

Training of caregivers of autistic children in intervention via SUS

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Abstract

Autism spectrum disorders are characterized by neurodevelopmental alterations with onset of symptoms in childhood. The literature has indicated that the models of intensive behavioral intervention can produce significant improvements in several areas of the development of people with this diagnosis. The offer of this type of therapy in Brazil is still scarce, especially in institutions financed by the Unified Health System. However, the training of caregivers has been pointed out as an alternative to promote access to this type of therapy to more autistic people. The aim of this study was to analyze the effects of caregiver training on the development of autistic children treated at an institution financed by the Unified Health System. Participants were assessed before and after the intervention, using an instrument that measured the children's development. The results indicated improvement in the development of six children out of a group of 17.

Keywords: autism spectrum disorders, Unified Health System, caregivers, applied behavior analysis, intensive behavioral intervention

CAPACITAÇÃO DE CUIDADORES DE CRIANÇAS COM AUTISMO EM INTERVENÇÃO VIA SUS

Resumo

Os transtornos do espectro do autismo constituem-se por alterações do neurodesenvolvimento com início dos sintomas na infância. A literatura tem indicado que os modelos de intervenção comportamental intensiva podem produzir melhoras significativas em várias áreas do desenvolvimento de pessoas com esse diagnóstico. A oferta desse tipo de terapia no Brasil ainda é escassa, especialmente em instituições financiadas pelo Sistema Único de Saúde. Contudo, a capacitação de cuidadores tem sido apontada como uma alternativa para promover o acesso a esse tipo de terapia a mais pessoas com autismo. O objetivo deste estudo foi analisar os efeitos da capacitação de cuidadores no desenvolvimento de crianças com autismo atendidas em uma instituição financiada pelo Sistema Único de Saúde. Os participantes foram avaliados antes e após a intervenção, por meio de instrumento que mediu o desenvolvimento das crianças. Os resultados indicaram melhora no desenvolvimento de seis crianças de um grupo de 17.

Palavras-chave: transtornos do espectro do autismo, Sistema Único de Saúde, cuidadores, análise do comportamento aplicada, intervenção comportamental intensiva

FORMACIÓN DE CUIDADORES DE NIÑOS CON AUTISMO EN INTERVENCIÓN VÍA SUS

Resumen

Los trastornos del espectro autista se caracterizan por alteraciones del neurodesarrollo con inicio de síntomas en la infancia. La literatura ha indicado que los modelos de intervención conductual intensiva pueden producir mejoras significativas en varias áreas del desarrollo de las personas con este diagnóstico. La oferta de este tipo de terapia en Brasil aún es escasa, especialmente en instituciones financiadas por el Sistema Único de Salud. Por otro lado, la formación de cuidadores se ha señalado como una alternativa para promover el acceso a este tipo de terapia a más personas con autismo. El objetivo de este estudio fue analizar los efectos de la formación de cuidadores en el desarrollo de niños con autismo atendidos en una institución financiada por el Sistema Único de Salud. Los participantes fueron evaluados antes y después de la intervención, utilizando un instrumento que midió el desarrollo de los niños. Los resultados indicaron una mejora en el desarrollo de seis niños en un grupo de 17.

Palabras clave: trastornos del espectro autista, Sistema Único de Salud, cuidadores, análisis de comportamiento aplicada, intervención conductual intensiva

Autism spectrum disorders (ASD) are severe, permanent neurodevelopmental changes with the onset of symptoms in childhood, which affect social interaction, communication, and are characterized by a pattern of repetitive behaviors and restricted interests. This is a complex situation, as the way symptoms affect development can vary significantly in each person. There is no cure for the disorder, but literature consistently indicates that the development of an autistic child can be improved when there is early and intensive intervention; however, it also indicates that autism is chronic, that is, there is no spontaneous improvement, and affected people may have their development aggravated when there is no adequate treatment, which can compromise the quality of life of the autistic person, as well as their families' (American Psychiatric Association [APA], 2013).

There are currently many treatments aimed at autism, but not all of them have sufficient scientific evidence to indicate significant improvement in the development of affected people. So far, the treatments that have shown the best results are those performed intensively (with many hours of stimulation per week) and based on behavior analysis. However, the stimulation of an autistic person cannot be limited to one area of knowledge: there is a need for specialized multidisciplinary monitoring, both in health and education (Medavarapu et al., 2019).

The need for intensive and multidisciplinary intervention makes the provision of adequate treatment scarce, complex, and of a high financial cost. Cakir et al. (2020) estimated that, in the United States of America (USA), the average lifetime cost of an autistic person is US\$ 3.6 million. Projecting that amount into the USA autism prevalence data, the cost of caring for people diagnosed between 1990 and 2019 is US\$ 7 trillion, which is about two years of total USA federal income. The researchers considered for the calculations only government-funded (not household) costs for medical and health care, therapies, education services, financial assistance for the autistic person and family members, accommodation, and temporary care. However, early and appropriate intervention can promote robust improvements in the development of autistic people, enabling many to achieve autonomy, independence, and quality of life, which will, consequently, make them more productive and reduce the financial costs of assistance throughout their life (Cakir et al., 2020).

In Brazil, data on prevalence, financial costs of treatment, and assistance in the public health network are still scarce (Garcia et al., 2017). There is also no description of public services, financed by the Unified Health System (in Brazil, *Sistema Nacional de Saúde*, known by the acronym SUS), that have the structure to carry out intensive interventions; in general, autistic people are assisted in weekly therapy sessions, with a workload well below that indicated in the scientific literature.

The intensive behavioral intervention models have been indicated by the scientific literature as those that produce the greatest gains in various areas of development of people with ASD (e.g., language, cognition, socialization, self-care, among others), from the 1980s to the present (Lovaas, 1987; Medavarapu et al., 2019). Known in Brazil as "ABA therapy" (Applied Behavior Analysis), these intervention models are characterized by stimulations that occur

predominantly in an individualized manner (one educator for one autistic child), performed for many hours a week (from 15 to 40 hours), for at least two consecutive years, which cover several areas of development simultaneously (e.g., language, cognition, socialization, self-care, among others) and which are based on principles of behavior analysis (Romanczyk & McEachin, 2016).

The implementation of intensive behavioral intervention models for the treatment of autism in Brazil is still scarce, due to the demand, which is greater than the number of professionals available to perform this type of intervention, and the high financial cost, due to the number of weekly hours of therapy (Gomes et al., 2019). However, these difficulties do not only occur in Brazil; Smith et al. (2000) highlighted that the scarcity of professionals and the high financial cost of this type of therapy occur all over the world. In addition, the researchers emphasized that it became impracticable to use specialized professionals to carry out the entire treatment and that the most common solution to carry out this type of intervention has been through the training of caregivers (parents, family members, nannies, therapeutic companions, among others), who become responsible for carrying out the stimulations, with the guidance and supervision of specialized therapists.

Gomes and Silveira (2016) published a book with the aim of directing the intensive behavioral intervention, implemented through the training of caregivers of autistic children. It is a manual, composed of activities (procedures and protocols) designed to teach a set of simple and initial behaviors, which, in turn, are requirements for more complex learning (Blanco & Genari, 2017). Data on the effectiveness of using this manual were presented in four studies.

In the first study, Gomes et al. (2017) evaluated the effects of the first year of intensive behavioral intervention, carried out by trained caregivers, on the development of nine autistic children, aged between 1 year and 3 months old and 2 years and 11 months old, attended by a specialized Brazilian center. The children were evaluated at the beginning and end of the intervention by instruments that measured several areas of child development, and the results indicated improvements in all areas, resulting from the intervention. In the second study, Gomes et al. (2019), using a group design, evaluated the effects of this type of intervention, carried out by trained caregivers, on the development of autistic children and compared children who underwent the intervention with children who did not. The children were evaluated at the beginning and end of the intervention by instruments that measured various areas of child development, and the results indicated significant improvements in all areas of children who underwent intensive intervention, while children in the other group showed less expressive gains. In the third work, Andalécio et al. (2019) presented a case study with an autistic child, severely compromised and non-speaker. The intervention took place for 40 hours a week in both the home and school environments, through the training of caregivers, over five consecutive years. Standardized instruments were used to measure the child's development over the years and the overall results indicated improvements in several areas of development. In the fourth study, Gomes et al. (2021) analyzed the effects of using information and communication technologies to train caregivers of

autistic children, in the context of intensive behavioral intervention. The study included 24 children diagnosed with autism, aged between 3 years and 2 months old and 8 years and 10 months old, and their respective caregivers. Caregivers performed behavioral and intensive stimulation with autistic children and were guided by specialized professionals, but this guidance occurred through the use of information and communication technologies, with professionals and caregivers in different locations. The development of the autistic participants was assessed before and after the intervention by standardized instruments that measure several areas of child development, and the results indicated improvements in all areas.

Despite the indications of improvements in the development of autistic children, derived from the procedures described by Gomes and Silveira (2016), the studies carried out described the application at a private institution and, so far, there are no data regarding the application at Brazilian centers funded by the SUS. The general objective of this study was to analyze the effects of applying the procedures described by Gomes and Silveira (2016) at an institution that provided care to autistic people financed by the SUS. Specifically, it was intended to describe the procedures used for the implementation of the care service for autistic children based on the training of caregivers, through the use of the manual by Gomes and Silveira (2016), and to analyze the effects resulting from this type of intervention in the development of participating autistic children. The results of this study may be important to expand the investigations regarding the treatment of ASD in the scope of the SUS.

Method

Participants

Autistic children, caregivers and psychology professionals from the Rehabilitation Center of the Association of Parents and Friends of the Disabled of Mato Grosso do Sul (*Reabilitação da Associação de Pais e Amigos dos Excepcionais de Mato Grosso do Sul* [CER/Apae]) participated in the study. The selection criteria for the children to participate in the study were to present a previous diagnosis of autism, carried out by a specialized physician, and to be between 1 and 6 years old at the beginning of the research.

The intervention with the children was carried out between January 2017 and December 2018. During this period, 55 children were evaluated and started the intervention, but 23 were removed from the institution for having many consecutive absences, 12 were excluded from the sample for presenting other diagnoses or by the option of the families not to participate in the study, and 20 remained in the intervention. However, out of the 20 children who remained in the intervention, three were not reevaluated, which means that there are no post-test data for these children. Thus, the final sample consisted of 17 autistic children and their respective caregivers. In addition to autistic children and their caregivers, nine professionals from the institution with a degree in psychology participated in the study.

Materials

Autistic children were assessed using the Operationalized Portage Inventory (OPI) (Williams & Aiello, 2001) and the Childhood Autism Rating Scale (CARS) (Schopler et al., 1988). The OPI, adapted and operationalized for the Brazilian population, assesses the pattern of child development in five areas: language, socialization, motor development, cognition, and self-care, at ages ranging from 0 to 6 years. The CARS, adapted and validated for the Brazilian population by Pereira et al. (2008), allows the identification of children with behavioral characteristics of autism. The results obtained by applying this instrument can be divided into three categories: normal development (15–29.5), mild/moderate autism (30–36.5), and severe autism (above 36.5). It is important to clarify that CARS is not an autism diagnostic tool, it evaluates the child according to the number and severity of symptoms (the higher the score, the more symptoms). Thus, “normal development” does not mean that the child is not autistic but rather indicates that the child presents very few symptoms of autism.

For the intervention with autistic children and their caregivers, the Basic Skills Curriculum (teaching procedures and registration protocols) was used, which is described in detail in the manual by Gomes and Silveira (2016), in order to favor replicability. The curriculum is divided into five areas: 1. attention skills, 2. imitation skills, 3. receptive language skills, 4. expressive language skills, and 5. pre-academic skills. Each area is made up of varied teaching programs; for example, the attention skills area is composed of the programs: 1.1 sit, 1.2 wait, and 1.3 eye contact. In total, there are 28 teaching programs.

Procedures

Before the beginning of the research, the institution offered psychological care to autistic children, in individual and weekly sessions, with an average duration of 30 minutes each. These sessions took place between the therapist and the child, without the participation of the child's caregiver during the session. The purpose of this research was that the 30-minute sessions would take place between the therapist, child, and caregiver, simultaneously, and the therapist's function would not be to assist the autistic child but to teach the caregiver to perform the activities and records described by Gomes and Silveira (2016). By teaching the caregiver to perform the activities and records, the objective was to intensify the weekly time of stimulation offered to the child, which would not be restricted to the 30 minutes of the session held in the institution, as the caregiver would do the activities with the child at other times, at the child's home.

The first step in implementing the intervention based on the training of caregivers consisted of training the institution's psychology professionals, which was provided by the authors of the manual (Gomes & Silveira, 2016). The objective of this training, undertaken in a course with a total duration of 16 hours, was to teach professionals to train caregivers to apply the teaching procedures and fill in the registration protocols presented in the manual. After the training, the institution started to outline the new intervention format.

Initially, the children were evaluated (A1: pretests) by psychology professionals from the institution. The OPI was applied through an interview conducted with those responsible for the autistic child. The CARS was filled out by a professional from the institution that provided care to the child. It took, for each autistic child, an average of four hours to apply the assessment instruments and carry out the data analysis. Then, the intervention was started. After 12 months, the children were evaluated again with the same instruments used in the initial assessment (A2: post-tests) in situations similar to the initial assessment. The same professional did not always apply the first and second assessments. The effects of caregiver empowerment were measured by comparing the developmental scores of the autistic children on assessments. As the caregivers performed the activities with the autistic children with, the improvement in the children's scores could indicate that caregivers followed the professionals' guidelines and were able to implement the teaching of the skills at home.

After the initial assessment, the coordinator of the institution's psychology sector talked to the child's family, explained the new intervention format, and, upon the family's consent, the child was assigned to the intervention. In order for the intervention to take place, the family had to indicate at least one caregiver to be guided in each psychology service session. It is important to emphasize that the caregiver of each child was designated by the child's family and was not always legally responsible for the child.

The service sessions lasted, on average, 30 minutes each and took place at the CER/Apae once a week. The sessions were attended by the institution's professional, the autistic child, and at least one caregiver who would be responsible for carrying out the activities with the child at their house. During the sessions, the psychology professional performed the activities with the child, in the presence of the caregiver, and taught the caregiver to do the activities and to record them in specific protocols, according to Gomes and Silveira (2016). As soon as the caregiver felt safe doing the activities and records, the professional would hand over a folder with the registration protocols so that the caregiver could do the activities and records at the child's home. The number of activities was gradually increased, depending on the performance and availability of the caregiver, that is, the professional only added new activities if the old ones were being performed and recorded properly, and the caregiver was willing to do new activities. Otherwise, no new activities were inserted. More than one activity could be performed simultaneously.

It should be noted that the teaching of skills specified in the manual was carried out by the caregivers, with the respective autistic child, following the systematic guidelines of specialized professionals. The professionals' instructions covered the teaching conditions – the preparation of the environment and materials –, materials presentation and instructions, the demand for an active response from the child, the presentation of consequences identified as potentially reinforcing, the criteria to complete each task or each program, among other aspects – such as the general management of the child's behavior. For each program, learning criteria, use of reinforcement, correction procedures, and the number of skills taught per session were specified. Caregivers also recorded, in specific protocols for each activity, the date of the activity, the

number of teaching attempts, and the child's performance. The protocols used were simple (in most cases, it was enough to mark × or ✓ for errors or successes), to facilitate the registration of caregivers, according to Gomes and Silveira (2016). The teaching procedures were based on behavior analysis, but no theoretical training was carried out with the caregivers, only practical and didactic guidelines were provided, with minimal use of technical terms.

In order to support the intervention of therapists, the coordinator of the psychology sector of the institution was guided by the authors of the manual, during sessions that took place once a week and lasted an average of one hour each. The coordinator was responsible for guiding the institution's psychology professionals and supervising the correct application of procedures.

Data collection was carried out in the psychology sector of the CER/Apae, through evaluations applied by professionals and activity registration protocols, completed by professionals and caregivers, which referred to the activities they performed with the children. Data collection and analysis were carried out between January 2017 and May 2020.

The procedures used in this study were approved by the Ethics Committee of the Faculty of Medical Sciences of Minas Gerais (Faculdade de Ciências Médicas de Minas Gerais [FCM-MG]). Two independent evaluators checked 30% of the evaluations, conducted by CER/Apae professionals. Interobserver agreement was calculated using the formula: agreements divided by the sum of agreements and disagreements, multiplied by one hundred (Kazdin, 1982). The coefficient of agreement for the evaluations was 100%.

Results

Participants were, on average, 3 years and 11 months old at the beginning of the intervention and 4 years and 11 months old at the end; 70.5% could speak at the beginning, and 82.3%, at the end. Table 1 presents the participants' individual scores in the OPI and CARS, in pre (assessment 1: A1) and post-tests (assessment 2: A2). At the bottom of the table, there are the data averages: the average OPI score indicated developmental gains; the average initial and final CARS score did not indicate significant change. The average of teaching programs introduced by professionals was 11.2, and the average of teaching programs carried out by caregivers at the children's homes was 9.7 (keeping in mind that, initially, the professional performed the activity with the child, in the presence of the caregiver, taught the caregiver, and this activity was only practiced at the child's home when the caregiver felt safe to do it). Most caregivers were the mothers.

Table 1

General characteristics of the participants: Participant; gender; chronological age; OPI score; CARS score; ability to speak; number of teaching programs introduced by the professional; number of teaching programs carried out at the child's home by the caregiver; caregivers

P ¹	Gender	Age		OPI ²		CARS ³		Speech		Programs	Home	Caregivers
		A1 ⁴	A2 ⁵	A1	A2	A1	A2	A1	A2			
P1	M	4y 9m	5y 9m	159	138	51.5	51.5	No	No	3	0	Grandmother
P2	M	3y	4y	173	231	33	36	No	No	5	4	Mother
P3	M	4y 10m	5y 10m	251	327	24	36	Yes	Yes	7	3	Grandmother
P4	M	4y 1m	5y 1m	188	311	32.5	30	Yes	Yes	7	3	Mother
P5	M	3y 1m	4y 1m	157	321	33	29	Yes	Yes	27	24	Mother
P6	F	2y 5m	3y 5m	183	260	27	30	Yes	Yes	23	20	Parents
P7	F	4y 9m	5y 9m	288	380	29	29	Yes	Yes	8	8	Mother
P8	F	4y 3m	5y 3m	291	413	35	36	No	Yes	19	19	Mother
P9	M	2y 5m	3y 5m	193	243	32.5	38	No	Yes	8	7	Mother
P10	M	3y 3m	4y 3m	267	364	29	29	Yes	Yes	6	6	Mother
P11	M	3y 10m	4y 10m	273	255	27	31	Yes	Yes	3	2	Mother
P12	M	5y 2m	6y 2m	414	472	35	36	Yes	Yes	4	2	Mother
P13	M	4y 4m	5y 4m	203	341	44.5	38	Yes	Yes	16	16	Mother
P14	M	4y 5m	5y 5m	159	190	34.5	36	No	No	5	4	Mother
P15	M	4y 4m	5y 4m	220	320	34	38	Yes	Yes	22	22	Mother
P16	M	3y 6m	4y 6m	408	311	38	31	Yes	Yes	6	6	Mother
P17	M	5y 1m	6y 1m	267	372	31	29	Yes	Yes	23	20	Mother
Average		3y 11m	4y 11m	240.8	308.7	33.5	34.3	70.5%	82.3%	11.2	9.7	

Note. ¹ P: participants; ² OPI: Operationalized Portage Inventory; ³ CARS: Childhood Autism Rating Scale; ⁴ A1: pretests; ⁵ A2: post-tests.

The data indicated variability in the number of educational programs carried out by the children. In relation to the programs introduced by the professionals, this number ranged from 3 to 27; in relation to the number of programs carried out by caregivers at the children's homes, this number ranged from 0 to 24. Due to this variability, the participants were divided into two groups for analysis: group 1 (G1), composed of children who participated in at least ten teaching programs (more than a third of the curriculum), and group 2 (G2), composed of children who attended less than ten teaching programs, as shown in Figure 1. A statistical treatment was performed using the Wilcoxon test (Field, 2009) for paired samples in order to verify whether there were significant differences in the performance of participants in pre- (A1) and post-tests (A2) in the OPI, considering groups 1 and 2. The means for G1 were 220.16 in A1 and 252.09 in A2, and, for G2, they were 337.87 in A1 and 292.90 in A2. Differences were considered significant at a probability level lower than .05 ($p < .05$). Above this value, the null hypothesis that the means

were identical would not be rejected. The results indicated a statistically significant value for G1 ($p = .02$) but not for G2 ($p = .68$).

Figure 2 shows the distribution of data for G1 and G2, in the initial (A1G1 and A1G2) and final (A2G1 and A2G2) assessments performed through the OPI. Regarding the initial assessments, there is greater variability in G2 than in G1, with higher mean and median. In the final evaluations, a greater variability is also observed in G2 than in G1, however, both the mean and median of G1 are higher than those of G2.

Overall, the data suggest that although the average score of the participants indicates improvements in children's development, due to the increase in the final average score compared to the initial score, a more detailed analysis of the participants, considering the number of teaching programs carried out, indicated that significant gains only occurred for the group that completed at least 10 basic skills teaching programs.

Figure 1

The bars represent individual score in the OPI, in the initial (A1) and final (A2) assessments. The rows represent the number of teaching programs introduced by professionals (programs) and the number of teaching programs that were carried out by caregivers at the children's homes (home)

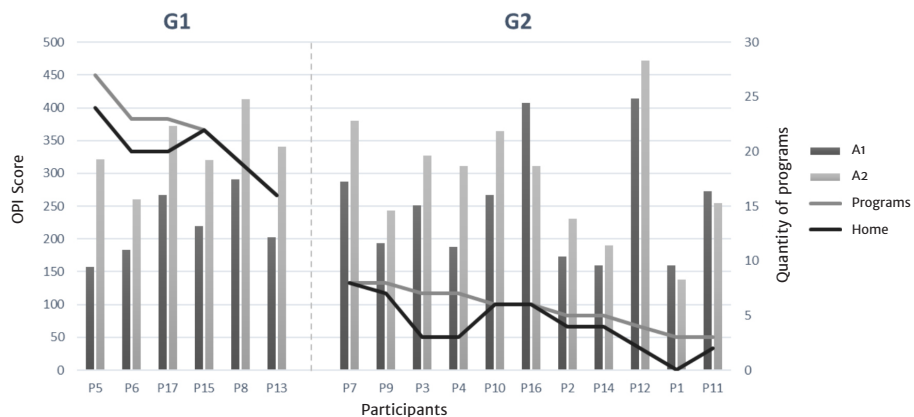
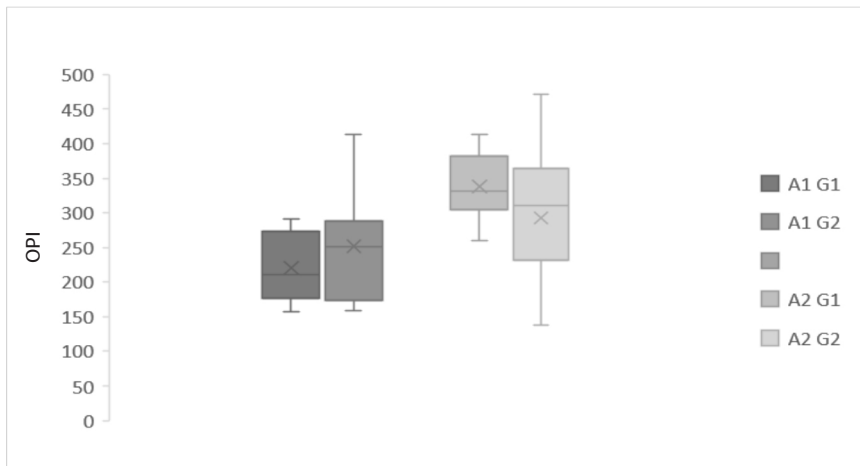


Figure 2

Data distribution for G1 and G2, considering the results of A1 and A2, carried out through the OPI



Discussion

The general objective of this study was to analyze the effects of applying the procedures described by Gomes and Silveira (2016) at an institution that provided care to autistic people financed by the SUS. Specifically, it was intended to describe the procedures used for the implementation of the care service for autistic children based on the training of caregivers, through the use of the manual by Gomes and Silveira (2016), and to analyze the effects resulting from this type of intervention in the development of the participating children.

The first topic to be discussed refers to the institution's receptiveness to the proposal of training caregivers and the availability of professionals to modify their previous practice, which made both the intervention and the research viable. However, the number of families who did not continue the treatment is high: out of the 55 children who started the intervention, 23 were dismissed for having many consecutive absences, which can be explained, in most cases, by social and financial reasons (e.g., lack of money/transport to go to the appointments, not having someone available to take the child). The analysis of the variables that compete with the permanence of families under care is essential to understand this situation and plan prevention or remediation strategies. It is important that future studies carried out with institutions similar to the one participating in this research plan the measurement of variables related to treatment dropout.

A group of 17 autistic children completed one year of intervention, and the data showed variability in relation to the number of educational programs carried out, thus, the children were divided into two groups for analysis. G1 was composed of six children who attended at least ten teaching programs, and G2 was composed of 11 children who attended less than ten teaching

programs. The development of children in both groups was measured before and after the intervention, as the increase in the OPI score (skills gain) could be an indicator of the effects of the intervention carried out through the training of caregivers. Statistical treatment was performed to check whether there were significant differences in the performance of participants in pre- and post-tests, and the analysis indicated a significant difference for G1 and not for G2. This fact is very interesting, as it suggests a relationship between the number of programs carried out and the gains in children's development, which makes a lot of sense, as more teaching programs indicate intensive intervention, and fewer programs indicate non-intensive intervention. Literature shows, quite consistently, that non-intensive interventions are not enough to promote significant improvements in various areas of development of autistic people (Medavarapu et al., 2019), which explains the fact that G2 did not show a significant difference in the analysis of pre- and post-tests. Another possibility is to consider that the improvement in the development score observed in G1 may have resulted from the children's maturation, as the passage of months may have resulted in gains in their development. However, this is unlikely. If that was the case, we would have similar results for G1 and G2.

In addition to the significant improvement observed in the assessments of the children in G1, which was probably due to the activities that caregivers performed with them, the results also indicated that it is possible to train caregivers at an institution financed by the SUS, as some caregivers were able to perform the activities under the guidance of specialized professionals. However, it is noteworthy that, despite the training of caregivers seeming to be a viable alternative for care via SUS, it was observed that only six caregivers, out of a total of 55 children, were able to follow the professionals' guidelines and perform intensive intervention. For most children, the attempt to train caregivers was not enough to promote significant improvements in development. Thus, the training of caregivers can be a valuable alternative to improve the low-intensity intervention carried out at institutions funded by the SUS, however, it is not an alternative that should be used indiscriminately and even less to replace the offer of specialized professionals and intensive, effective, and adequate interventions. Variables of caregivers (e.g., age, educational level, socioeconomic class, among others), professionals (e.g., education, experience, age, gender, among others), and children (e.g., time of therapy, medication, among others) should be investigated in further studies, in order to better understand which other aspects not explored in this study can influence the training of caregivers at this type of institution.

Final considerations

The results of this study are partially encouraging because they indicate an alternative to intensify the stimulation of autistic children who are treated at low intensity at institutions financed by the SUS. However, new studies should investigate other possibilities, as well as to explore the possibilities demonstrated here, with a stricter methodological control (in addition to the pre and post-test design), which provide other measures of the performance of children, caregivers, and professionals.

References

- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed). American Psychiatric Publishing.
- Andalécio, A. C. G. S. A. M., Gomes, C. G. S., Silveira, A. D., Oliveira, I. M., & Castro, R. C. (2019). Efeitos de 5 anos de intervenção comportamental intensiva no desenvolvimento de uma criança com autismo. *Revista Brasileira de Educação Especial*, 25(3), 389–402. <https://doi.org/10.1590/s1413-65382519000300003>
- Blanco, M. B., & Genari, A. P. G. A. (2017). Ensino de habilidades básicas para pessoas com autismo: Manual para intervenção comportamental intensiva. *Revista Diálogos e Perspectivas em Educação Especial*, 4(1), 131–134. <https://doi.org/10.36311/2358-8845.2018.v4n1.11.p131>
- Cakir, J., Frye, R. E., & Walker, S. J. (2020). The lifetime social cost of autism: 1990–2029. *Research in Autism Spectrum Disorders*, 72, 101502. <https://doi.org/10.1016/j.rasd.2019.101502>
- Field, A. (2009). *Descobrimos a estatística usando o SPSS-2*. Bookman.
- Garcia, S. C. M., Nascimento, M. A., & Pereira, M. (2017). Autismo infantil: Acolhimento e tratamento pelo Sistema Único de Saúde. *Revista Valore*, 2(1), 155–167.
- Gomes, C. G. S., & Silveira, A. D. (2016). *Ensino de habilidades básicas para pessoas com autismo: Manual para intervenção comportamental intensiva*. Appris.
- Gomes, C. G. S., Souza, D. G., Silveira, A. D., & Oliveira, I. M. (2017). Intervenção comportamental precoce e intensiva com crianças com autismo por meio da capacitação de cuidadores. *Revista Brasileira de Educação Especial*, 23(3), 377–390. <https://doi.org/10.1590/s1413-65382317000300005>
- Gomes, C. G. S., Silveira, S. D., Estrela, L. P. C. B., Figueiredo, A. L. B., Oliveira, A. Q., & Oliveira, I. M. (2021). Efeitos do uso de tecnologias da informação e comunicação na capacitação de cuidadores de crianças com autismo. *Revista Brasileira de Educação Especial*, 27, e0085. <https://dx.doi.org/10.1590/1980-54702021v27e0085>
- Gomes, C. G. S., Souza, D. G., Silveira, A. D., Rates, A. C., Paiva, G. C. C., & Castro, N. P. (2019). Efeitos da intervenção comportamental intensiva realizada por meio da capacitação de cuidadores de crianças com autismo. *Psicologia: Teoria e Pesquisa*, 35, e3523. <https://doi.org/10.1590/0102.3772e3523>
- Kazdin, A. E. (1982). *Single-case research designs: Methods for clinical and applied settings*. Oxford University Press.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3–9. <https://doi.org/10.1037//0022-006x.55.1.3>
- Medavarapu, S., Marella, L. L., Sangem, A., & Kairam, R. (2019). Where is the evidence? A narrative literature review of the treatment modalities for autism spectrum disorders. *Cureus*, 11(1), e3901. <https://doi.org/10.7759/cureus.3901>
- Pereira, A., Riesgo, R. S., & Wagner, M. B. (2008). Autismo infantil: Tradução e validação da *Childhood Autism Rating Scale* para uso no Brasil. *Jornal de Pediatria*, 84(6), 487–494. <https://doi.org/10.1590/S0021-75572008000700004>
- Romanczyk, R. G., & McEachin, J. (Eds.). (2016). *Comprehensive models of autism spectrum disorder treatment: Points of divergence and convergence*. Springer.
- Schopler, E., Reichler, J. R., & Renner, C. (1988). *CARS: The Childhood Autism Rating Scale*. Western Psychological Services.
- Smith, T., Buch, G. A., & Gamby, T. E. (2000). Parent-directed, intensive early intervention for children with pervasive developmental disorder. *Research in Developmental Disabilities*, 21(4), 297–309. [https://doi.org/10.1016/s0891-4222\(00\)00043-3](https://doi.org/10.1016/s0891-4222(00)00043-3)
- Williams, L. A., & Aiello, A. L. R. (2001). *Inventário Portage operacionalizado*. Mennon.

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