Effects of 5 Years of Intensive Behavioral Intervention on the Development of a Child with Autism[1]

Efeitos de 5 Anos de Intervenção Comportamental Intensiva no Desenvolvimento de uma Criança com Autismo

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ABSTRACT: The purpose of this single case study is to describe and evaluate the application of an Intensive Behavioral Intervention model, carried out through the training of caregivers, with a child with severely compromised and non-speaking autism. The intervention occurred for 40 hours a week in a home and school environment, during five consecutive years. Standardized instruments were used to measure child development. Overall results indicated gains in child development and the feasibility of training of caregivers for this type of intervention.

KEYWORDS: Autism. Special Education. Caregivers. Applied Behavior Analysis. Intensive intervention.

RESUMO: O objetivo deste estudo de caso único é descrever e avaliar a aplicação de um modelo de Intervenção Comportamental Intensiva, realizado por meio da capacitação dos cuidadores, com uma criança com autismo gravemente comprometida e não falante. A intervenção ocorreu por 40 horas semanais em ambiente domiciliar e escolar, ao longo de cinco anos consecutivos. Instrumentos padronizados foram utilizados para medir o desenvolvimento da criança. Os resultados gerais indicaram ganhos no desenvolvimento da criança e a viabilidade da capacitação dos cuidadores para esse tipo de intervenção.

PALAVRAS-CHAVE*:* Autismo. Educação Especial. Cuidadores. Análise do comportamento aplicada. Intervenção intensiva.

1 Introduction

Intensive Behavioral Interventions have demonstrated significant effects on the development of people with autism since the 1980s (Boyd & Corley, 2001; Campbell, Schopler, Cueva, & Hallin, 1996; Dawson et al., 2010; Lovaas, 1987; Smith, 1999; Warren et al., 2011). This type of intervention is characterized by individualized stimulation (an educator for a child with autism), performed for many hours a week (from 15 to 40 hours) for at least

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two consecutive years, covering several areas of development simultaneously and supported principles of Behavior Analysis (Green, 1996), defined as Applied Behavior Analysis - ABA (Baer, Wolf, & Risley, 1987).

The first study on Intensive Behavioral Intervention applied to the treatment of autism was published by Lovaas (1987), and, after this publication, dozens of subsequent studies partially replicated the results of the initial study (Smith, Buch, & Gamby, 2000; Warren et al., 2011), which used different educators (students, practitioners and families) and multiple contexts (specialized institutions, schools and children's residence). The research indicated, in general, improvement in the development of the participants after performing this type of intervention. These studies have reported mixed results in relation to the proportion of intervention gains but, overall, indicated gains in the development of children, especially when performed early (Smith et al., 2000; Warren et al., 2011).

In Brazil, two studies described the effects of an Intensive Behavioral Intervention model applied to the treatment of Brazilian children with autism. Gomes et al. (2019) evaluated the effects of this type of intervention, performed through the training of caregivers, in the development of children with autism, and compared the children who performed the intervention with children who did not perform it. Participants were assigned to two groups: Group 1 comprised of 22 children who completed the first year of intensive intervention, and Group 2 was composed of 11 children who did not have intensive intervention. The results indicated significant gains in all areas of development of children with autism who underwent the first year of Intensive Behavioral Intervention, whereas children in the group without intensive intervention presented less expressive gains. Younger children, who spoke and had milder autism symptoms, had better results.

In another study, Gomes, de Souza, Silveira and Oliveira (2017) evaluated the effects of the first year of Intensive Behavioral Intervention on the development of nine children with autism, aged between 1 year and 3 months and 2 years and 11 months, who were assisted by a specialized Brazilian center. The intervention, conducted for approximately 15 hours per week, was performed at the participants' homes through the training of caregivers. The children were assessed at the beginning and at the end of the intervention. Data were analyzed individually, and the results indicated gains in development.

The objective of this single case study was to verify the effects of the application of an Intensive Behavioral Intervention model, carried out through the training of caregivers, in the development of a child with severely compromised and non-speaking autism. The intervention occurred for 40 hours a week in a home and school environment, during five consecutive years. Two standardized instruments were used annually to measure the development of the child, allowing to evaluate possible gains from the intervention.

2 Method

In this section, we will present the participant of this research, the evaluation instruments and procedures, the intervention, the teaching procedures of the skills worked in each program and the ethical procedures.

2.1 Participant

A 2-year and 2-month old, non-talking child with a prior diagnosis of autism without a diagnosis of comorbidities, conducted by a specialized child psychiatrist, following the criteria of the International Classification of Diseases - ICD 10 (World Health Organization [WHO], 1993), participated in this study. The child was accompanied by the Center for Studies and Intervention for Human Development between May 2012 and May 2017, totaling 5 years of intervention.

2.2 Evaluation instruments

In order to evaluate the child's development, the Psychoeducational Profile-Revised - PEP-R (Schopler, Reichler, Bashford, & Marcus, 1990) and the Operational Portage Inventory – OPI (Williams & Aiello, 2001) were used. The use of these two instruments was chosen because both were adapted for the Brazilian population; they measure important developmental areas in years and months in isolation, and also provide an overall measure of development, which allows comparing the evaluated child with what is expected for the chronological age; they allow us to evaluate the effects of intervention on the child's development in specific areas and development as a whole.

PEP-R assesses both developmental delays and typical autism behaviors and provides information on seven areas on the Development Scale: imitation, perception, fine motor coordination, gross motor coordination, eye-hand integration, cognitive and verbal cognitive development, and also four areas in the Behavior Scale: language, relationship and affection, sensory responses and interest in materials. It can be used with children from 6 months to 12 years of age. It was adapted and validated for the Brazilian population (Leon, Bosa, Hugo, & Hutz, 2004). In this study, data from the Development Scale (not the Behavior Scale) were used.

OPI evaluates the pattern of child development in five areas: language, socialization, motor development, cognition and self-care, in periods ranging from 0 to 6 years. It is not an instrument to specifically evaluate the development of children with autism, but it evaluates the development of any child, regardless of diagnosis. The inventory was adapted and operationalized for the Brazilian population (Williams & Aiello, 2001).

In addition to the PEP-R and the OPI, the Childhood Autism Rating Scale - CARS (Schopler, Reichler, & Renner, 1988) was also used to identify children with autism behavioral characteristics and to distinguish between autism and developmental delay without autism. According to the scale, the results of the evaluation can be divided into three categories: normal development (15-29.5), mild/moderate autism (30-36.5) and severe autism (over 37). It can be used with children over 36 months of age. This scale was adapted and validated for the Brazilian population by Pereira, Riesgo and Wagner (2008).

2.3 Evaluation procedures

Annually, the child was evaluated by two practitioners of the Center for Studies and Intervention, one with a background in Psychology and the other in Occupational Therapy, through the application of PEP-R, OPI and CARS (considering the minimum and maximum ages of the instruments). The application of PEP-R occurred in a room with few stimuli, where

one therapist presented the activities and the other recorded the performance of the child. OPI was applied in the child's home, in a situation closer to the natural one, based on the observation of the child's behavior and the caregivers' report. It is important to note that some skills were measured by the two instruments, but in different ways and with different criteria.

The application of the PEP-R was performed in an artificial environment (room with few stimuli) and on demand (the evaluator asked the child to do the activity); the application of the OPI was performed in a natural environment (the participant's residence) through the observation of the child and the caregiver's report, without demands directed at the child. The CARS was completed by the evaluators based on the observation of the child's behavior. It took an average of two weeks for the application of the evaluation tools, analysis of the data and writing of a report with the results.

2.4 Intervention

The intervention occurred in the residence of the child with autism and in the school that the child attended, through the training of the caregivers (parents, nanny and trainees of Psychology), carried out by practitioners of the Center for Studies and Intervention; in this sense, those who performed the activities with the child were the caregivers, following the guidelines given by the practitioners of the Center for Studies and Intervention.

At the residence, the child was accompanied by the parents, by the nanny and by an undergraduate trainee in Psychology. The trainee did the daily activities with the child for 2 hours, from Monday to Friday, totaling 10 hours of stimulation per week, and was responsible for the performance of the basic, speech and academic skill teaching programs (Gomes & Silveira, 2016; Gomes, 2015), which will be described below. Parents and nanny were responsible for teaching self-care skills (Silveira & Oliveira, 2018; Silveira & Gomes, 2019), in the natural context, and for the maintenance and generalization of the skills learned in the activities carried out with the trainee.

Two practitioners, one graduated in Psychology and the other in Occupational Therapy, were present at the child's home twice a week (each practitioner once a week) in sessions of one hour each. The Psychology practitioner directed the trainee, the parents and the nanny to the teaching of basic, speech and academic skills; the Occupational Therapy practitioner instructed parents and nanny to teach self-care skills. The practitioners' role was to teach caregivers to perform activities with the child with autism in the environment in which these skills would be taught (there was no theoretical training for caregivers, only contextual teaching). In addition, the practitioners also taught caregivers to systematically record the child's performance in the activities (in protocols developed by the Center for Studies and Intervention, specific to each activity, see Gomes & Silveira, 2016) and supervised the correct performance of the activities and records to ensure the reliability of the intervention.

The child attended a regular private school, 5 times a week, 4 hours a day, totaling 20 hours of weekly stimulation, and was followed up in full time by a mediator (trainee in Psychology). A practitioner of the Center for Studies and Intervention with a Psychology background attended the child's school once a week and systematically guided the mediator in sessions lasting one hour each. The guidelines at the school dealt with both the teaching conditions (preparation of the environment and materials, how to present the instructions,

the requirement of active response of the child, the presentation of consequences identified as potentially reinforcing, among others), and the general management behaviors of the child. The mediator also made systematic records of the activities performed by the child in the school environment (Gonzaga & Borges, 2018).

It is estimated that the intervention occurred for 40 hours a week: 10 hours with the trainee in the child's home in structured activities; 10 hours with the parents and the nanny in activities of self-care, maintenance and generalization of the learned skills; 20 hours in school, with individualized and systematic guidance of the mediator. In addition, the child had weekly sessions of speech therapy, occupational therapy (sensory integration) and music therapy in the office, lasting approximately one hour each. He also underwent systematic psychiatric follow-ups and use of medication (atypical antipsychotic).

It is important to emphasize that, during the five years of intervention, exchanges of trainees and professionals of the Center for Studies and Intervention took place, in the residence and in the school; in general, trainees and practitioners stayed for a year or more. In this period, the child was accompanied by four trainees in the residence and five in the school (at different times); in the residence, four Psychology practitioners and two Occupational Therapy practitioners; in the school, four Psychology practitioners.

2.5 Teaching programs

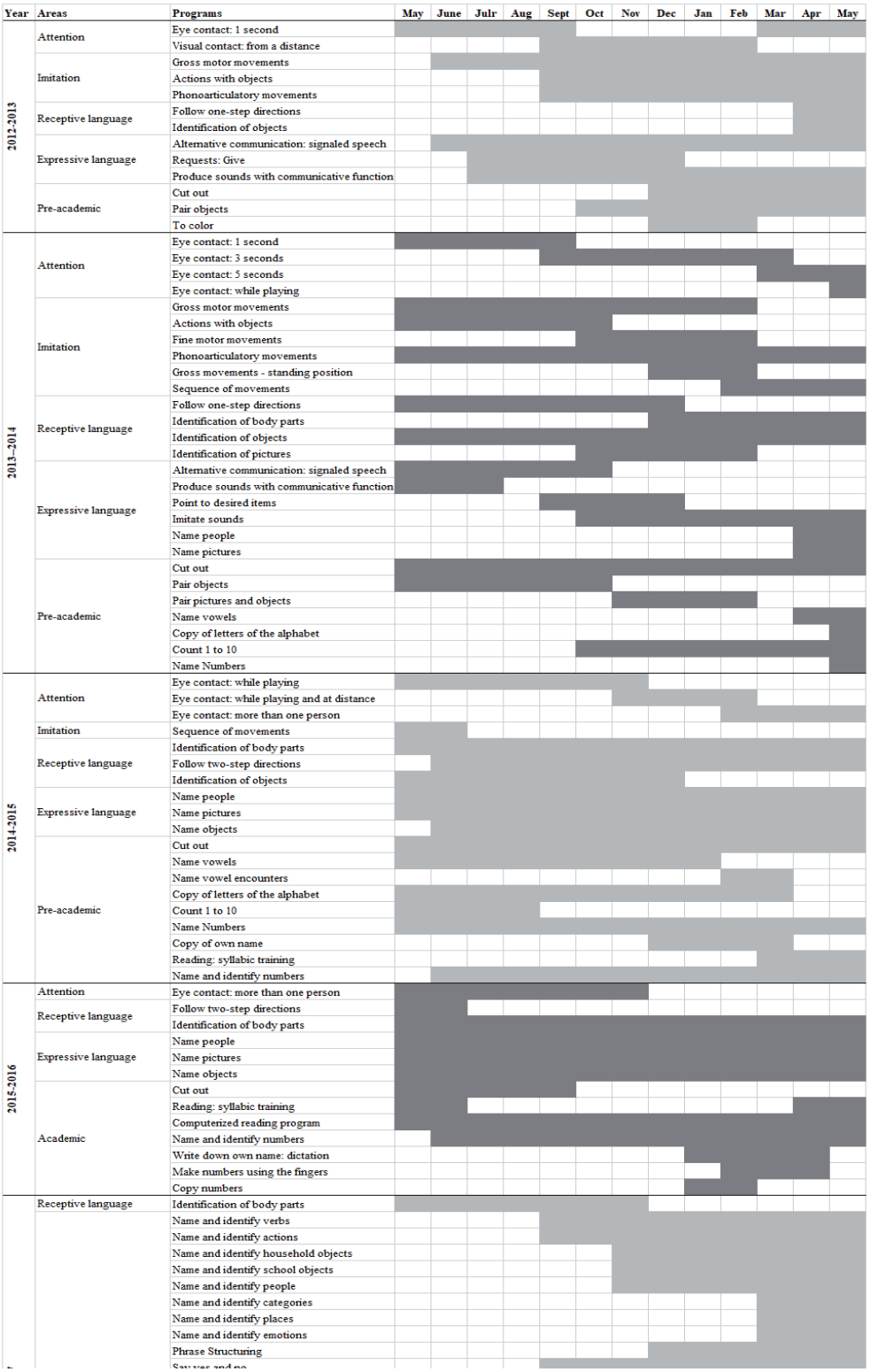
Table 1, below, presents the sequence of introduction of the teaching programs and the months of each of them, between May 2012 and May 2017. These programs were carried out at the child's home, through the training of the trainee. In all, 96 teaching programs were carried out: 13 in the first year, 27 in the second, 19 in the third, 13 in the fourth and 24 in the fifth.

The procedures for teaching the skills worked on in each program were based on behavior analysis and for each program the criteria for beginning and ending were defined. After the end of each program, strategies were planned for maintenance and generalization of the skills learned, preferably in the natural environment. The detailed description of the programs of basic skills teaching is found in Gomes and Silveira (2016), in order to favor its replicability. Information about the teaching procedures of reading and Math skills can be found in Gomes (2007, 2015).

2.6 Ethical considerations and reliability

The procedures used in this study were approved by the Ethics Committee of the Faculty of Medical Sciences of Minas Gerais (Opinion No. 923.913) for a larger research project on training of caregivers for Intensive Behavioral Intervention.

Two independent and uninformed evaluators regarding the purpose of the survey counted evaluations (performed by the professionals of the Center for Studies and Intervention) and 30% of the protocols for recording activities (filled by caregivers). The concordance between observers was calculated using the following formula: concordances divided by the sum of concordances and disagreements, multiplied by 100 (Kazdin, 1982). The agreement coefficient for the evaluations was 100%; the agreement coefficient for the activity records was approximately 80%.


Year
Areas
Programs
May
June
Julr
Aug
Sept
Oct
Nov
Dec
Jan
Feb
Mar
Apr
May
2012-2013
Attention
Eye contact: 1 second
Visual contact: from a distance
Imitation
Gross motor movements
Actions with objects
Phonoarticulatory movements
Receptive language
Follow one-step directions
Identification of objects
Expressive language
Alternative communication: signaled speech
Requests: Give
Produce sounds with communicative function
Pre-academic
Cut out
Pair objects
To color
2013-2014
Attention
Eye contact: 1 second
Eye contact: 3 seconds
Eye contact: 5 seconds
Eye contact: while playing
Imitation
Gross motor movements
Actions with objects
Fine motor movements
Phonoarticulatory movements
Gross movements - standing position
Sequence of movements
Receptive language
Follow one-step directions
Identification of body parts
Identification of objects
Identification of pictures
Expressive language
Alternative communication: signaled speech
Produce sounds with communicative function
Point to desired items
Imitate sounds
Name people
Name pictures
Pre-academic
Cut out
Pair objects
Pair pictures and objects
Name vowels
Copy of letters of the alphabet
Count 1 to 10
Name Numbers
2014-2015
Attention
Eye contact: while playing
Eye contact: while playing and at distance
Eye contact: more than one person
Imitation
Sequence of movements
Receptive language
Identification of body parts
Follow two-step directions
Identification of objects
Expressive language
Name people
Name pictures
Name objects
Pre-academic
Cut out
Name vowels
Name vowel encounters
Copy of letters of the alphabet
Count 1 to 10
Name Numbers
Copy of own name
Reading: syllabic training
Name and identify numbers
2015-2016
Attention
Eye contact: more than one person
Receptive language
Follow two-step directions
Identification of body parts
Expressive language
Name people
Name pictures
Name objects
Academic
Cut out
Reading: syllabic training
Computerized reading program
Name and identify numbers
Write down own name: dictation
Make numbers using the fingers
Copy numbers
Receptive language
Identification of body parts
Name and identify verbs
Name and identify actions
Name and identify household objects
Name and identify school objects
Name and identify people
Name and identify categories
Name and identify places
Name and identify emotions
Phrase Structuring

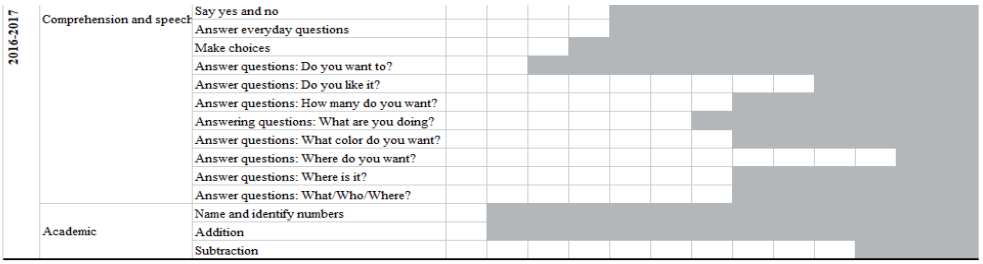


Table 1. Sequence of introduction of the teaching programs and the months of completion of each of them, between May 2012 and May 2017.
Source: The authors.

3 Results

The participant was evaluated annually through PEP-R, OPI and CARS. The evaluations were applied with an interval between them of approximately 12 months. The PEP-R was applied six times and the OPI four times, depending on the age limit defined by the instrument (0 to 6 years). CARS was applied 5 times, also considering the criterion of age (above 36 months).

Figures 1 and 2, at the end of this section, present the results of the participant by age in the PEP-R and the OPI, by area of development and in the sum of all areas (Global). The two instruments present specific scores for each chronological age; the child is in agreement with what is expected for the chronological age when they obtain a score compatible with the determined score for that age; score below the given indicates developmental delay.

According to the PEP-R, the child presented delay in all areas and in the sum of the areas before the beginning of the intervention (Figure 1). In general, the child presented gains in all areas, in most evaluations. Lower performances were observed in some areas in the assessment performed at 5 years and 4 months. This evaluation coincided with a period in which the child was agitated, with a lot of behavioral problems and many stereotypies due to an alternative treatment performed by the family, which was quickly interrupted. Regarding the gains by area, there are smaller gains in cognitive and verbal cognitive; more expressive gains in these areas occurred after the onset of speech, between 4 and 5 years of age.

At the OPI, the child was delayed in most areas except motor development, before the intervention began (Figure 2). Gradual gains are seen in all areas as the intervention takes place. Lower performances were observed in language; more robust gains in this area were observed after the onset of speech, between 4 and 5 years of age.

In the first evaluation, performed through CARS, at 3 years and 3 months of age, the child presented a score of 40.5 characterized as severe autism. From the second evaluation, the child presented a score compatible with the category of mild/moderate autism: 33 at 4 years and 3 months of age; 30 at 5 years and 4 months; 34.5 at 6 years and 5 months; and 33 at 7 years and 4 months of age.

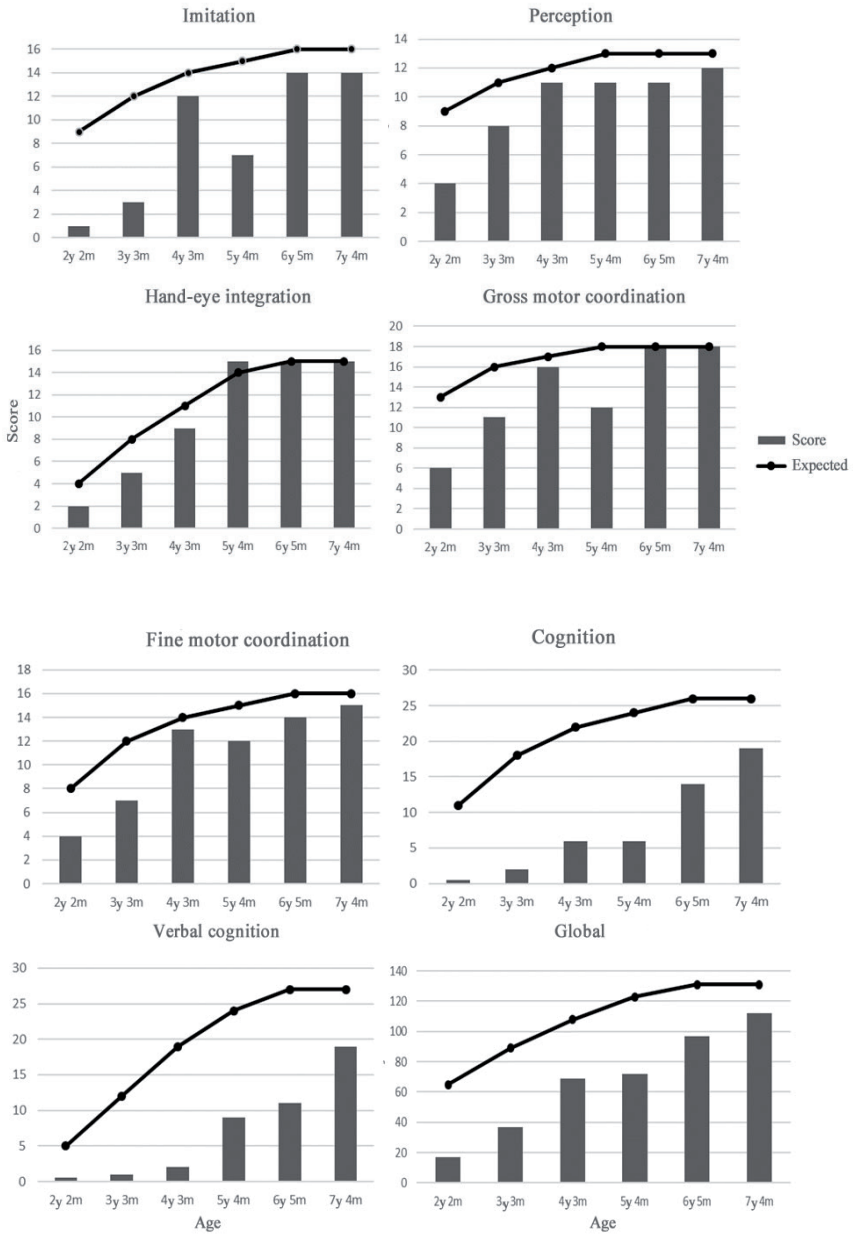


Figure 1. Annual results by area of development and in sum of all areas, according to the PEP-R. The line indicates expected score for the chronological age and the bars indicate the participant's result.
Source: The authors.

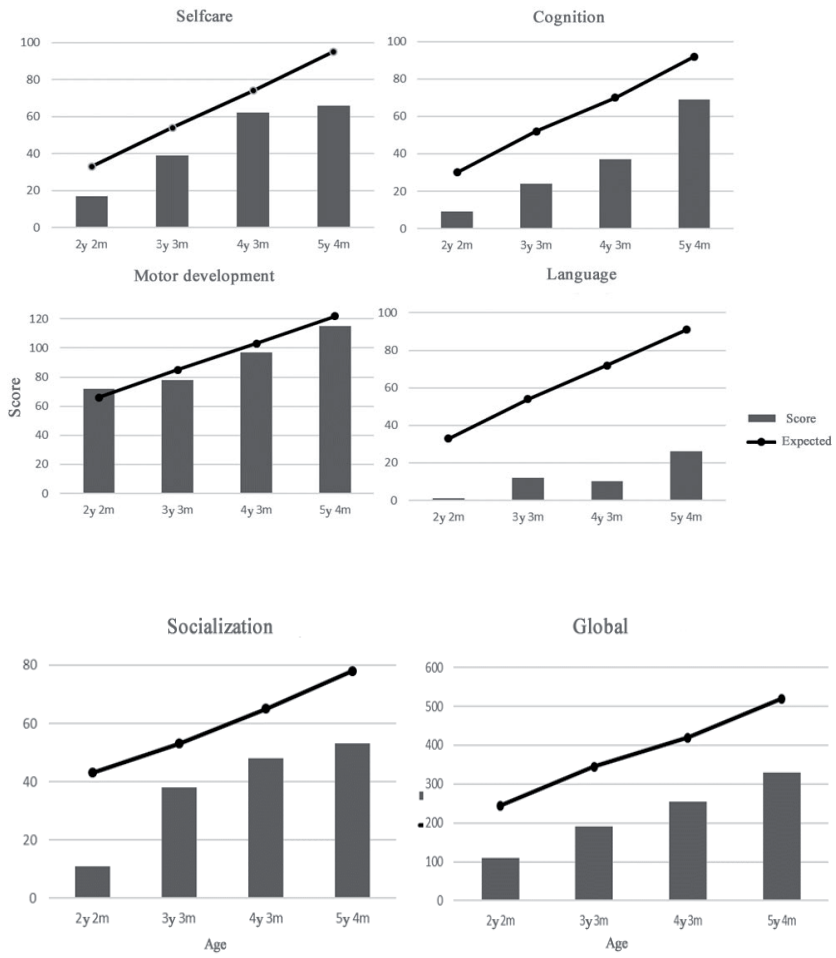


Figure 2. Annual results by area of development and in sum of all areas, according to the OPI. The line indicates the expected score for the chronological age and the bars indicate the result of the participant.
Source: The authors.

4 Discussion and conclusions

The purpose of this single case study was to describe a model of Intensive Behavioral Intervention performed through the training of varied caregivers with a child with autism who was initially severely compromised and did not speak. In addition, the study aimed to evaluate the effects of this type of intervention, performed for 40 hours a week in a home and school environment, in the development of the child, during five years of intervention. Two standardized instruments (PEP-R and OPI) were used annually to measure child development, allowing the evaluation of possible gains due to the intervention.

In general, the child presented gradual gains in development, year after year. Faster gains were observed in PEP-R in more basic skills such as hand-eye integration, perception, fine motor and gross motor coordination. More expressive gains in verbal cognition and cognitive performance, involving more complex abilities, began to appear after the onset of speech, between 4 and 5 years of age, which, in turn, seems to have had an improvement in imitation skills as a precursor, suggesting that, for this child, the refinement of imitation skills may have favored the emergence of speech.

Another important aspect is that the improvement of the imitation skills happened after the application of many imitation teaching programs (2013-2014), suggesting a possible relation between the intervention, the imitation improvement and the emergence of speech. The OPI data seem to reinforce the indications of PEP-R: more expressive gains in cognition and language occurred after the onset of speech. In this regard, the literature has indicated that children with autism who speak have greater developmental gains when compared to children who do not speak (Green, 1996), similar to what was observed in this current study when comparing the child's gains when they did not speak and after the realization of speech.

Regarding the training of caregivers, literature has indicated that this can be a viable and effective alternative for the performance of Intensive Behavioral Interventions. According to Smith et al. (2000), the use of trained practitioners to carry out the entire intervention may be infeasible due to the reduced number of trained professionals, in relation to the demand of people with autism to be attended, and the high cost of execution, due to the need for many hours of weekly intervention. In this way, the solution found for these problems has been the training of caregivers, similar to what was described in this study. In this context, several studies have used different caregivers to perform the intervention (e.g., Anderson, Avery, DiPietro, Edwards, & Christian, 1987: parents, psychologists, speech therapists and Special Education teachers; Dawson et al., 2010: practitioners and parents; Eikeseth, Smith, Jahar, & Eldevik, 2002: teachers; Lovaas, 1987: practitioners and trainees; Sheinkopf & Sielgel, 1998: parents; Sherman, Barker, Lorimer, Swinson & Factor, 1988: parents and practitioners; Smith et al., 2000: parents and trainees).

Another aspect worth mentioning is the number of years the intervention was performed with this child. Literature indicates that Intensive Behavioral Interventions should happen for at least two consecutive years or more (Dawson & Osterling, 1997; Dawson et al., 2010; Smith et al., 2000; Lovaas, 1987). It can be observed that the child in this study presented gradual gains with the intervention, but more robust gains in the areas of language and cognition (see verbal cognition and cognition in PEP-R and language and cognition in the OPI, Figures 1 and 2) only happened from the third consecutive year of intervention. Before that, gains are minimal in these areas, which in turn are compounded by complex behaviors that require time to be learned. In this sense, on the one hand, data from this study may suggest that, for the more severe autism, characterized by significant developmental delay, lack of speech and high scores in CARS, as was the profile of the participant in this study, the stimulation should be broad (many hours per week) and long (many consecutive years) occurring for more than two or three consecutive years. On the other hand, the data may also suggest that interruption of the intervention in the first or second year of stimulation could compromise the onset of speech and learning more complex behaviors, which would

consequently increase the child's developmental delay. However, this is only a hypothesis, since the lack of a more robust experimental control in this study does not allow a precise statement about this aspect.

Literature consistently indicates that Intensive Behavioral Interventions may promote significant gains in the development of children with autism, although the description of the proportion of gains is varied (Lovaas, 1987; Sherman et al., 1988; Smith, 1999; Warren et al., 2011). The results described in this study corroborate with the indications in the literature regarding the good effects of this type of intervention with children with autism, since the interventions performed had significant effects on the development of the participant. However, because there is no robust experimental design for controlling the variables, the study is limited in relation to the generalization of the data to other children with autism, because it presents only one participant, besides problems in the control of variables that may have influenced the results, such as maturation of the child and other treatments as intervening variables. It would be important for the study to be replicated with a larger number of participants, with a better control of the variables, besides the use of a more adequate design, as in the case of the multiple baseline design (Gast, Skouge, & Tawney, 1984) , which would make the following of the whole process of learning possible, before the skills were taught, during and after teaching.

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