with head gestures and sign language.

She constantly communicates with her family, more often with people who take care of her, answering to requests to turn devices on and off (radio), go to the bathroom and often with her eyes fixed on the board.

Interlocutors were unanimous in their opinions about the importance of the communication board. Maria sometimes uses the scanning system, looking at the symbols or her interlocutor points at a symbol and Maria answers “yes” or “no” with her head. Sometimes,

she starts a word, her interlocutors complete it and Maria agrees or disagrees with her head. Maria's movements are restricted due to her motor skill disabilities, which have been increasing in the upper limb, making the scanning system and abbreviation of words more feasible.

In scientific literature we find that for AAC users with cerebral palsy the family represents the central figure for adherence to communication systems, being important partners in intervention and need constant training, because "children do not become capable users of gestural, graphic and tangible signs without help and support of family members"¹⁷.

This is confirmed when Maria communicates with her mother and grandmother, the more detailed conversations about what she wants. She goes with her mother to the mall, they make small trips and grocery shopping. Sometimes, she follows her in lectures on her communication process, telling her history, requested by the academic community. At the farm, her grandmother tries to maintain a country life with Maria, experiencing routine activities. Many people visit the farm and some have time to talk to Maria using the board.

We call attention to the necessity of training interlocutors in different communication skills, so that children and young adults with cerebral palsy may share their wishes and knowledge with different people, in different contexts^{18,19}.

Three interlocutors suggested a change in the board, with the inclusion of more words. It would make communication easier, because the process of assembling words from the letters makes conversations longer, making Maria express her opinions with slowness and, therefore, exhausting conversation topics. Interlocutors, in turn, give up waiting and finish Maria's sentences. One of her interlocutors said that she often feels "lazy", starting phrases, but not finishing them, hoping people would complete or guess what she was trying to say.

Under this perspective, it is necessary that the family participate in the process of evaluating, choosing and introducing graphic symbol systems together with children and young people with cerebral palsy. Family members are the main interlocutors of graphic symbol systems users and they must be the most attentive informers of other communication abilities of young people with disabilities⁸.

Regarding social activities, her weekends and holidays at the farm were the most mentioned, where Maria talks to family members and there are some differentiated activities such as cooking, mentioned by an interlocutor: Maria's role is to knead the dough. One

of the interlocutors mentioned that Maria sometimes spontaneously asks about someone in the family. Another recurring topic mentioned by most interlocutors is weekday's activities. They said they use this topic to make conversation easier.

AAC studies emphasize attention to be given to the different partners in each environment, to communication opportunities and how they interact, for most communication difficulties of non-oralized individuals are low expectations their conversation partners have in their ability to transmit and produce new complex information^{20,21}.

It was also mentioned as social activities the holidays such as Christmas and family members birthdays. On these occasions, Maria asks to go to the mall to buy gifts. One interlocutor said that they sporadically go together to the mall.

Another interlocutor said that conversation is made especially with games, creating a more infantile structure than expected for her age. The interlocutor said that Maria eventually stays longer in the same topic. He realized that their communication has decreased a lot, as well as their daily activities. Absence of diversification and reduced number of interlocutors in her routine may be one of the factors that explain decreased communication quality, i.e., interruption of social activities compromised knowledge she had acquired and its evolution.

Accepting that the AAC user's social activities can be limited when compared to oralized individuals of the same age group, there is a concern with issues regarding AAC use in communication in social interaction, understanding that the successful implementation of a particular resource will occur when the AAC user expand his or her functional capacity³.

Maria does not use the computer and other technologies frequently. When she uses the Ipad, it is restricted to typing, always to answer questions.

When she learned the alphabet, conversation showed significant improvement, limited, however, to answer questions related to her basic care. Maria began not to start conversations and she hardly makes any questions or opposes to anything.

Family and other interlocutors are sometimes indifferent to AAC users' attempts to communicate. They dominate interactions, acting in ways which do not help users: they give few opportunities to communicate; do not make open questions, only yes/no questions; interrupt the user when he or she is using AAC and, moreover, focus on the resource or communication strategy, instead of focusing on the user and the message²².

Three interlocutors clearly stated that to create more dialogue opportunities it is essential to have time, patience and desire to have a conversation with Maria.

It was possible with this case study to highlight that interventions with AAC users must choose appropriate resources to their needs, promote inclusion in places frequented by their peers and train different conversation partners. It is also necessary to stimulate AAC use to enhance the different activities in the user's routine.

CONCLUSION

The AAC implemented using the board with words and letters was the most used resource by the user in her daily life and facilitated communication and social interaction.

With the reduction of her activities, as well as motor and emotional difficulties that Maria started to

present in the past few years, time to formulate words using the alphabet increased and we noticed that with more word symbols in her board, her communication could be faster, facilitating and improving interaction with her interlocutors.

This case study has identified in the user's and her interlocutors' report the positive effect of AAC implemented by the occupational therapist and the speech therapist since the user was a child, for this is how the user interact with her family members.

We believe that the occupational therapist and the speech therapist involved in the implementation of AAC systems must have as their priority, together with the family, the training of interlocutors for daily use of AAC resources at users different ages. They should also create together significant possibilities and routines for the user to communicate, granting the right to real social inclusion.

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