Parents' perceptions about the participation and communication of their children with non-speaking cerebral palsy

Percepções dos pais acerca da participação e comunicação de seus filhos com paralisia cerebral não oralizados

Percepciones de los padres sobre la participación y comunicación de sus hijos no oralizados con parálisis cerebral

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Abstract

Introduction: Knowing family members' perceptions about the participation and communication of their children with non-speaking CP (Cerebral Palsy), contributes to educational and therapeutic processes centered on the person and family. **Aim:** Become acquainted with participation and communication aspects of children and adolescents with non-speaking CP, as well as factors that favor or hinder AAC (Augmentative Alternative Communication) use in the family environment and school. **Method:** Descriptive and cross-sectional study with a qualitative approach, with a sample of five mothers of students with non-speaking CP. **Results:** Mothers report barriers to their children's participation and recognize the importance of communication in family interactions and activities. They mention not having achieved functional use of AAC at home, but express satisfaction with the

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level of communication they have with their children. On the other hand, they address communication difficulties when they are unable to identify their children's wishes or when their children are with other interlocutors. **Conclusion:** The findings show reduced participation of the children and the adolescent in the study, as well as little or no AAC use. In view of the difficulties reported by the participants, the findings reinforce the need to equip family members, in order to promote these children's communication and participation. The importance of AAC professionals and special education teachers working in partnerships with families is reinforced. These professionals can help expand the ways in which mothers interact and communicate with their children, and vice versa, aiming at greater participation among them.

Keywords: Disabled Children; Cerebral Palsy; Language Development; Communication Barriers; Communication Aids for Disabled; Social Inclusion.

Resumo

Introdução: O conhecimento das percepções de familiares acerca da participação e comunicação de seus filhos com PC (Paralisia Cerebral) não oralizados contribui com processos educacionais e terapêuticos centrados na pessoa e na família. **Objetivo:** Conhecer aspectos da participação e comunicação de crianças e adolescentes com PC não oralizados, bem como fatores que favoreçam ou dificultam o uso da CSA (Comunicação Suplementar e/ou Alternativa) no ambiente familiar e na escola. **Método:** Estudo descritivo e transversal de abordagem qualitativa, com amostra de cinco mães de alunos com PC não oralizados. **Resultados:** As mães relatam barreiras à participação de seus filhos e reconhecem a importância da comunicação nas interações e nas atividades familiares. Mencionam, também, não terem alcançado uso funcional da CSA, em casa, mas expressam satisfação com o nível de comunicação que têm com seus filhos. Por outro lado, abordam dificuldades de comunicação quando não identificam os desejos de seus filhos ou quando eles estão com outros interlocutores. **Conclusão:** Os achados evidenciam participação reduzida das crianças e do adolescente do estudo, e pouco, ou nenhum uso da CSA. Diante das dificuldades relatadas pelas participantes, os achados reforçam a necessidade de equipar os familiares, no sentido de promoverem a participação e a comunicação de seus filhos. Reforça-se a importância de profissionais de CSA e professores de educação especial trabalhar em parceria com os familiares, a fim de expandir as maneiras como interagem e se comunicam com seus filhos, e vice-versa, visando uma maior participação dos mesmos.

Palavras-chave: Crianças com Deficiência; Paralisia Cerebral; Desenvolvimento da Linguagem; Barreiras de Comunicação; Auxiliares de Comunicação para Pessoas com Deficiência; Inclusão Social.

Resumen

Introducción: Conocer las percepciones de los familiares sobre la participación y comunicación de sus hijos con PC (Parálisis Cerebral) no hablantes, contribuye a procesos educativos y terapéuticos centrados en la persona y la familia. **Objetivo:** Conocer aspectos de la participación y comunicación de niños y adolescentes con PC no hablantes, así como factores que favorecen o dificultan el uso de la CAA (Comunicación Aumentativa y Alternativa) en el ámbito familiar y en la escuela. Método: Estudio descriptivo y transversal con enfoque cualitativo, con una muestra de cinco madres de alumnos con PC no hablantes. **Resultados:** Las madres relatan barreras para la participación de sus hijos y reconocen la importancia de la comunicación en las interacciones y en las actividades familiares. Mencionan no haber logrado uso funcional de la CAA en casa, pero expresan satisfacción por el nivel de comunicación que tienen con sus hijos. Por otro lado, abordan las dificultades de comunicación cuando no identifican los deseos de sus hijos o cuando ellos están con otros interlocutores. **Conclusión:** Los hallazgos muestran una participación reducida de los niños y adolescente en el estudio y poco o ningún uso de CAA. Los hallazgos refuerzan la necesidad de equipar a las familias para promover la participación y comunicación de sus hijos. Se refuerza la importancia de que profesionales de CAA y maestros de educación especial trabajen en colaboración con las familias para ampliar las formas en que interactúan y se comunican con sus hijos, y viceversa, buscando una mayor participación de estos.

Palabras clave: Niños con Discapacidad; Parálisis Cerebral; Desarrollo del Lenguaje; Barreras de Comunicación; Equipos de Comunicación para Personas con Discapacidad; Inclusión Social.

Introduction

Children and adolescents with Cerebral Palsy (CP) are reported as one of the population groups that are at greater risk of having their participation reduced[1]. In this sense, "participation" is defined by the International Classification of Functioning (ICF) as "involvement in life situations", which is a goal to be achieved with regard to the health of all children[2]. The sociocultural environment in which children live during childhood has a great impact on their participation in life situations, as well as their maturational and developmental factors[3]. Participation habits and patterns are based on the interest shown by children or adolescents, as well as the opportunities they have in their environment and the way they are exposed to different types of activities[4].

In the context of the concept of "activities and participation", the ICF also describes aspects of communication in its third chapter, including the production and reception of messages, and the use of communication devices and techniques[2]. The chapter details that the way children *communicate* is related to the way they *relate* to other people and *participate* in their environment[2,5,6].

In this sense, some authors[5] reported that children and adolescents with CP, and other neurological disorders, had greater restrictions in their participation than groups with other disabilities or chronic diseases. Such authors described factors that have a direct impact on the participation of a child with cerebral palsy in day-to-day activities, such as levels of functionality in the areas of cognition, communication and fine motor function.

Another study[6] showed that children with loss of communication functionality did not have participation similar to that of children in the same age group without impairments in communication functionality.

Given the importance that the communication of non-speaking individuals has on the way they participate in their environment, there is a great need to better understand the aspects of communication of non-speaking children with CP in order to expand their possibilities of communication and participation in the spaces in which they live, starting with the family context.

Recent studies in the area of communication of non-speaking children and adolescents with CP are investigating the knowledge that parents have about their children's communication. In this context, a study carried out in the USA found a close correlation between parents' perceptions about the communication of their non-speaking children with CP and the results of communication and language assessments conducted by professionals[7].

Another study[8] addressed decades of research proving the positive aspects of providing family-centered services with Augmentative and Alternative Communication (AAC) in order to maximize the results in the use of AAC, since family members know well the needs of their children and can be of great help in the development of communication children with complex communication needs.

Despite the consolidated understanding of the relevance of family involvement in therapeutic intervention and in the school inclusion process, some authors[8] discuss qualitative evidence that there is still a great gap between the principles of family-centered speech-language pathology care and the reality of its practice. In addition, a study[9] addressed the existing gaps between the philosophy of AAC care and the practice of such care by discussing the challenges faced by both family members and professionals with regard to AAC intervention services. Among the challenges reported, the authors addressed the perspective of family members that professionals do not have enough sensitivity or involvement with the family. On the other hand, professionals also report obstacles in the relationship with family members of AAC users, such as limited time to develop a partnership and collaboration work, as well as family expectations that may not be in line with the objectives of the AAC intervention. Among the biggest challenges reported by professionals, the authors report the parental conception of having efficient communication with their children, despite the use of AAC.

Some authors[10] even report that current expectations in the area of AAC have been focused on greater social participation, in the different contexts of users, whether at school, at home or in the community.

Given this scenario and context of AAC, several authors have reported the importance of knowing the perceptions of family members of AAC users, as well as the factors that may hinder or promote its functional use. It is essential to be aware of such factors with regard to the development of therapeutic objectives and intervention strategies,

which could open the way for professionals to adapt their services to the demands of each user and their family members, promoting active family participation[11-13].

Therefore, this article aims to describe aspects of participation and communication of non-speaking children and adolescents with CP in the family environment. Knowing these aspects can contribute to reinforce the role of professionals in the area of AAC, aiming at the development of a partnership and collaboration work with the family of non-speaking children and adolescents users of AAC. Several professionals, such as speech-language pathologists, caregivers, teachers, special education teachers, pedagogical advisors and other agents involved in promoting communication and participation of non-speaking students with CP, would also benefit from knowing the perceptions of families about the communication and participation of their children with complex communication needs, as well as the factors that favor or hinder the use of AAC, in a functional way, in everyday life, and its impact on their participation.

Method

Methodological Design

This study was approved by the Research Ethics Committee of Unicamp, under the Decision No. 2.847.397 and CAAE *[Certificate of Presentation for Ethical Consideration]* No. 93634518.4.0000.5404. This is a descriptive and cross-sectional study with a qualitative approach, which was developed based on the results of the Master's dissertation of one of the authors.

The study was presented to the Departments of Education of two cities in the state of São Paulo, one large city and the other medium-sized, to request the Term of Consent. After obtaining consent, the Special Education Centers of the Departments of Education provided information about students with Cerebral Palsy, users of AAC. Then, the authors contacted the schools to confirm the enrollment of the referred students and contacted the family members, with the support of the special education teacher or the pedagogical advisor.

Next, the students' family members were invited by one of the signatory researchers. After a detailed explanation of the study and consent, the family members were asked to sign the Informed Consent Form (ICF).

Sample composition and inclusion criteria

The sample consisted of 5 participants, all mothers of non-speaking students with CP. Inclusion criteria were family members of non-speaking students diagnosed with cerebral palsy who were enrolled in municipal schools in the two cities selected for the study and who used AAC at school.

Procedures for data collection

Data were collected through interviews with a semi-structured script to survey mothers' perceptions about their children's participation and communication, as well as the use of AAC, in the child's or adolescent's family context.

An acculturation interview was performed with a mother of twins with CP in order to validate the data collection instrument.

The interviews were carried out in the school environment, except for one of the students who was homeschooled. In this specific case, the interview with the mother was scheduled and held at the family's residence, after contact by telephone and authorization from the mother.

All interviews with the mothers were scheduled through the school, with the support of the special education teacher or the pedagogical advisor.

The interviews were recorded in an audio file using a mobile note recording application, as authorized by the participants.

In addition, data on the sociodemographic profile of each participant were also collected, as well as data on the level of motor function (Gross Motor Function Classification System – GMFCS) and the level of communication function (Communication Function Classification System – CFCS). The GMFCS levels were provided by the mothers based on the information and medical reports they received from their children's neurologists or pediatricians. The CFCS levels were defined by the researchers based on the mothers' answers about the level of communication functionality of their children, using the cross-cultural adaptation of the CFCS classification instrument as a reference[14].

Form of data analysis

The researchers transcribed the interviews and categorized the data according to thematic axes, based on repetition and relevance criteria. The repetition criterion investigates the similarities

between the reports, highlighting the recurring statements and considering all the emerging ones. On the other hand, the relevance criterion highlights an excerpt from the report that does not necessarily present repetition in the set of collected material, but that can confirm or refute the initial hypotheses of the investigation[15].

Finally, categories and subcategories were defined after several readings of the data, as shown in Chart 1.

Chart 1. Categories and subcategories of analysis of interviews with participating mothers

Categories	Participation of the child or adolescent and actions of the interlocutors	Communication in the family routine	AAC in the family routine
Subcategories	Participation in family activities	Child's or adolescent's own forms of communication	Use of AAC in the family
	Social interactions	Interlocutors' forms of communication	Favorable factors to the use of AAC
	Family care	Communication difficulties	Adverse factors to the use of AAC
	Clinical-therapeutic assistance	Expectations regarding the communication of the child or adolescent	

Results

The results regarding the characterization of mothers and their children, as well as their families, are shown in Table 1.

The results of the answers to the interview questions are presented by categories and subcategories:

Table 1. Demographic-educational characterization of mothers and characteristics of students

Partici-pant	Age during study	Educatio-nal level	Main caregiver?	Beneficiary of the BPC Program?	Stu-dent's code	Stu-dent's sex	Stu-dent's age (years)	Grade the student is attending	GMFCS of the stu-dent	CFCS of the stu-dent	Student's forms of communi-cation
M1	35	8th grade of PS	Yes	Yes	A1	F	7	1st Grade	V	II	2, 3, 5
M2	32	5th grade of PS	Yes	Yes	A2	F	9	2nd Grade	IV	I	2, 3, 4, 5
M3	50	5th grade of PS	Yes	Yes	A3	M	14	7th Grade	V	IV	2, 3, 5
M4	44	High School	Yes	No	A4	M	8	2nd Grade	V	IV	2, 3
M5	43	High School	Yes	Yes	A5	M	8	3rd Grade	V	IV	3, 5

Abbreviation:
*BPC: Benefício de Prestação Continuada [Continuous Cash Benefit Program]
*GMFCS: Gross Motor Function Classification System
*CFCS: Communication Function Classification System
*PS = Primary School
Forms of communication = 1: Speech; 2: Sounds; 3: Staring, Facial Expressions and Gestures; 4: Hand signals; 5: Communication binders, boards, panels; 6: Voice synthesizer.

ARTICLES

Participation of the child or adolescent and the action of the interlocutors

The results regarding the participation of the child or adolescent and the action of the interlocutors in the mothers' perceptions are shown in Table 2.

Table 2. Participation of the child or adolescent and the action of the interlocutors in the perceptions of the participating mothers (n=5)

Subcategory	No. of Reports
Participation in family activities	5
Social interactions	2
Family care	5
Clinical-therapeutic assistance	5

Participation in family activities

All mothers (*n=5*) reported reduced participation of their children in the family context. They reported that they allow their children to watch the TV for long periods of time, usually while doing other activities, as shown in the report of the mother M1: *"We don't do anything together, we just watch TV. (...)"* (M1)

The mother of participant A3, a 14-year-old adolescent, reported that one of the TVs is usually turned on to children's cartoon channels. And that there are always two televisions on at the same time in her house. In her own words:

> *"I usually put the other television like this in front of it, because this TV is on the cartoon channel. When my husband is watching the news, then he turns on the one in the living room and turns on the other one. Then I say: Mom is going to turn on the TV on Cocoricó [TV show for kids]. He likes Cocoricó, Abelhinha, Pingo... and other TV shows [for kids] like that, right?"* (M3)

In addition, two mothers (*n=2*) reported that they take their children outside, to places such as shopping malls and ice cream parlors:

> *"I go out with him and go to the mall... When there's something like that, I show him everything (...), I usually go out a lot, I go around with him (...) I told the pediatrician that I didn't give him ice cream. And she replied "You can give him an ice cream on a hot day". So, I give him ice cream, the one that is very creamy..."* (M3)
> *"Recently, I went for an açaí [Brazilian frozen açaí palm fruit] bowl with my husband. And my son took so much açaí that he even had a sore*

throat. He stood there looking at me, looking and saying "aaaa... aaa... aaaa" (...) and it was really cold." (M5)

None of the other mothers reported taking walks outside the home when asked about the activities they do as a family.

Social interactions

Two mothers (*n=2*) addressed the way in which they interact with their children, as shown in the reports of participants M1 and M3:

> *"Well... I usually play with her more when she is on the stabilizer, which is a device that she stands on. And if you don't entertain her, she won't stay. The TV stays on, but I also pay attention to her. (...). I bring the dolls, these things... (...) because TV alone is not enough to entertain her. Otherwise, she starts complaining..."* (M1)
> *Sometimes he asks for a toy when I say "Do you want to play with this?" So I get the toy and he wants it. So, he is very happy (...) and I remove the battery and turn down the sound. But he doesn't want the sound so low. He likes the sound very loud to put in his ear. So, he positions himself lying down like this all pretty."* (M3)

The other mothers did not talk about how they play with their children, and two other mothers (n=2) reported the way their children interact with other children, in family and social life, as follows:

> *"She loves to play with my niece. Every weekend, when my niece is there, they don't call me all the time. "Auntie, she wants this or that." No. My niece*

knows everything she wants. This is due to her experience with her. (M2)
"When he's enjoying something, like when he sees children, he smiles and he's like that, excited and happy." (M4)

The other mothers (*n=3*) did not address the ways in which they interact with their children or how they interact with other children, in family or social life.

Family care

A theme frequently mentioned in the interviews was the *attention and care* that families dedicate to their children, which were highlighted in a subcategory of analysis. The reports of all mothers (*n=5*) have elements that reflect the concern with comprehensive care and a holistic view of the child. The following report shows this attention and care, as well as respect for each child's way of being:

"You have to be very patient, you know? We have to pay close attention to understand them. We can't do it our way, because our way is all wrong. You have to pay close attention to them, so as not to run over everything." (M1)

Clinical-therapeutic assistance

All mothers (*n=5*) reported taking their children to weekly therapeutic follow-ups, in addition to addressing the support received in these cases. According to the participants, three students (*n=3*) attend therapeutic sessions in public institutions; while one student (*n=1*) has access to private care, thanks to a court injunction, and another (*n=1*) attends health insurance services.

As for the services, all students (*n=5*) have weekly monitoring by Speech-Language Pathology and Physical Therapy professionals; while two (n=2) attend Occupational Therapy care; one (n=1) attends private Hydrotherapy care (by means of a court injunction) and another (n=1) attends Hydrotherapy care at the APAE (Association of Parents and Friends of the Disabled) in his city. In addition, one student (n=1) has access to Equine-Assisted Therapy.

The institutions attended by the students are: public (C.1, C.3, C.5); a clinic linked to a university (C.2), private clinics (C.4), and clinics of the Health Plan (C.5).

The results regarding the distribution of the place and areas of therapeutic follow-up per child or adolescent are shown in Chart 2.

Chart 2. Distribution of the place and areas of therapeutic follow-up by child or adolescent

Child	Institution	Speech-language pathology	Physical therapy	Occupational Therapy	Hydrotherapy	Equine-Assisted Therapy
C.1	APAE [Association of Parents and Friends of Exceptional Children]	x	x		x	
C.2	University	x	x	x		
C.3	APAE [Association of Parents and Friends of Exceptional Children]	x	x			
C.4	PC	x	x	x	x	
C.5	HI and EAT	x	x		x	x

Abbreviation: C = Child; PC = Private Care; HI = Health Insurance; AEC = Campinas Equine-Assisted Therapy Association

In her report, M1 addresses the support received by the physiotherapist regarding the ideal stabilizer for the child.

"(...) on the stabilizer, which is a device that she stands on. The device that the physiotherapist wanted to use was discontinued, which is the same available at APAE. It's that entire device, where the user stands." (M1)

In turn, M2 referred to the support/guidance of the speech-language pathologist at the institution attended by the child.

The speech-language pathologist who assists us at Casa da Criança Paralítica taught us how to take the stickers (pictograms) and stick them around the house." (M2)

An example stands out about the benefits of Equine-Assisted Therapy and Hydrotherapy for one of the students. According to M5, as a result of Equine-Assisted Therapy, the child was able to develop trunk support and was able to sit down without support:

"He rides a horse. He was able to correct his posture with Equine-Assisted Therapy. And also Hydrotherapy." (M5)

This mother also discussed the use of Parapodium, for unloading weight on the legs and pre-venting hip dislocation. She received the necessary support from her son's physiotherapist to make the Parapodium.

"He stands on the Parapodium every day. Thank God he never had a hip dislocation." (M5)

Communication in the family routine

The results regarding the communication in the family routine n the mothers' perceptions are shown in Table 3.

Table 3. Communication in the family routine in the perceptions of participating mothers (n=5)

Subcategory	No. of Reports
Child's or adolescent's own forms of communication	5
Interlocutors' forms of communication	5
Communication difficulties	5
Expectations regarding the communication of the child or adolescent	5

Child's or adolescent's own forms of communication

All the mothers (*n=5*) reported different ways of communicating with their children, such as: star-ing to express desires; indicative gestures (move-ment of hands, arms and head); home gestures (hair pulling, clapping hands, changes in muscle tone), among others, such as: vocalizations, screams, smiles, cries and grumbles, to which the family attributes meaning, as can be seen in the examples of each of the participants:

"She draws attention by making little noises, you know? And so we end up realizing what she wants. When she wants to go to the bathroom, she stiffens her legs like this, and her expression also changes." (M1)

"She speaks with her eyes, you know? She speaks with her eyes. She does this when she wants some-thing (showing how the child looks at what she wants). *Sometimes she screams, a scream comes out. And that means there is something she doesn't want. When she gets mad, she throws tantrums, kicks, pulls hair... That's how she reacts."* (M2)

"The other day, he took my hand so I could take my cell phone and play the music he likes." (M3)

"When he's enjoying something, like when he sees children, he smiles and he's like that, excited and happy." That's the way he is, he makes some little sounds... Ãh, ãh..." (M4)

"He cries, he groans, he smiles, he claps his hands and he screams... 'aaaaaa' (...). When he wants something, he opens his mouth, but not to speak. So, as I live with him, I already know everything he wants." (M5)

All mothers (*n=5*) reported the use that their children make of "expression" when they want to call the interlocutor's attention or express their desires.

Three mothers (*n=3*) reported the use of gestures in the child's communication attempts, including hair pulling, pushing, clapping and hold-ing objects.

All mothers (*n=5*) addressed how their chil-dren use different vocalizations and sounds in their own forms of communication, such as screaming and mumbling.

M1 also reported that the child is able to say the caregiver's name at school, whose nickname resembles the father's name. This same child can also say her brother's name.

Interlocutors' forms of communication

All mothers (*n=5*) communicate with their children orally. According to their reports, their children understand the speech of communication partners without difficulties.

All mothers (*n=5*) describe some ways they make sure of their children's wishes when they are in doubt: they ask more than once to confirm

the answer; they ask different questions (trial and error) until the definition of what the child wants; they show objects so that the child confirms what he/she wants; they wait until the child confirms, through a smile or head movement.

Two mothers (*n=2*) said they have pre-established times for meals and for offering water to the children. In these cases, they don't offer options, they just inform their children that they will feed them or give them water.

> *"I speak normally as if I were talking to my other child. I know she understands me because she keeps watching me. Then I know she understands me."* (M1)
>
> *"I believe I understand everything she says. Sometimes, she makes fun and that can make it a little difficult to understand, so I ask twice, so I can understand..."* (M2)
>
> *"I set a specific time. And that's when he eats and when he drinks water. So he doesn't get hungry or thirsty either."* (M4)

Communication difficulties

All mothers (n=5) reported some type of difficulty communicating with their children and their communication with other interlocutors, as shown by the following examples:

> *"Sometimes I give her what I think she wants, but she keeps asking for something. That's how I get lost sometimes. Because I think she wants something, but she wants something different."* (M1)
>
> *"It's rare for her to leave the house without me. Other people won't know what she wants or doesn't want. For me, it's very difficult for her to leave without me. Because I always want to be around so*

I can say what she wants, what she doesn't want. But I have to let her go her own way, right?" (M2)

Expectations regarding the communication of the child or adolescent

All mothers (*n=5*) shared expectations of the most diverse levels in relation to their children's communication, from the expectation that children would be able to point something out accurately to the expectation that they would develop functional speech.

> *"I hope she can point something out. That she can point out what she wants, which is something she still can't. And I hope she can talk... Sometimes I don't know if it's because we want to listen so much, and end up hearing something, or if she really talks."* (M1)
>
> *"I want to see her being able to read and write. Even if she doesn't know how to write, but she could read and communicate more with others."* (M2)
>
> *"My biggest wish is for him to be able to walk and talk. They told me he won't be able to walk. But they never said he won't be able to speak. And I believe he will be able to speak."* (M3)
>
> *"I'm aware of his condition, but... If he could only speak a few words, that would be fine with me."* (M4)
>
> *"... she keeps asking, asking, and asking for something. So I say 'M., if you could only say what you want...'"* (M1)

AAC in the family routine

The results regarding the AAC in the family routine n the mothers' perceptions are shown in Table 4.

Table 4. AAC in the family routine in the perceptions of participating mothers (n=5)

Subcategory	No. of Reports
Examples of the use of AAC in the family	5
Favorable factors to the use of AAC	3
Adverse factors to the use of AAC	4

Use of AAC in the family

All mothers (*n=5*) reported being aware of some low-tech AAC resource. Four of the mothers (*n=4*) gave examples of using the AAC at home, at times, even though they discontinued its use.

> *"They taught me how to use it (the AAC) there (in the Casa da Criança Paralítica). They told me to ask her and show her the picture of the bathroom:*

> *"Look at this, do you want to go to the bathroom?" Teaching her in this way to understand what the bathroom is. Or "Do you want to eat?" "Shall we play with dolls now?" Or Barbie?"* (M2)
>
> *"He pays attention when I go to get a picture of anything, like a fruit. One of these days, there were a lot of cashews, bananas, so I showed him a lot of things, like the colors, and he likes all the colors.*

And I could see that he paid attention to everything. To all drawings." (M3)

One mother (*n=1*) discussed the use of the "yes" and "no" symbols by her son, who points them out on the communication board, as shown below:

"Raise your hand (to point YES and NO on the communication board). *Sometimes he raises his hand. Sometimes he just gives a little touch like that on the hand. Then we already know that he wants to raise his hand. But he only gives a little touch with his hand. A small movement, like moving his little fingers."* (M4)

Favorable factors to the use of AAC

Three mothers (*n=3*) also addressed favorable factors or perceived benefits of using AAC in their children's social contexts.

The report of one of the mothers (M2) shows that she is aware that the AAC can help the child to express their choices autonomously:

"She doesn't eat with her father, she doesn't eat with anyone. She only eats when she is with me and my nephew. It would be easier to ask what she wants to eat. But I say the options and she says 'yes' or 'no'. But it's good for her to know what kind of fruit, things like that, so she can choose. So I don't choose what to give her. Other people won't know what she wants or doesn't want. So I don't force her to eat what I chose and that's it, right? (...) As for the bathroom, too. I think it would help. Because I really want her not to wear diapers anymore. So if she could say "I'm going to the bathroom now"...". (M2)

The following examples are related to the perceived benefit in the areas of focus, attention or visual-motor coordination of students with the use of the AAC:

"It's good because he's paying attention to the figure there. Then he looks at it... (...) It's good, you have to show him. A picture, a drawing, starting a conversation..." (M3)

"It helps with vision and stimulation. I've already made many figures with him (...) when he was very small, he was sent to CAIS, and we did the visual stimulation. We used figures a lot. Because his eyesight had a little problem... In his eyesight." (M5)

Adverse factors to the use of AAC

Four mothers (*n=4*) referred to some type of factor that did not favor the use of the AAC at home, or on the perception that they did not need to use the AAC at home, as follows:

"Oh, I don't know... I think she understands me. And I understand her, so I don't need it. I get kinda lost. I get lost if I use this. I have my way of communicating with her, just like all nieces do too. It is more difficult for uncles and grandparents to communicate, it is difficult..." (M2)

"My husband doesn't know anything about that." (M3)

"He doesn't know how to use it, to point at something." (M4)

Pointing to something is difficult. He doesn't always do that. Perhaps another resource will work better for him. This depends on the options that are created. Just like the tablet, for example..." (M5)

One mother (*n=1*) did not answer this question, since she never used AAC with her daughter at home, although the child used it at the institution and at school. Her comment reflects that she is unaware of any AAC resources. And she believes that this lack of knowledge is due to the constant change of speech-language pathologists at the institution attended by her daughter (APAE). According to the mother, the speech-language pathologist who assisted the child would start introducing AAC, but there was a change in the staff of APAE professionals and the new speech-language pathologist uses a different therapeutic approach. In addition, the mother reported that the child had seen a total of three different professionals in less than 5 years.

"The speech-language pathologist was going to start working with this resource (AAC), but then they changed the professional again. The speech-language pathologist was changed. They removed the speech-language pathologist who worked there and put in another one. Then my daughter started working with other things. She started from the beginning with M, but then this professional who was with her also left. Then she went back to working with the former professional, with the first one to assist her." (M1)

Discussion

The findings show that there is still very little participation of children and adolescents in family activities, and that this participation is limited to long periods of exposure to television in the same room as some family members. These results are in line with data from studies that show the risk of reduced participation among children and adoles-

cents with CP[1,5,6]. It should be noted that, due to the passive role that children and adolescents play in periods of exposure to TV, the habit of watching television does not constitute an activity that involves the participation of the family. However, the participating mothers believe that this is a way in which they participate in activities at home, since, at times, they talk and interact with the children during periods of exposure to television, either to confirm the choice of show or to comment on what they are watching. Only two mothers reported that they take their children to some kind of outing, such as shopping malls and ice cream parlors, and even so, these same mothers allow long periods of exposure to TV when they are at home. The other mothers did not report taking their children outside. In all cases, reports show limited or reduced participation in their routines.

The acceptance of the invitation to participate in the research by only the children's mothers is in line with other studies that show that the role of caregiver of the disabled person is centered on the mother figure in most Brazilian families[16-18]. It should be noted that, in most cases, as found in studies, the mother is not only the main caregiver, but is also responsible for housekeeping, preparing meals for other family members, among other responsibilities. Naturally, this situation overloads the mother as a caregiver, which can affect the quality of interactions and care provided to the child with a disability[19].

The results about how mothers know their own forms of communication used by their children and the ways they develop to communicate with each other are in line with findings from studies that point to the level of knowledge of parents of non-speaking children with CP about their own forms of communication, as well as reinforce research data that describe how parents of non-speaking children with CP develop successful ways of communicating with them[7]. However, if on the one hand, the mothers participating in the study claim that they understand their children; on the other hand, there are contradictions in their reports when they state that they cannot always accurately identify their desires or understand them "to a certain extent". These results reinforce the importance of introducing the AAC in order to expand the child's communication, as recommended by authors[20] who advocate that children be exposed to various AAC resources in a timely manner so that the AAC favors the organization of their language structures and expands their communication possibilities.

One study[21] detailed the importance of better describing the forms of communication of non-speaking children with complex communication needs. The use of staring, for example, which is recurrent in the students of this study and in several children with severe motor impairment, has already been listed as a very important form of communication that still requires a clinical description that is universally applicable to all these children. According to the authors[21], the child who stares at something and begins to look to highlight different points of interest in the environment, does so with the knowledge of the interlocutor and uses it as an efficient strategy for the construction of the message. However, AAC support can further favor the language, interaction and participation of these children, since it is capable of expanding their communication possibilities, as well as increasing the number of communication partners with whom they interact, beyond the familiar context. Interlocutors who do not live with the children do not always understand them, as they are not familiar with their own forms of communication, and this further restricts the communication partners with whom these children and adolescents interact and the activities in which they participate, without the presence of the mother. These results are in line with other studies[22] that claim that many of these children have communication intentions, but their interlocutors do not always understand the message.

The findings of this study also show a gap between the expectations of mothers and professionals, regarding the development of the communication of these students. This gap can be observed in the reports of mothers who show difficulties in using the AAC at home, although professionals from institutions and clinics have encouraged its use in everyday life, according to their reports. A study[9] that investigated this gap from expectations of family members and professionals highlighted the importance of involving the family in the therapeutic process, in order to optimize the development of communication and use of AAC among non-speaking students with CP[8]. The mothers' reports reinforce the importance they give to their children's power of choice and the desire for them to have greater autonomy and expand communication with other interlocutors.

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But, although they have this intention, on the other hand, they express difficulties in the functional use of the AAC to expand their children's communication, interaction and participation. These results reinforce the conclusions of authors[23] who claim that professionals are also responsible for promoting listening, welcoming and training of family members of AAC users to perform their roles as interlocutors. Some mothers reported this type of support, while others resent and express lack of continuity or support from professionals. The difficulty in the functional use of the AAC that was observed in the mothers' reports reinforces the importance of care in the selection of Augmentative and Alternative Communication resources, which can contribute to the social inclusion of children.

Still with regard to the gap between therapeutic practice on the use of AAC, and the child's daily practice, the findings reinforce the need for professionals who work with AAC to establish therapeutic goals and intervention strategies that are better aligned with the demands of each user and their family members, while at the same time reinforcing the need for a closer and continued partnership between professionals and family members, as observed by researchers[11-13].

The findings reinforce what was pointed out by authors[24] on the occasion of the 25th anniversary of ISAAC (International Society for Augmentative and Alternative Communication), that is, that even though the possibilities for individuals with complex communication needs are already known, the next challenge would be to expand this possibility to millions of individuals with complex communication needs and their families around the world. Given that these children and adolescents have not achieved functional communication and their participation is restricted, this reiterates the need for greater dissemination of the AAC among family members of children and adolescents with complex communication needs, in order to expand their possibilities of communication, interaction and participation.

Conclusion

The findings show that there is still very little participation of children and adolescents in family activities, and that this participation is limited to long periods of exposure to television, with few outings and little diversification of activities, in most cases.

Thus, although these students have used or are using AAC at the institution they attend or at school, the results show that mothers rely on their children's own forms of communication and do not apply a functional use of AAC at home. Given that the family is an essential group of interlocutors, it is necessary to have a close partnership between family members and professionals in the field of AAC in order to develop in family members an attitude consistent with the functional use of AAC at home, as well as the necessary skills to do it effectively.

In addition, the knowledge that family members have about their children's forms of communication is also essential, so that family members can attribute meaning to their children's forms of communication, and can expand the communication possibilities of these children and adolescents and get to know their desires and preferences in more depth.

In this context, knowledge about the ways in which children and adolescents communicate, combined with work in partnership between family members and professionals in the AAC area, can further contribute to the participation and social inclusion of these students.

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