



# Individualized program of alternative communication for mothers of children with cerebral palsy without oral communication

Programa individualizado de comunicação alternativa para mães de crianças com paralisia cerebral não oralizadas.

Programa individualizado de comunicación aumentativa y alternativa para las madres de niños con parálisis cerebral

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## Abstract

**Introduction:** Children with cerebral palsy, in which disorders of cognitive, communicative, perceptual and sensory-motor nature may be present, can benefit from additional and/or alternative communication. **Objective:** To evaluate an Individualized Program of Augmentative and Alternative Communication for mothers of children with Cerebral Palsy without oral communication. **Method:** The participants in this study were three mothers and their children, diagnosed with Cerebral Palsy without oral communication. The Multiple Baseline Design across individuals was used and the experimental procedure involved three phases: baseline, intervention and follow up. **Results:** The results demonstrated that children with cerebral palsy showed improvements in communication skills and made use of alternative communication procedures successfully. There was an increase of expressive skills by non oralized means; attention span and the active participation of children in dialogic activity with their mothers were evident. **Conclusion:** By the intervention, the mothers' repertoire was significant and they had an excellent performance using the communication resources and a strong performance by children to communicate their wishes by figures means. The procedures used, demonstrated increased children

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interaction and communicative autonomy.

**Keywords:** Communication Aids for Disabled People; Family; Special Education.

### Resumo

**Introdução:** Crianças com paralisia cerebral, na qual desordens de natureza cognitiva, comunicativa, perceptiva e sensório-motora podem estar presentes, podem se beneficiar da comunicação suplementar e/ou alternativa. **Objetivo:** avaliar um Programa Individualizado de Comunicação Suplementar e/ou Alternativa para mães de crianças com Paralisia Cerebral não oralizadas. **Método:** Os participantes desta pesquisa foram três mães e seus respectivos filhos, com diagnóstico de Paralisia Cerebral não oralizada. Foi utilizado o Delineamento de Linha de Base Múltipla por Indivíduos e o procedimento experimental envolveu três fases: linha de base, intervenção e followup. **Resultados:** Os resultados mostraram que as crianças com paralisia cerebral apresentaram melhoras nas habilidades comunicativas e fizeram uso de procedimentos de comunicação alternativa com sucesso. Houve aumento das habilidades expressivas por meios não oralizadas; o tempo de atenção e a participação ativa das crianças na atividade dialógica com sua mãe ficaram evidentes. **Conclusão:** A partir da intervenção, o repertório das mães mostrou-se significativo e houve um excelente desempenho das mesmas em utilizar os recursos de comunicação bem como um desempenho expressivo por parte das crianças em comunicar seus desejos por meio das figuras. Os procedimentos empregados evidenciaram aumento da interação e autonomia comunicativa das crianças.

**Palavras-Chave:** Auxiliares de Comunicação para Pessoas com Deficiência; Família; Educação Especial.

### Resumen

**Introducción:** Los niños con parálisis cerebral, en la que los trastornos del desarrollo cognitivo, comunicativo, de percepción y de la naturaleza sensorial - motor pueden estar presentes pueden beneficiarse de la comunicación adicional. **Objetivo:** Evaluar un Programa Individualizado de la Comunicación Alternativa para las madres de niños con parálisis cerebral. **Método:** Los participantes en este estudio fueron tres madres y sus niños con un diagnóstico de parálisis cerebral sin lenguaje oral. Delimitación de la línea de base múltiple fue utilizada por individuos y el procedimiento experimental comprendió tres fases: basal, intervención y seguimiento. **Resultados:** Los resultados mostraron que los niños con parálisis cerebral mostraron mejoras en las habilidades de comunicación y hicieron uso de procedimientos alternativos de comunicación con éxito. Hubo un aumento de las habilidades expresivas por medios sin lenguaje oral, la capacidad de atención y la participación activa de los niños en la actividad dialógica fueron evidentes con su madre. **Conclusión:** Tras la intervención, el repertorio de las madres era importante y había una gran actuación de ellos a utilizar los recursos de la comunicación alternativa, así como un buen comportamiento de los niños a comunicar sus deseos a través de figuras pictográficas. Los procedimientos mostraron una mayor interacción y autonomía comunicativa de los niños con sus madres que se expresan de manera más independiente.

**Palabras clave:** Comunicación Ayudas para personas con discapacidad, Familia, Educación Especial.

## Introduction

Research indicates that there is a growth of disabled child's family involvement in the field of Special Education with emphasis on the relationships that occur in the family microenvironment<sup>1-2</sup>.

The family microenvironment is essential for the child's communicative development, because it represents one of the most basic contexts in social interaction, characterized by stable and significant interpersonal relationships<sup>3</sup>. In this sense, communication becomes an important resource for child's development since children acquire communication skills and relate to others<sup>4</sup>.

Mother, father and other family members play a key role as partners in the insertion and child adjustment in different social environments and thereby, contribute to the promotion of their own development. In the Augmentative and Alternative Communication (AAC), the parents' participation in the therapeutic process is evidenced mainly in the care of children with cerebral palsy, in which disorders of cognitive, communicative, perceptual and sensory-motor nature may be present<sup>5</sup>.

In recent years, studies in the speech therapy field, special education, psychology, occupational therapy among other related areas, sought to investigate how the family members of children with cerebral palsy accept and use the AAC.

The results of this research revealed that parents know the communicative profile of their children<sup>6</sup>; demonstrated that family members recognize the need to use alternative sources of communication<sup>7-8</sup> and showed the importance in empowering parents and caregivers to the widespread use of these resources in different social environments<sup>9-10</sup>.

Looking for continuing the research already carried out in this field on that theme, it is remarkable the relevance to describe on the mothers participation process in the design, implementation and choice of supplementary and/or alternative communication resources for their children.

Considering the AAC an essential resource for children with severe disturbances in oral and written communication, and by the need to invest in new research, using the familiar partnership, it is hypothesized that AAC programs promote communicative autonomy of these children.

Note that this research presents part of a dissertation, which aimed to design, implement and evaluate a AAC Individualized Program for mothers of children with cerebral palsy<sup>11</sup>. As part of this larger study, this paper aimed to evaluate an Individualized Program of Augmentative and Alternative Communication for mothers of children with Cerebral Palsy without oral communication.

## Method

This study was conducted after receiving a favorable opinion by the Ethics Committee of UFSCar, under Resolution 196/96 under number 444/2011.

### 2.1 Local

The survey was conducted in a clinic-school, of a higher education public institution located in a city of São Paulo state.

### 2.2 Participants

The participants in this study were three mothers, called participating family (Pf) and their children, diagnosed with Cerebral Palsy without oral communication, called participating children (Pc).

Table 1 reflects the characterization of the participating family. Participants were three mothers, whose average age was 41 years old. Level of education shows variation between the lowest level of education - Complete High School and the highest Higher Education Incomplete. Regarding the number of children, only a mother has 1 child, and the other participants have two and five children, respectively. All participants work in their own homes, and in relation to socioeconomic class, two families were from B1 class and one family from B2 class.

Table 2 reflects the characterization of the participating children. Participated in this research 3 children, one male and two females, whose average age was 8 years old. Studying the medical records, hearing, vision and cognition of children were found as normal. Only one of the children does not attend school, and between the two children who attend school, only one child attends school in the regular classroom.

**TABLE I** - Participating family (pf) characterization

Participating family (Pf)	Age	Educational Level	Number of Children	Profession	Economic classification criterion
Mother1	40	Complete Secondary School	1	Housewife	B 1
Mother2	48	Incomplete Elementary School	2	Housewife	B 2
Mother3	34	Incomplete High School	5	Housewife	B 1

**TABLE II** - Participating children (pc) characterization

Characteristics	Participant 1	Participant 2	Participant 3
<b>Age</b>	8 years old	12 years old	4 years old
<b>Gender</b>	Female	Male	Female
<b>Diagnosis</b>	Cerebral Palsy	Cerebral Palsy	Cerebral Palsy
<b>Hearing</b>	Normal	Normal	Normal
<b>Vision</b>	Normal	Normal	Normal
<b>Cognition</b>	Normal	Normal	Normal
<b>GMFCS</b>	Level IV	Level V	Level IV
<b>School</b>	Goesto regular school	Goes to special education school	Doens't go to school

### 2.3 Data collection instruments

In order to collect all the information to reach the research objective, the following instruments were used. **1. Cerebral Palsy Rating Scale: the Gross Motor Function Measure Classification System – GMFCS** aimed to make the motor classification of the participating children<sup>12</sup>. **2. Characterization of Participating Family Protocol:** aimed to describe the characteristics of participants such as gender, age, educational level and profession<sup>11</sup>. **3. Children Characterization Protocol:** aimed to describe the characteristics such as gender, age, education level, type of school

they attend and clinical diagnosis<sup>11</sup>. **4. Analysis of baseline sessions, intervention and follow up Protocol:** aimed to analyze the baseline filming, intervention and follow-up, which was prepared by the researcher based on Bondy and Frost<sup>13</sup>. **5. Selection of Figures Protocol:** selected by mothers' reporting, figures of the children's interest<sup>11</sup>. **6. Economic Classification Criterion of Brazil:** aimed to measure the family income and classify the population in five socioeconomic classes. **7. Behavioral Observation Protocol:** aimed to analyze the communication skills of children before and after the intervention<sup>14</sup>.

## 2.4 Materials e equipments

The equipment used were: computer, video camera, camera, EVA sheet, contact paper, spiral, plain leaf notebook for information continuous registration, photos, illustrations and graphic symbols from Boardmaker software.

## 2.5 Study design

To check the intervention program effects the Multiple Baseline Design across Individuals was used. This is an experimental design of single individuals that compares the subject with himself. For this design at least three subjects are needed to demonstrate that the behavior of each subject only changes when the intervention is applied.

Although this design is placed in the experimental analysis of behavior context, it has been used in education and health areas to assess the different types of intervention effects. Therefore, intervention with each subject at different times is to demonstrate the effects of the independent variable on the dependent variable<sup>15</sup>.

The experimental procedure involved three phases: baseline (BL), intervention (I) and follow-up (FU).

The BL sessions recorded the initial repertoire of mothers in offering an activity for children through pictographic figures of alternative communication, and, consequently, also described the initial behavior of children in relation to express any interest or mention about getting the pictographic figure provided by the mother.

The intervention phase aimed theoretical training, practical training, implementation and use of the supplementary and/or alternative communication by mothers. At this stage, the researcher carried out the intervention, encouraging mothers to offer objects for children and concomitantly the researcher taught the mothers how to use the pictographic figures, i.e., present a concrete object for the child, show the purpose of it, to compare this to the pictographic figure and ask the child if she wants that object. For this, some of the activities that were performed at baseline were also used in the intervention phase.

The follow-up phase aimed to observe whether the behaviors taught to mothers were kept and perform maintenance of them. Finally, this step also measured the children communication skills responses.

<sup>15</sup>The protocol was completed by a research assistant graduated in speech therapy through the shoot analysis

## 2.6 Collection and data analysis procedures

Data collection and analysis involved three steps:

**Step 1: of the Participants characteristics knowledge** - After contacting the participants and them accepting to participate in the research, the GMFCS was applied in the participating children (Pc) and thus identified the gross motor function classification of each child. Then, the two protocols Participating Family Characterization (Pf) and Participating children (Pc) were applied, with sole and exclusive purpose to characterize the participants as age, gender, level of education and others. Finally, the Behavioral Observation Protocol was used to detect the children communicative functions before the intervention<sup>i</sup>

**Step 2: Intervention-** This step was to perform with the participating family members in the first instance the *Mimes Dynamics*, and in a second stage, the participants practical training/qualification. The theoretical training consisted of a lecture to the participants about supplementary and/or alternative communication, conceptualizing the theme, its implications and objectives of alternative communication resources. The training happened through a presentation of explanatory slides made through *Microsoft Office Power Point* and rack. This material was prepared by the researcher and was named *Manual of Individualized Program of Augmentative and Alternative Communication for Children with Cerebral Palsy*<sup>11</sup>.

After these steps, the practical training of the participants was realized, in which the family members learned to use through the computer the *Boardmaker software* to select and develop a communication folder for their children. For this step we used the figures selection Protocol drawn up by the researcher in order to select items from the center of each child's interest, reported by the participating family in order to make the communication board.

After selecting all the pictures on the *Boardmaker Software*, the communication board was made by the researcher according to the specific needs of each child. The board was given to the child to use it in different social contexts.

Finally, the researcher conducted the intervention helping the mother to offer objects for the child and concomitantly using pictographic figures and the communication board.



### Step 3: Program Effectiveness Evaluation

– At this stage, all the filming was evaluated through the use of the baseline sessions analysis protocol, intervention and *follow up*. This protocol evaluated the mothers' and children' behavior to situations and proposed activities. The Behavioral Observation Protocol was reapplied to detect the communicative functions of children after the intervention.

## Results

The results were derived from a post graduate work at Masters level and represent part of the data indicated in collection procedures. Data were collected during one year and showed: a) the participating family performance using alternative communication, b) the performance of the participating children to communicate their wishes, needs and center of interest by alternative communication resources means and c) participating children acquisition of new communication skills.

The results of this research were organized in two phases: Phase I presents *Mothers and Children Performances data and Phase II presents the Communication skills of children before and after the intervention*.

### Phase I

This phase aimed to describe mothers and children performance during the course of the baseline, intervention and follow up.

Figure 1 represents the total number of baseline sessions, intervention and follow-up for each participant.

According to Figure 1, P1 required 3 baseline sessions, P2 was exposed to 5 sessions, P3 required 7 baseline sessions. At this stage, the participants reached stability to be exposed to the intervention sessions by the sum of the resources used by mothers to provide an activity for the child.

The intervention phase was composed by theoretical training, practical training and mothers intervention, that is, the total participants (P = mother + child) P1 were exposed to 19 intervention sessions, the P2 required 10 intervention sessions and P3 were exposed to 13 intervention sessions. However, all participants had three follow up sessions.

The proposed activities and games were planned in advance according to the individual characteristics and of each participating child center

of interest, and these data were raised through the Child's characterization Protocol and figure selection Protocol completed by the children' mothers.

The mothers' scores were described in two behaviors: appropriate and inappropriate. For this research it was considered appropriate behavior every time the mother gave opportunities for her child, that is, the mother offered the activity for the child and waited 15 seconds for the child to express her will and the child replied; and inappropriate behavior every time the mother only offered the activity without giving time for the child to express her will.

Baseline sessions, intervention and follow-up were developed in order to observe the behaviors: mothers offering an activity for children through alternative communication figures and children demonstrating their willingness to perform the activity or not.

Figure 2 showed the percentage score calculated by the protocol for baseline sessions analysis, intervention and follow-up.

By figure 2, we found a discrepancy between the appropriate and inappropriate behaviors scores in the baseline sessions. It is observed that all mothers got high score in inappropriate behavior in the baseline sessions. This event is due to the fact that they offered activities for their children "mechanically", giving no opportunity for children to express their wishes, that is, they were not aware on how to use alternative communication figures.

In contrast, the low score of mothers in appropriate behaviors in the baseline sessions was due only to mothers offering activities for their children, waiting 15 seconds for the children to give the answer, but when the children did not respond, mothers did not give any support to help them.

The mothers' lack of understanding during conversations, with the children without oral communication, absence of alternative resources for communication, and the lack of training of the family to use pictographic figures of communication during conversations with their children were measured factors in the baseline of this research.

Regarding the intervention process, it is noteworthy that there was a decrease in this discrepancy, i.e. the inappropriate behaviors were decreasing and the appropriate behaviors were increasing in the intervention course.

Regarding the beginning of the intervention, it was noted that appropriate behaviors of the mother

1 and mother 3 had a significant increase between the first and second intervention session. This score does not meet mother 2 data, because this participant has missed the intervention between session 1 and 2. According to the picture, the scores of appropriate behaviors in the intervention process of mother 2 begin to stabilize in the intervention session 3.

Despite inequality from the baseline data and the beginning of the intervention data, it was noted in Figure 2 that the follow up data remained stabilized according to the latest intervention process data.

Data from the baseline process, intervention and follow-up have been essential to the understanding of this study design, as they showed that when the baseline stabilized mothers were not aware of how to use alternative communication figures and this corresponded to the higher scores of inappropriate behavior; when started the intervention process there was a significant reduction in the data of inappropriate behavior and the appropriate behavior increased, i.e. the increase in appropriate behavior is directly related to the intervention process with the mothers and, finally, data stabilized in the follow up sessions, showing that the behavior was learned in the intervention and maintained after the intervention.

Figure 3, below, represents the percentage score of children according to the mothers' appropriate behaviors, respectively. For example, a mother had 10 of proper score and the child had 3 points, meaning that the child answered 30% of what the mother offered her.

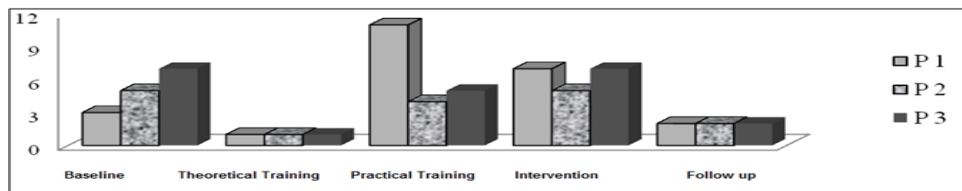
By analyzing the filming, and relating it to Figures 2 and 3, it was noticeable that in the baseline sessions the mothers' score of appropriate behaviors was low hence the children's answers as well.

This data can be justified reassessing figure 2, as in the baseline inadequate behaviors prevailed. Appropriate behavior was the limiting factor causing children reach low score because they could not express their wishes.

From Figure 3, it was possible to note the influence of mother's appropriate behavior on the child's response. Furthermore, by analyzing the filming it was noted that children sent some answers to the mothers as looking, body movement or smile, but mothers did not understand and continued giving opportunities "mechanically" (without considering the possible meanings of these gestures) for children. This fact has made the appropriate behaviors of mothers remain low.

Comparing Figure 2 to Figure 3, it is noted that in the intervention sessions, the child scores increased, when the appropriate mother's behavior score was rising and the scores of inappropriate behavior decreased or stabilized. This data can be understood because in the intervention mothers participated in theoretical and practical training on the topic of alternative communication; and were also empowered to use pictographic figures with their children.

Finally, the same result obtained in the intervention stage remained in the follow up sessions due to the mothers' and children's scores stabilization. About this result, it can be seen that mothers



**Figura 1** – Representation of the total number of baseline sessions, intervention and follow-up

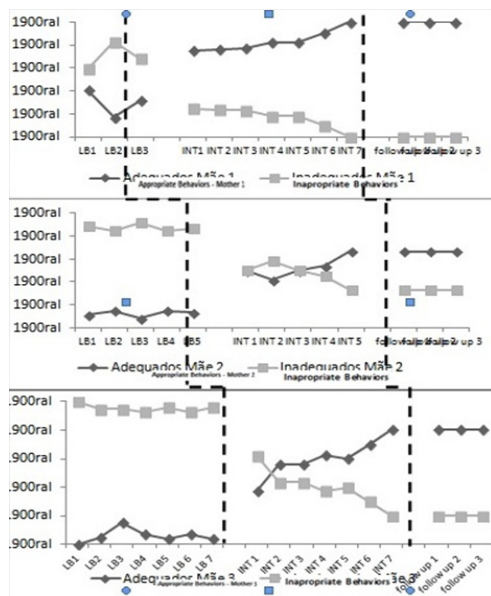
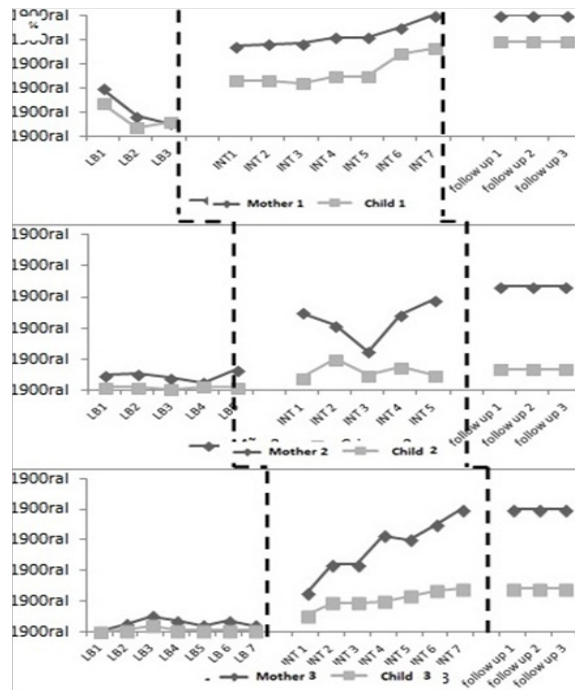


Figure II - Score intended to mothers at baseline, intervention and follow up sessions





**Figure III** - Score in percentage of appropriate behaviors of mothers and children’s responses

were able to generalize the intervention step learning to the follow up step.

### Phase II

This phase aimed to describe the *Children communication skills before and after the intervention* by applying the Behavioral Observation Protocol. The protocol has three areas, but in this study we used only the area of communication skills, including items 1.a – dialogical skills (maximum score of 20 points) and 1.c – communication means (maximum score of 20 points for gestures and verbal means).

Figure IV is the score of dialogical skills before and after the intervention. The first subsection dialogical skills aimed to verify the presence of intentional communication and the children involvement in communicative exchanges.

About the subsection *First Place* it can be seen by Figure IV that before the intervention only child 1 and the child 2 started a conversation with low frequency; with the intervention these children started a conversation often and the child 3 started a conversation.

Data revealed that in subsection *Responds to Interlocutor* only the first child responded to the caller before the intervention, however, with the intervention, it was noted that the child 1 and child

2 began to often respond to the caller and the child 3 began to answer to the other party.

Figure IV provided important data regarding the sub-item *Wait your Turn*. This subsection described wait your turn conceptualizing the child does not precipitate interrupting the speaker. Before the intervention all the children waited for their turn, but with the intervention it was possible to notice that the child 1 didn't wait his turn anymore interrupting the speaker during a dialogue. Children 1, when observing the figure on the communication board, started interrupting the speaker naming the figure through vocalizations and verbalizations, and also intended to catch the figure not waiting for the mother's verbal command. This data refers to a meaningful, effective and autonomous communication.

Regarding the sub-item *Participates Actively* of Dialogic Activity, the data revealed that before the intervention, only child 1 and child 2 participated in the dialogue activity. With the intervention implementation, in contrast to these data, child 1 and child 2 began to participate frequently in the dialogical activity in an active way, and child 3 rarely participated actively.

Through figure IV, it was noted that with the intervention implementation children had a

significant increase in the score of the dialogical skills, mainly in sub-item *Wait your Turn*.

Figure V conceived the communication means score before and after intervention. The protocol described the communication means as verbal and nonverbal means. According to the protocol, non-verbal means are characterized by the use of vocalizations and gestures. The verbal means are characterized by the use of single words.

Through Figure V, it was possible to note that the non-verbal means were used by all children before the intervention. The first child got a point by using vocalizations and all children got a point by using gestures.

After the intervention, in the item non-verbal means, the first child got two points and child 2 and child 3 got one point. Even in non-verbal means - use of gestures, child 1 got five points; child 2 and child 3 got two points. It is observed that only child 1 started to use verbal means of communication after intervention, reaching nine.

Finally, this phase showed that the implementation of Alternative Communication Program for Mothers of Children with Cerebral Palsy without oral communication was effective and favored the interaction expansion and acquisition of new communication skills of children participating in this study.

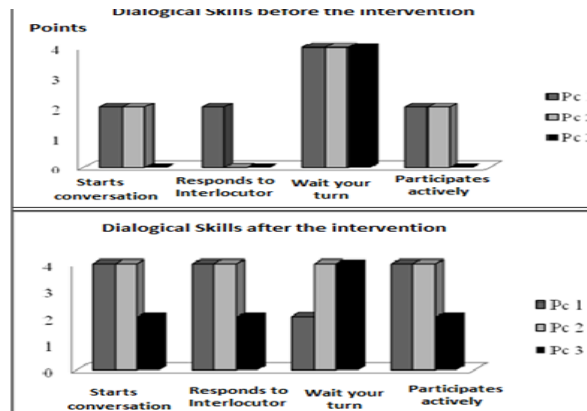
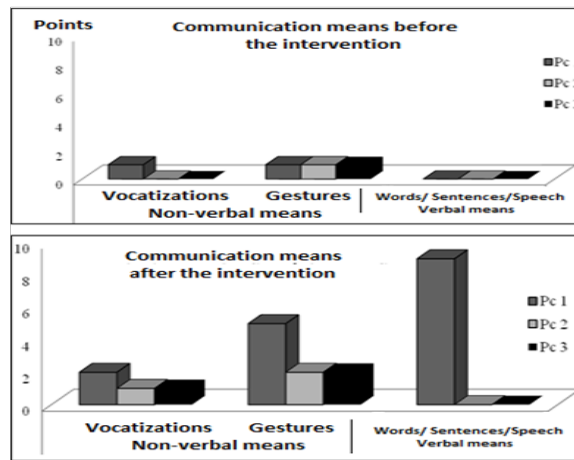


Figure IV - Score from dialogical skills before and after intervention



**Figure V** - Score of the means of communication before and after intervention

## Discussion

Despite the positive results, some limitations were found throughout the study hindering the participants' commitment of the frequency, such as: participants' absence in attendance, holidays, lack of public transportation to bring the child to the institution, health problems of the child as colds, flu and respiratory problems.

Other factors that limited the study were the lack of a control group of mothers or children, and data collection being held by the responsible for the intervention. Also specific limitations were found in relation to the mothers' behavior, such as low educational level, and difficulty using the computer.

Despite the limitations, this study provided important information for the use of alternative communication resources with mothers of children with cerebral palsy. Although the intervention process has been permeated by many complications, all study participants were successful in the use of alternative communication resources.

During the baseline process, intervention and follow up it was decided to use play activities. These activities are essential for the development of typical or atypical children, because they give meaning to the joke, building a new repertoire of knowledge, and is a simple source of encouragement to the cognitive, social and emotional development of the child<sup>16</sup>.

The communication is used at different times during the game, to get the attention of the partner,

to ask for the desired toy, to express an opinion for the game choice, to request an adult or another child action, to change the game, to express feelings and to interact with the game.

The data found in the baseline process corroborate the findings in the literature<sup>7</sup>, in which categories such as disagreements, difficulty and limitation during the conversation with people without oral communication are common, mainly by relatives.

Although the literature discuss that the look, indicative gestures, representative gestures and body movements expand the possibilities of interaction with the child's routine partners<sup>17-19</sup>, this study showed that alternative communication resources do not guarantee understanding when the parties are not able to use them correctly.

Support for the implementation of augmentative and alternative communication resources should be provided to various child development contexts, since children language disorders represent one of the major risk factors for future learning problems<sup>14</sup>.

This study confirms a survey conducted in 2011, in which after the implementation of alternative communication resources with the family aid in a child with lack of speech, it was evaluated the effectiveness of the intervention program through the family generalization to use them in different social environments<sup>20</sup>.

Interlocutors in these environments, as parents, relatives and teachers should understand and be able to know how to use the communication system

that the child is using in order to provide development of communication skills.

In this context, children, youth and adults with complex needs of oral and written communication need help from the supplementary and/or alternative communication to enlarge the communicative exchanges<sup>21</sup>, learn new communication skills<sup>22</sup>, allow the inclusion in social environments<sup>23</sup> and interact during daily activities<sup>24</sup>.

## Conclusion

This study brought an important contribution by privileging an unexplored context, the performance of mothers of children with cerebral palsy without oral communication using the alternative communication resources for children to communicate their wishes, needs and center of interests, using the communication alternative resources.

Through the presented data, it was found that mothers and children before the intervention process did not have an input repertoire about the issue of alternative communication and use of pictographic figures. After the intervention, the mothers' repertoire was significant and there was an excellent performance of them using alternative communication resources and a strong performance by children to communicate their wishes through pictographic figures.

The results showed that children with cerebral palsy in this study made use of alternative communication procedures successfully. The alternative communication increased expressive skills, attention time and the active participation of children in dialogic activity with their mothers.

In general, it can be said that the present study yielded positive results of the procedures used, showing that besides the increase of communicative interaction of children with their mothers, communicative autonomy of the child expressing himself more independently.

It was observed that the partnership with families to optimize the communication development of children with complex communication needs is possible and desirable. Regarding clinical aspects, the partnership between therapists and mothers is extremely important in order to be legitimate partners of communication with the child.

In conclusion, this study achieved its goal; it was effective favoring the acquisition of new communication skills by children and satisfactory

performance of the mothers to the use of communication resources.

Further studies are indicated, both longitudinal (to track the trajectory of the children with severe communication disorders development in the use of alternative communication resources) and in conjunction with the child's developmental contexts (clinical, family and school environment).

In addition, there is a need for further large-scale of participants' research and the need to transform the technology research in community and public policy services.

Finally, there is the importance of investing in public health policies so that they can be touched by the Brazilian socioeconomic and leverage the development of research in alternative communication.

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