

Covid-19

Impact of Social Distancing on Parents of Children with Autism Spectrum Disorder

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Abstract

COVID-19 brought worldwide changes to the parenting routine. This study mapped the impact of social distancing on the interventions of parents of children with Autism Spectrum Disorder (ASD). Five hundred and fifty-three caregivers (98.7% mothers) of children with ASD responded to an online questionnaire about their interventions and formal support before and after the beginning of the pandemic. The results showed that a statistically significant number of parents exchanged a schedule of once-a-week professional supervisions for a schedule of “on-demand” supervisions during the pandemic. Furthermore, the hours of intervention conducted by parents at home remained unchanged during the pandemic, although they reported spending more time with their children in this period. Parental training on Applied Behavior Analysis (ABA) is discussed, but perhaps because parents seldom received prior training, more time with their children did not translate into an increase in well-planned and guided interventions by systematic professional supervision.

Keywords: Social Distancing; COVID-19; Autism Spectrum Disorder; Parents training; Applied Behavior Analysis.

IMPACTO DO DISTANCIAMENTO SOCIAL PARA OS PAIS DE CRIANÇAS COM TEA

Resumo

A COVID-19 trouxe mudanças na rotina de milhares de pais no mundo todo. O presente estudo mapeou o impacto do distanciamento social sobre pais de crianças com Transtorno do Espectro Autista (TEA). Quinhentos e cinquenta e três cuidadores (98.7% mães) de crianças com TEA responderam a um questionário online sobre suas intervenções e apoio formal recebidos antes e depois do início da pandemia. Os resultados demonstraram que, durante a pandemia, um número estatisticamente significativo de pais trocaram uma programação de supervisões profissionais uma vez por semana por supervisões “sob demanda”. Além disso, os horários de intervenção realizados pelos pais em casa permaneceram inalterados durante a pandemia, embora eles relatasse passar mais tempo com os filhos nesse período. O treinamento dos pais em *Applied Behavior Analysis* (ABA) é discutido, uma vez que, talvez por raramente terem recebido treinamento prévio, mais tempo com seus filhos não se traduziu em aumento de intervenções bem planejadas e orientadas por supervisões sistemáticas.

Palavras-chave: Distanciamento social; COVID-19; Transtorno do Espectro Autista; Treinamento de pais; Análise Aplicada do Comportamento.

IMPACTO DE LA DISTANCIA SOCIAL PARA LOS PADRES DE NIÑOS CON TEA

Resumen

COVID-19 trajo cambios en la rutina de miles de padres en el mundo. El presente estudio mapeó el impacto de la distancia social para los padres de niños con TEA. Quinientos cincuenta y tres cuidadores (98,7% madres) respondieron a un cuestionario en Internet sobre intervenciones y apoyo formal recibido antes y después del inicio de la pandemia. Los resultados mostraron que durante la pandemia, varios padres intercambiaron un horario de supervisión profesional una vez a la semana por supervisión “a pedido”. Además, los programas de intervención realizados por los padres en casa se mantuvieron sin cambios durante la pandemia, aunque informaron pasar más tiempo con sus hijos durante este período. Se discute la formación de los padres en ABA, ya que tal vez porque rara vez recibieron formación previa, más tiempo con sus hijos no se ha traducido en un aumento de intervenciones bien planificadas guiadas por una supervisión sistemática.

Palabras clave: Distancia social; COVID-19; Trastorno del espectro autista; Entrenamiento para padres; Análisis de comportamiento aplicado.

1. Introduction

Social distancing is a recognized and globally adopted practice to minimize the spread of the new Coronavirus (Covid-19), but it is a difficult reality for individuals who care for children who need regular therapeutic assistance, such as autistic children (American Psychological Association, 2020). In addition to limiting individuals' interaction in different work, social, and cultural contexts, the distancing brought about challenging changes in education and health care routines. With the closing of schools and clinics, interventions were interrupted, and parents need to deal with their child in this context, as well as coordinate new conditions brought about by social withdrawal, financial impact, and emotional distress (Gudi & Tiwari, 2020; World Health Organization, 2020).

Children with Autistic Spectrum Disorder (ASD) exhibit differentiated behaviors and deficits in domains that include impaired communication, social reciprocity, as well as restricted and stereotyped repertoire, which implies possible difficulties in linguistic and behavioral development (American Psychiatric Association, 2013; Myers & Johnson, 2007; Lord, Elsabbagh, Baird, & Veenstra-Vanderweele, 2018). Several prior studies have shown that the early administration

of intensive interventions based on the principles of applied behavior analysis (ABA) mitigates the main developmental and learning difficulties of children with ASD (Dueñas, Plavnick, & Bak, 2019; Gomes et al., 2019; Lovaas, 1993; Reichow, Barton, Boyd, & Hume, 2014; Wong et al., 2015).

Early intensive behavioral intervention (or EIBI) is an ABA treatment for young children that involves a one-to-one teaching procedure at the beginning (i.e., one adult to one child), which is subsequently implemented at home and school for two or more years, with a typical work schedule of 20 to 40 hours per week (Dueñas et al., 2019; Reichow et al., 2014; Wong et al., 2015). Prior studies have shown that children who received EIBI performed better on intelligence tests, social skills, language, and symptoms of autism than children who received other treatments (Gomes et al., 2019; Remington et al., 2007; Virués-Ortega, 2010). However, some authors note that several design limitations, such as small samples, lack of control groups, and randomization issues, as well as procedural differences among the extant studies (such as studies in which professionals' versus researchers' collected data) prevent a broader consensus about the strength of the current evidence supporting the EIBI (Reichow et al., 2014; Strauss et al., 2013).

However, there is consensus that families are an important factor for the success of behavioral interventions for children with ASD. Professional intensive care promotes cognitive improvements, but parents' inclusion extends these improvements and promotes adaptive and social benefits, such as a greater generalization and maintenance of learned behaviors (Rogers et al., 2012). Thus, in times of social distancing, an apparently viable alternative to avoid substantial losses in children's learning is to rely on parents' direct action in interventions. There is evidence that the efficiency of programs mediated by parents is greater when parents are actively involved in the interventions and when they receive the appropriate training (Beaudoin, Sébire, & Couture, 2014; Bagaiolo et al., 2018; Gomes et al., 2019; Lord et al., 2018; Strauss et al., 2013). For example, when parents are appropriately trained, parental management can improve the acquisition of daily living skills and reduce emissions of disruptive behaviors, even within short intervals (Bagaiolo et al., 2018, Virués-Ortega, 2010).

The efficiency of parental training involves several aspects, among them: (a) the expansion of the children's repertoire and the implementation of teaching techniques in daily routines; (b) changes in the patterns of interaction between

parents and children, which includes parents' confidence in their children's capacity to learn, and the perception of their ability to educate them; (c) changes in the parents' knowledge about ASD, development, and learning; (d) decrease in family stress, and; (e) decrease in the economic costs of interventions made exclusively by professionals (Estes et al., 2014; Rogers et al., 2012; McConachie & Diggle, 2006). We can prospect that, in the context of a planetary pandemic, all these spheres gain expression. Here, however, we focus on the patterns of interaction between parents and children with ASD, as well as on the parents' perceptions of these interactions when they need to conduct the therapeutic interventions, them being properly trained for that or not.

Parental training can be considered one of the most important pillars of the behavioral interventions for ASD, as it allows continuous learning opportunities for children by increasing the skills of their parents, who can achieve the status of "co-therapists" (Bagaiolo et al., 2018; McConachie & Diggle, 2006). However, recent studies suggest that parental training and parents' involvement as mediators or co-therapists is underutilized, as families of children with ASD continue to report parental training as an unattended service necessity (Ingersoll, Straiton, & Caquias, 2020). Studies have emphasized that many parents are dissatisfied with the available services and do not feel able to contribute to their children's treatment (Andrade et al., 2016; Pickard & Ingersoll, 2016; Pickard, Rowless, & Ingersoll, 2019).

Parents of children with ASD tend to exhibit high levels of stress, physical and psychological suffering, even though they report positive perceptions of having a child with autism (Sharabi & Marom-Golan, 2018; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Studies comparing parental stress and parenting responsibility between mothers and fathers of children with ASD revealed that mothers show greater responsibility than fathers (Hastings et al., 2005). In this sense, the combination of formal and informal social support would be the closest to what is adequate to guarantee families' quality of life and children's development. In general, the informal support provided by friends and family has been seen as sufficient to reduce mothers' stress (Sharabi & Marom-Golan, 2018). Formal support, that is, professional care and parental training, has different effects on the quality of the repertoires learned by children and on the continuity of treatment in everyday environments.

Considering the current scenario, relative to the effects of COVID-19, people with disabilities can be considered belonging to a risk group due to secondary health conditions, a fact that increases the caregiver's stress. Thus, although parental involvement in interventions is generally considered beneficial, we face a completely atypical situation in which changes in the routine, lack of knowledge, lack of proper planning, and emotional exhaustion can be factors that further increase parental stress. In this situation, we can assume that the ideal would be for parents to be better prepared, which seems far from the reality, since access to quality information about ASD is limited. In addition, a small portion of family members get involved in training programs, and even when they participate, the effectiveness of these programs is not guaranteed, especially in the Brazilian scenario (Bagaiolo et al., 2018).

Thus, the question that guided us in this study was: How do parents perceive and manage the current context in which they were compelled to act as co-therapists of their children? Therefore, our goal was to map the initial impact that social distancing had on the perception and performance of parents with their children with ASD. Along with some data to characterize the sample, the following main factors were mapped: hours of intervention applied by caregivers at home; frequency and type of weekly supervision received from professionals; hours dedicated to studies on ASD, and perceived effectiveness of their role in teaching skills to their children.

2. Method

2.1 Sample

The recruitment of the sample was carried out by advertising the study on the social networks. Three profiles of the researchers on Instagram were used, one of them being a profile especially focused on ASD and motherhood topics, and a national WhatsApp group for parents and caregivers of children with ASD and other neurodevelopmental disorders. Five hundred and fifty-three Brazilian parents of children with ASD participated in the study. The inclusion criteria for sample selection were two, clearly explained at the beginning of the questionnaire. They consisted of having a child diagnosed with ASD and having received some type of in-person therapeutic assistance for the child diagnosed with ASD before

the pandemic. The research was part of a broader project on the relationship between professionals and parents of children with ASD, and was approved by the Research Ethics Committee of the Federal University of Minas Gerais (CAAE: 49078215.8.0000.5149, parecer 1350922).

2.2 Materials and procedures

An online questionnaire was available for three weeks (from March 30th to April 20th of 2020) and was answered individually by parents of children with ASD. The questionnaire had “yes” or “no”, and multiple-choice questions (which allowed only one answer).

After participants read and agreed with the Consent Form, 24 questions were presented, divided into four sections: Section 1 was a sociodemographic survey, which served to broadly characterize participants for age, gender, number and age of children, education, and professional activity. Sections 2 and 3 comprised questions that served to characterize the interventions and services received and performed by parents, especially asking about changes in interventions before and after the beginning of the pandemic. These questions aimed to identify the frequency and type of the professional supervision received, hours of intervention prescribed by the therapist and applied at home by parents, and hours dedicated to the study of ASD, before and after the beginning of social distancing. Section 4 focused on identifying factors that promote or prevent the effectiveness of the parents' interventions, and aimed specifically at producing a general map of how parents perceive their performance in teaching skills to their children.

2.3 Data analysis

The strategy used for the analysis of the data was quantitative and descriptive, with the characterization of the participants' relative frequencies of responses. In the statistical analysis, we used Chi-square tests for data on the frequency of supervision received by parents, and t-tests to compare the average hours of intervention and the average hours of study performed by parents, before and after the beginning of the pandemic.

3. Results

3.1 Section 1

Figure 3.1.1 shows the data of the sociodemographic characterization of the sample. We highlight the fact that the sample was mainly composed of women (98.7%) and most participants were between 21 and 40 years of age (87.6 %). As for schooling, 78,7 % had undergraduate or graduate degrees. Most responders had only one child (58%) and had children with 2 to 4 years of age (68.6 %). Considering the parents' professional activities, 44.1% of participants reported not working, whereas 27.1% responded that were working at home during the pandemic.

Figure 3.1.1. Sociodemographic results.

Variables	n (553)	%
Sex		
Female	546	98.7
Male	6	1.1
Did not answer	1	0.1
Age (years)		
Less than 20	4	0.7
Between 21 and 30	143	25.9
Between 31 and 40	341	61.7
Between 41 and 50	63	11.4
More than 50	2	0.3
Educational level (complete or incomplete)		
Primary education	6	1.1
High school	112	20.3
University graduate	241	43.6
Postgraduate	194	35.1
Job status		
Doesn't work	244	44.1
Working from home during quarantine	150	27.1
Lost or left a job in the pandemic	66	11.9
Keeps going out to work	93	16.8

Figure 3.1.1. Sociodemographic results.

Variables	n (553)	%
Number of children		
One child	321	58
Two children	186	33.6
More than three children	46	8.4
Age of the child with ASD (years)		
One or less	20	3.6
Two	130	23.5
Three	145	26.3
Four	104	18.8
Five and six	98	17.7
Seven or more	56	10.1

3.2 Sections 2 and 3

Considering the theoretical-scientific basis of the interventions received by children, when parents were asked whether they were based on Behavior Analysis (i.e., ABA, DTT, DENVER, or similar), 77.3% answered yes, that the intervention was based on Behavior Analysis, while the remaining 22.7% answered no. We, then, performed a comparison between the responses of the participants about the characteristics of the interventions before and after social distancing regarding: frequency of professional supervisions per week, hours of intervention conducted by parents per week, and hours dedicated for the study of ASD per week.

The results for the frequency of supervision received by professionals per week are shown in Figure 3.2.1, before and after the beginning of social distancing. From the 553 parents who responded to the questionnaire, 321 (58.0%) responded positively about having professional supervision before the pandemic, a number that dropped to 311 (56.24%) during the pandemic. As can be seen in Figure 3.2.1, while the number of parents receiving one professional supervision per week diminished drastically after the beginning of social distancing, the number of parents receiving professional supervision on demand increased considerably in the same period. Interestingly, there was no evident change in the frequency of parents having 2 or more days of supervision per week. To verify whether such patterns are statistically significant, we conducted a Chi-Squared independence test in a 2 x 3

contingency table for the factors before/after (before and after the beginning of social distancing) and frequency of professional supervisions per week (1, 2 or more, on-demand), with the significance level of $p < 0.05$. The Chi-Squared yielded a significant effect, $\chi^2(2, N = 311) = 15.17, p = .001$, suggesting that the patterns shown in Figure 3.2.1 represent a reliable effect.

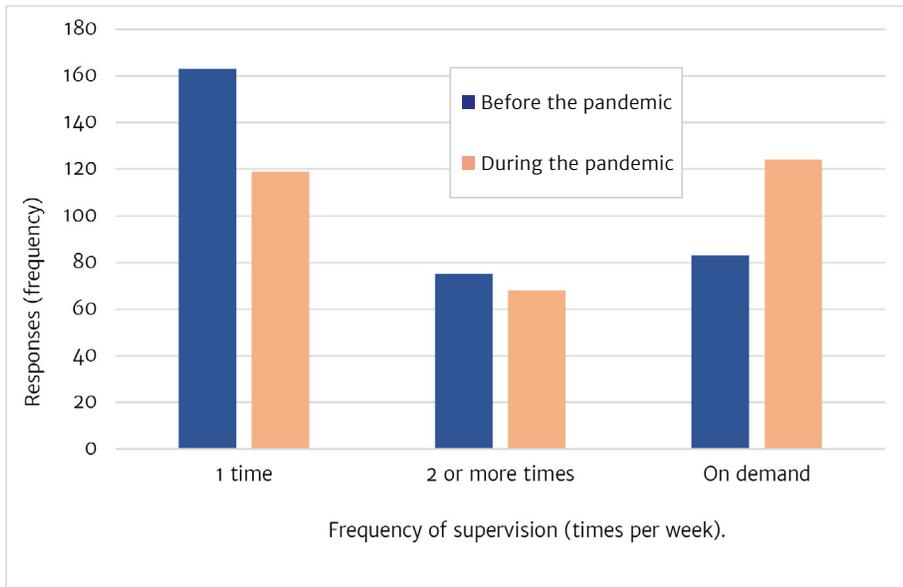


Figure 3.2.1. Frequency of supervision received by parents before and during the pandemic, in weekly hours.

To analyze the hours of intervention performed by the parents, we conducted a t-test, contrasting the mean weekly hours of intervention performed by parents before and during the pandemic. Before the onset of the pandemic, parents performed, on average, 3.33 hours of intervention per week ($SD = 4.10$), while during the pandemic, they performed on average 3.39 hours of intervention per week ($SD = 3.92$). This difference was not statistically significant, $t(552) = 0.36, p = 0.718$.

The detailed results concerning the hours of intervention prescribed by therapists and applied weekly by caregivers are shown in Figure 3.2.2. The data

shown in the table is consistent with the statistical results, and further suggest that the hours of intervention parents conducted per week were not affected by the onset of social distancing.

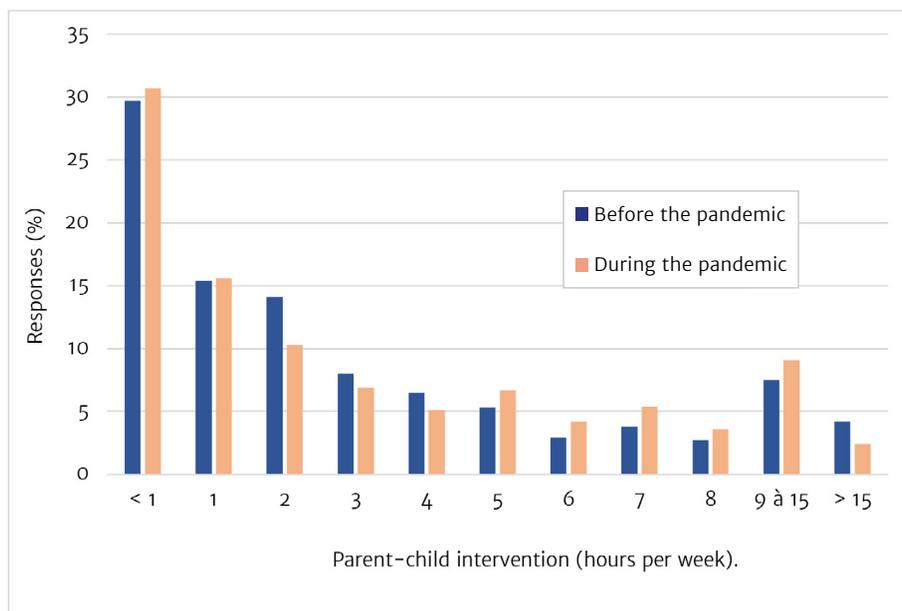


Figure 3.2.2. Frequency of weekly hours of parent-child interventions at home, before and during the pandemic.

In response to the question “Have you ever participated in person in any classroom training for parents before the pandemic?”, most parents answered “no” (72.8%), a finding that indicates that most parents lacked more formal training on how to intervene with their children. However, for the broader question “How frequently have you participated on classes, online courses, watched videos, or read online materials about autism?”, 80.83% of the parents responded “yes” before the pandemic, a number that dropped to 66.91% during the pandemic.

To formally examine whether the mean amount of hours dedicated by parents to the study of autism diminished after the beginning of social distancing, we conducted a t-test comparing the average hours dedicated by parents to the

study of autism before and after the beginning of the pandemic. The test showed a significant result, $t(552) = 2.49, p = 0.013$, indicating that parents diminished the hours per week they dedicated to the study of autism after the beginning of the pandemic. A more detailed exposition of these findings is shown in Figure 3.2.3. As can be seen in the figure, a great amount of parents who dedicated a few hours per week for the study of autism before the beginning of the pandemic (1 to 3 hours), reported dedicating less than 1 hour of study per week after the beginning of the pandemic.

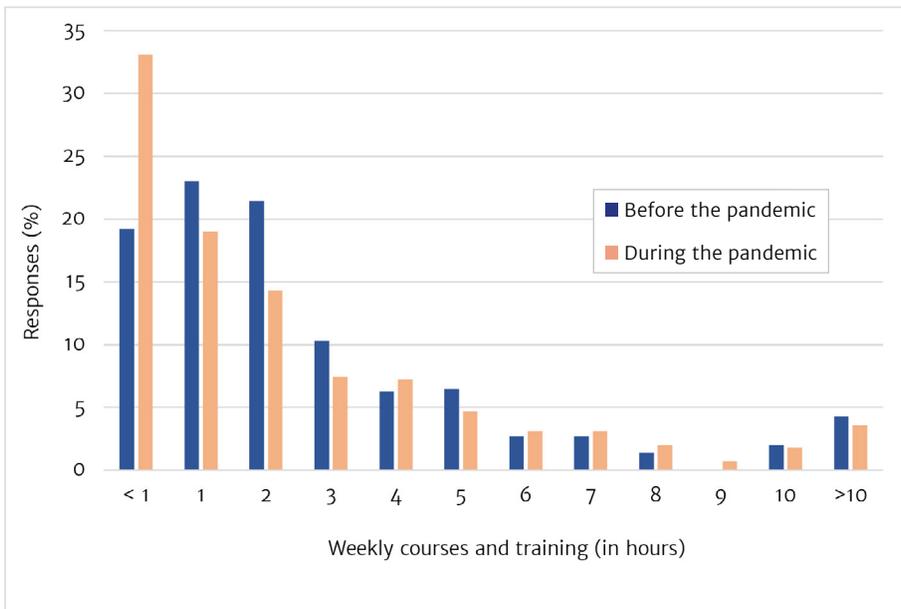


Figure 3.2.3. Weekly hours dedicated by parents to studies on ASD.

3.3 Section 4

On this section, the participants responded to two questions about the routine at home after the beginning of the pandemic. The first one was whether there was a well-established daily routine at home during the pandemic, to which 34.4% of parents answered yes and 65.6% answered no. The second question was:

“Can you follow the planned/established routine most of the time?”, to which 31.8% of the parents answered yes and 68.2% answered no.

Also, after the beginning of the social distancing, 48.8% of the parents reported that they have daily teaching goals to work with the child, while 51.2% answered that did not have daily goals. Interestingly, most parents (84.8%) reported perceiving themselves as not skilled in the interventions they were conducting. Nonetheless, a rate of 70.7% of them responded perceiving an increase in the child’s motivation during the activities they conducted, and 68.2% evaluated that they managed to teach their children something new.

Regarding the probable factors that hinder the interaction with their children, 70.7% of the sample answered that they feel that the child was more “unregulated” or with greater behavioral difficulties after the beginning of social distance. When asked if they feel more capable of playing and proposing activities for their child after the beginning of the pandemic, 52.1% answered yes, while 47.9% who answered no.

4. Discussion

The goal of the current study was to map the impact of social distancing on parents’ role in their interventions for children with ASD. It was possible to identify some effects brought by the social distancing on the quality of the parents’ interventions with their children, as well as their perception about their interventions. The results revealed that, with the beginning of the pandemic, the number of parents who replaced a schedule of professional supervision once a week for supervision “on demand” increased; conversely, the hours dedicated to the study of ASD per week decreased during the pandemic. Furthermore, the intervention schedules performed by parents at home remained unchanged during the pandemic, although they reported spending more time with their children during this period. Focusing specifically on parents’ interventions, the new conditions of social distancing revealed the need for planned training and further professional supervision/monitoring for parents.

Our sample was composed mainly by mothers (98.7%). We speculate that the pandemic and the social distancing intensified the stress faced by mothers, considering that the responsibility tends to fall on women in caring for their children, possibly due to cultural factors related to outdated gender norms about

the roles of mothers as caregivers and fathers as financial providers (Rankin et al., 2019). Despite the importance of this issue, which should be approached in future research, we do not intend to make an in-depth analysis of this aspect here, especially because one of the limitations of the current study is that the marital status of the participants was not questioned, so part of these mothers may be single or divorced. Regardless, there is a reported gap in the literature concerning the underrepresentation of fathers in research, which justifies further investigations on their role in working with children with ASD (Rankin et al., 2019). In sum, future research may circumvent this important limitation by investigating whether the participants' marital status can have an effect on the interventions conducted by parents on children with ASD. For example, are there any differences in the hours dedicated to professional supervision or to the study of ASD between mothers who are married and single mothers who live alone with their children? Or are there any differences in the type of formal and informal support mothers receive according to their marital status?

Considering education, our participants have a high educational level (78.7% had undergraduate or graduate degrees). However, 44.1% reported not working even before the pandemic, and, considering the predominant participation of mothers, it is a result that reinforces the hypothesis about cultural factors related to the gender norms of maternal and paternal roles. Specifically in the case of disabled children, higher levels of education in mothers was correlated to increased knowledge about child development and care, although the assumptions are considered still exploratory regarding the relationship between parents' education and their knowledge about children development. Education is also related to the welfare of the parents, so that a higher degree of formal education seems to be positively related to parents' positive affect, as well as more access to formal and informal support (Sharabi & Marom-Golan, 2018; Trivette, Dunst, & Hamby, 2010).

Thus, regarding the characterization of our sample, it is important to make it clear that it was a sample selected by convenience, recruited through publication on social networks, which certainly can bring bias regarding the generalization of the data if we took into consideration a population without easy access to the internet. Although socioeconomic status was not part of the study's questions, we can assume that facilitated access to social networks probably limited the sample

to a more educated population with a higher socioeconomic status. Future research may be devoted to investigate the same issues with a population with lower socioeconomic and educational levels.

Considering professional activity, about 27% of the participants responded they were working at home since the beginning of the pandemic. Adding this percentage to those who reported not having a professional activity, together with those who lost or quit their jobs, over 80% of the participants were with their children at home at the beginning of social distancing. This fact, however, apparently does not reflect on the quality of the intervention they performed with their children, as evidenced by the results for formal support (frequency of supervisions, hours of intervention, and hours dedicated to the study of ASD), and the responses indicating that parents did not perceive themselves as appropriately skilled in their interventions. Interestingly, however, around 70% responded that they perceived their child's motivation to grow during the interventions they conducted, and considered that they managed to teach something new during social distancing. Such incongruence in their responses suggests that they considered that their interventions had some positive effect on their child, but they did not relate this effect to formal knowledge, which, in their case, is presumably deficient.

The present study showed that, after the beginning of the pandemic, there was stability in the distribution of the weekly time devoted by parents to interventions at home. Importantly, a large percentage of the parents conducted an hour or less of intervention per week, both before and after the pandemic. Based on EIBI and other behavioral interventions, there is some evidence that treatment effectiveness, especially for younger children, depends on intensity and frequency (Eldevik, Titlestad, Aarlie, & Tønnesen, 2020). Our results show, therefore, a certain urgency: more hours of dedication to interventions at home imply, among other factors, greater frequency and quality of professional supervision and training.

Approximately half of our sample received weekly supervision with their child's therapist, both before and during the pandemic, which can be considered a low percentage of parents given their sociodemographic characteristics (time available and education). However, the results show a change that was statistically relevant in the frequency of this formal support, that is, parents received more

supervision on-demand after (39.9%) than before (25.9%) the beginning of the pandemic. Another fact that we highlight is that, although it is a relatively low percentage of the sample, more parents started to receive supervision on a daily basis (from 2.8% to 6.4%).

The change in the supervision frequency is probably due to social distancing, which required that the parents themselves intervened at home with their children. A result supporting this hypothesis is that, while parents resorted to supervision on demand, the weekly hours dedicated to studying ASD decreased. That is, the need to perform interventions on their own increased the need for professional supervision, but the existence of further demands resulting from social distancing left the parents without enough available time to focus on qualifying their knowledge about ASD.

We argue that parental training is one of the most important pillars of behavioral intervention for ASD. Our results led us to conclude that several factors seem to indicate the need for formal training and efficient support for parents. Thus, we highlight the need for more training opportunities for parents (72% had never received training), accompanied by professional monitoring of the quality of the interventions performed by them.

Nonetheless, it is important to consider that ABA-based interventions involve an elevated number of hours of dedication. Consequently, it implies high financial costs and a great amount of emotional commitment from parents. However, some principles of the approach are important to guarantee, such as structuring training with goals, discrete attempts, and one-to-one interventions. The challenge is to preserve these principles in training without necessarily needing an average of 30 hours per week, which seems to be unfeasible for parents overwhelmed with the new routine at home, especially during social distancing.

An alternative that can boost future research on this field is the implementation of behavior analytic teaching strategies for children with ASD via planning and evaluation of online training for caregivers (Blackman, Jimenez-Gomez, & Shvarts, 2020; Hamadneh Alazzam, Kassab, & Barahmeh, 2019; Pennefathera, Hienemanb, Raulstona, & Carawaya, 2018). Researchers can design trainings with different characteristics and for different purposes and examine how they affect the effectiveness of parents and the quality of repertoires learned by children, and what specific tools or resources parents have found to be more useful. In sum, the current results reveal the need for further investments in the

qualification of ABA professionals, in a manner that they can create greater opportunities for interaction, guidance, and interventions with parents of children with ASD through the web.

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