PARENT IMPLEMENTED INTERVENTION AND PARENT EMPOWERMENT FOR AUTISM SPECTRUM DISORDER

Jéssica Jaíne Marques de Oliveira 1; Carlo Schmidt 2; Daniele Pincolini Pendeza 2

ABSTRACT

The literature has highlighted the importance of the active role played by the family in interventions with autistic children. Parental empowerment redefines the situation for parents. They cease to be passive subjects and grow into active agents in control of their actions, contributing to the achievement the desired goals. The objectives of this study were: 1) to produce an assessment on the effects of an intervention implemented by the parents on the socio-communicative skills of the mother and her autistic child; 2) to verify the influence of this intervention on parental empowerment. Sixteen episodes of mother-child interactions were filmed before and after the intervention in order to assess its effect on the socio-communicative skills of a mother and her autistic child. A scale assessed parent empowerment in the pre- and post-intervention moments. The results showed an increase in both the dyad’s socio-communicative skills and parent empowerment.

Keywords: Early intervention; Autism Spectrum Disorder; Empowerment.

Intervención implementada por los padres y empoderamiento parental en el trastorno del espectro autista

RESUMEN

La literatura ha destacado la importancia del papel activo de la familia en las intervenciones con el niño con autismo. El empoderamiento parental viene resignificar el papel de los padres, sacándolos de una posición pasiva, sumisa, para actuar como agentes activos que asumen el control de sus vidas, contribuyendo para alcanzar las metas deseadas. Los objetivos de este estudio fueron: 1) evaluar los efectos de una intervención implementada por los padres sobre las habilidades socio comunicativas maternas y del hijo con autismo; 2) verificar la influencia de esta intervención sobre el empoderamiento parental. Dieciséis episodios de interacción del acople madre-niña fueron filmados antes y después de las orientaciones a los padres para evaluar el efecto sobre las habilidades socio comunicativas de una madre y su hijo con autismo. Una escala evaluó el empoderamiento parental en los momentos antes y tras intervención. Los resultados apuntan un aumento tanto de las habilidades socio comunicativas del acople cuanto del empoderamiento parental.

Palabras clave: Intervención precoz; Autismo; Empoderamiento.

Intervenção implementada pelos pais e empoderamento parental no transtorno do espectro autista

RESUMO

A literatura tem destacado a importância do papel ativo da família nas intervenções com a criança com autismo. O empoderamento parental vem ressignificar o papel dos pais, tirando-os de uma posição passiva, sumissas, para atuarem como agentes ativos que assumem o controle das suas vidas, contribuindo para alcançar as metas almejadas. Os objetivos deste estudo foram: 1) avaliar os efeitos de uma intervenção implementada pelos pais sobre as habilidades sociocomunicativas maternas e do filho com autismo; 2) verificar a influência desta intervenção sobre o empoderamento parental. Dezesseis episódios de interação da díade mãe-criança foram filmados antes e depois das orientações aos pais para avaliar o efeito sobre as habilidades sociocomunicativas de uma mãe e seu filho com autismo. Uma escala avaliou o empoderamento parental nos momentos pré e pós intervenção. Os resultados mostraram um aumento tanto das habilidades sociocomunicativas da díade quanto do empoderamento parental.

Palavras-chave: intervenção precoce; autismo; empoderamento.

1 Faculdade Integrada de Santa Maria – Santa Maria – RS – Brasil; jessica.oliveira@fisma.com.br
2 Universidade Federal de Santa Maria – Santa Maria – RS – Brasil; carlo.schmidt@ufsm.com.br; danielependeza@gmail.com
INTRODUCTION

Autism Spectrum Disorder (ASD) is characterized by difficulties in social communication combined with restricted and repetitive behaviors, activities and interests (American Psychiatric Association [APA], 2013). ASD is classified as a developmental disorder. Understanding this condition requires a developmental approach that situates its differences and similarities in comparison to typical development processes. Some of the earliest and most predictive signs of subsequent communication difficulties associated with this disorder can be identified in the first year of life (Rice, Adamson, Winner, & McGee, 2016). According to the pragmatic approach of communication, the basis of children’s socio-communicative development begins in the first semester of life with the recognition and reciprocal coordination of intentions in the interaction between mother and baby, named primary intersubjectivity (Trevarthen, 1974). This stage is characterized by the simultaneous occurrence of two activities, the first one is the adoption of a focus of Shared Attention (SA). The second one is an agreement regarding the nature of communication between mother and child. However, especially during the secondary intersubjectivity, in the second semester of life, there is the emergence of behaviors reflecting shared interests in the social world, including a third object of attention, in addition to the mother-baby dyad. At this stage, the first difficulties in children with autism are associated with the use of gestures and eye contact in order to direct another person’s attention to objects or events. These failures in reciprocity and synchronicity of shared attention affect the entire subsequent communication process, including language (Trevarthen, 2016).

Intersubjectivity is gradually constructed by means of newborns’ acquisitions of various vital skills throughout their developmental stages, and by means of their engagement in social interactions that lead to the development of affective bonds of attachment (Trevarthen, 1974). The latter are essential because they are resources at the service of our human social nature. They are capable of ensuring the survival of our species. For this reason, it is understood that affection processes are inseparable from cognitive processes. They are intertwined processes underlying the initial development of communication, which justifies the fact that interventions with children with autism affect these aspects (Bosa, 2002).

Despite the existence of a variety of interventions aimed at promoting the development of socio-communicative skills of children with autism in the literature, few have been recognized as really effective (Camargo & Rispoli, 2013). The most recent report by the NPDC (National Professional Development Center) highlights 27 interventions considered effective for children, young people, and adults with autism, called Evidence-Based Practices (EBP), or “Práticas Baseadas em Evidências” (PBE) (Wonget al., 2014). The Intervention Implemented by Parents (Parent-Implemented Intervention - PI) has met the criteria required by the NPDC to be considered an EBP, with nine randomized or almost experimental studies with children between two and nine years of age (NPDC, 2018).

In this intervention model, parents are instructed on how to develop skills in areas such as social communication, conversation, spontaneous language, shared attention, and interaction in their home environment (Wetherby et al., 2014). There are two central pillars supporting the Parent-Implemented Intervention; the first one concerns the partnership between parents and researchers. The adoption of an ecological perspective for the intervention is recommended since it is an approach centered not only on the demands of the child, but also on the whole family. The second aspect is parental participation. Parents must be intensely involved in the intervention so that they become active agents in this process. In other words, intervention can also empower parents, by increasing their resources, in addition to the benefits for the children (Stahmer & Pellecchia, 2015).

There is a consensus in the literature that families of people with autism need interventions that, in addition to the benefits for their children, consider the maintenance and strengthening of their family unit (Franco, 2015; Serrano & Pereira, 2011). The Family Centered Approach (FCA), OR “Abordagem Centrada na Família” (ACF), is based on an understanding that the family is the matrix for promoting children’s social and cognitive development and, therefore, needs to be considered as a central factor in interventions (Serrano & Pereira, 2011). According to this type of approach, in addition to the direct benefits for children, interventions should aim to assist parents regarding the decisions to be made in favor of their children, such as in the management of their behaviors or even in the choice of health and education services. Thus, it is necessary to strengthen the partnership between family and professionals so that individualized services can be selected according to the beliefs, values and objectives of each family (McConnell, Parakkal, Savage, & Rempel, 2015; Jones & Passey, 2004). Encouraging results have been reported in studies using the FCA on people with autism, including increased family involvement in interventions (Christon, Arnold, & Myers, 2015; Dunst, Trivette, & Hamby, 2012; Fernandes, 2009; Serrano & Pereira, 2011; Weiss, MacMulin, & Lusky, 2015).

In this sense, the empowerment of parents begins to take prominence as an important variable in several studies aimed at the development of people
with disabilities (Vivanti et al., 2018). The term empowerment is defined as the process in which people acquire better control of their lives, which contributes to the achievement of their desired objectives, by means of access to knowledge, as well as to the resources and techniques of developed skills (Anuradha, 2004; Singh & Titi, 1995; Turnbull & Turnbull, 2001). Parent empowerment allows parents to overcome their passive position, in which they must accept everything and submit, and become proactive players who can, in addition to discussing their problems, find solutions in order to make wise decisions in the process of social transformation (Kate, Ross, & Sara, 2014).

Thus, parent empowerment is a dimension that accompanies the current trend of interventions for the strengthening of families and their positive aspects. According to Roux, Sofronoff, and Sanders (2013), “when caregivers are well informed and trained, a smaller amount of their mental health is at risk, in addition to greater benefits to the adaptive functioning of children” (p. 415).

Studies involving the active participation of families in the context of intervention with autism are scarce. For example, Fernandes’s review (2009) revealed that out of 1096 articles found in a search in publications such as the “Journal of Autism and Developmental Disorders”, and “Focus on Autism and Other Developmental Disorders and Autism” between 2005 and 2009, only 5% (39) involved family and autism. Only five of these 39 studies involved interventions that actively included families.

One of the few studies of this nature in the Brazilian reality is the one by Fernandes, Amato, Balestro and Molini-Avejonas (2011), which aimed to verify the results obtained after the realization of ten specific orientation sessions for mothers of children with ASD on the communication and language skills of their children. The participants (26 dyad mothers and children) were patients of a speech therapy service specialized on ASD. The mothers attended ten sessions, five orientation sessions, and five group follow-up sessions, concomitant with the maintenance of the children’s speech therapy process. Filming of therapy sessions identified the functional profile and communication and the socio-cognitive performance of the children, and the mothers were also interviewed individually. Results show that, concerning communication and language, it was possible to perceive aspects related to getting children to pay more attention, the search for activities to do together or communication initiatives, as well as the use of toys of interest to the children as important tools for success in interactions. The individualized analysis of the children showed that all individuals made progress in one of the areas investigated, highlighting the importance of family involvement in interventions.

Another recent study also involved a family directly in an intervention with their autistic child (Schmidt, Kubaski, Bertazzo, & Ferreira, 2015). With the support of other intervention professionals (facilitators), the parents were the protagonists when they became daily involved, for 12 months, in an intensive intervention with their child at home. Despite the gains reported in the development of communication and interaction skills of children with autism, the results pointed at the influence of the implementation of this program on the family routine, largely due to the daily presence of facilitators in the family residence. The authors highlighted the importance of protecting the families from such stressor, reinforcing the importance of parents as active agents in interventions.

A systematic review of the literature on intervention implemented by parents assessed 15 articles on the development of social skills in children with autism (Andrade, Ohno, Magalhães, & Barreto, 2016). Results corroborate the benefits of this intervention on social communication, resulting in an increase in the frequency of communicative acts and fuller social engagement by the children, as well as an increase in spontaneous social responses. Concerning parents, most studies reported increased levels of quality of life, while the results on parental stress were controversial, showing that this variable remained unchanged in some studies and decreased in others. However, the authors note that parental empowerment was not directly contemplated as a variable by any of the studies in this review (Andrade et al., 2016).

Parent-implemented Interventions on autistic children show promising results, especially on the development of the children’s socio-communicative skills. However, studies disregard possible influences on parent empowerment. Thus, in view of what was pointed out in the literature, the objectives of the previous study were: 1) to assess the effects of a parent-implemented intervention on the socio-communicative resources of mother and autistic children; 2) to verify the influence of this intervention on parent empowerment.

**METHOD**

**Research Design and Participants**

In order to verify the effect of a Parent-Implemented Intervention (independent variable) on the socio-communicative skills of the dyad (dependent variable), a single-case A-B-type design (Nunes & Walter, 2014) was used. In order to verify the effect of this intervention on parent empowerment, the Family Empowerment Scale (FES) was applied before and after the intervention (Sampieri, Colado, & Lucio, 2013).

The study focused on a family composed of a father, a mother, and their autistic son, living in a city in the countryside of the state of Rio Grande do Sul.
The mother was 31 years old and had formation in healthcare, but was not operating professionally in the field, while the father, aged 36, worked in a railway company. Their child was 15 months old at the beginning of the study, when he was examined for suspected autism. The child did not yet attend a regular school and did not present verbal language, or any other associated disorders (motor, visual, auditory), or known medical conditions. The child’s restlessness in the mother’s arms and lack of eye contact caught the mother’s attention and made her decide to seek medical assistance. The diagnosis of Autism Spectrum Disorder was confirmed by a neuro-pediatrician based on the DSM-5 criteria (APA, 2013).

Instruments

**Family sociodemographic data sheet:** general family data, such as sources of information on autism, places and contexts of parents’ daily interactions with the child, family routines, anamnesis and current behaviors of the child.

**Field diary:** Written by the researcher after each meeting with the parents. It consisted of four axes: 1) Themes approached during the meeting; 2) Guidance given to parents; 3) Parents’ questions; and 4) Parents’ engagement to the guidelines.

**Family Empowerment Scale - FES – Modified version** (Koren, Dechillo, & Friesen, 1992): Likert scale of 5 points with a total sum of 34 items that assess the perception of empowerment by families whose children have some disability, originally composed of two scale dimensions: level of empowerment (family, services and community); and expression of empowerment (attitude, knowledge, and behavior). The present research used only the level of family empowerment of the first dimension and the three forms of the second (attitude, knowledge, and behavior). The total sum was 12 items. The methodology of translation, back translation, and evaluation of semantic equivalence of the scale was used. The instrument was translated from English to Portuguese by a bilingual translator. Then another translator, without any reference to the original version, performed the translation back from Portuguese into English (backtranslation). The final stage consisted of the formal assessment of semantic equivalence in which the general and referential meanings of the terms and expressions of the 12 items of the adapted scale were evaluated. The two versions were compared, and questions were answered by an external judge. A good level of equivalence was verified between the items.

**Script for interview on parents’ knowledge and expectations regarding their child’s communication skills:** Assessment on the family’s previous knowledge about autism and intervention, as well as their expectations about the child’s development, including the perception of the child’s abilities and difficulties.

**Protocol for observing parent-child interaction:** Used to codify two classes of socio-communicative behaviors (Sharing of Topics and Shared Attention) during episodes of parent-child interaction, based on an observation manual adapted from Bosa and Sousa (2007). The topic-sharing category includes verbal and nonverbal gestures and behaviors used by the mother to share a topic with the child, engage the child in play/activities, and focus attention on activities already initiated by the child, maintaining interaction by means of objects and events. The shared attention category is characterized by childish behaviors in which the child aims to start an activity/play, shares interests and discoveries with parents, or responds to their stimuli.

**Procedures**

The parents answered the Sociodemographic Data Sheet of the Family and the FES scale, in their residence, before starting the intervention, followed by the interview on knowledge and expectations regarding the child’s communication skills. In the second meeting, the researcher and the parents agreed on the standardization of the filming, while defining that the mother’s interaction with the child would be filmed by the father, in the place chosen as the most appropriate in the house (toy room), with the provision of objects of interest that favored interaction (toys, table, chair...). Each filmed episode lasted 5 minutes. The filming took place weekly for 3 months (total number of 16 meetings). The baseline comprised the first four episodes and was closed after verification of the stability of the socio-communicative behaviors of the dyad (variance <50%). The intervention phase comprised 12 meetings between researcher, research assistant, and parents.

The researcher conducted the meetings and organized space for reports by both parents, while the research assistant produced audio recordings, and provided assistance with materials and other resources (e.g., footage presentation). The meetings took place in the family room, in a quiet environment equipped with a TV set in order present the video recordings of the interventions, for approximately 1h and 30 minutes. The meetings were divided into: 1) report on the family routine of that week; 2) discussion of the themes previously planned for that meeting; 3) discussion of mother’s strategies and behaviors displayed in the filmed episodes by means of autoscopy. The autoscopy methodology uses video recordings of the action as a resource for analysis and self-assessment by one or more protagonists in the scene (Sadalla & Larocca, 2004).

A mixed set of themes for each meeting was chosen. Some of the themes were defined a priori.
(knowledge, or lack of it, on autism previously identified in the Interview on parents’ knowledge and expectations concerning their child’s communication skills, plus mothers’ strategies and behaviors for the development of socio-communicative skills, identified by means of baseline videos) and some of them were defined a posteriori (family demands arising during the intervention). At the end, the meetings included the following contents: knowledge on autism (social characteristics and specific behaviors); recognition and development of socio-communicative skills (sharing of topics, shared attention); strategies for engagement and expansion of social interaction.

Data recording and analysis

The social skills of the dyad (shared attention and topic-sharing behaviors) were independently coded in the footage by means, of a protocol for observing the parent-child interaction, by two unbiased examiners who were unaware of the objective of the study. The first minute of each shoot was disregarded in order to allow participants some warmup time, and the remaining 4 minutes of each episode were encoded (Silva, Santos, & Rhodes, 2014). The four images that made up the baseline were also used in order to familiarize the examiners with the instrument. Disagreements between examiners about the coded behaviors were discussed and the respective videos analyzed one more time. After the second analysis, the calculation of the reliability rate among the observers (total agreement/total behaviors x 100) resulted in an agreement index of 75%, which is considered acceptable for studies of this nature (Sampieri et al., 2013). The influence of the intervention on family empowerment was observed by means of comparative analysis of the total score in the Family Empowerment Scale – FES – between the pre- and post-intervention phases.

Ethical considerations

The research was approved by the Ethics Committee of the Federal University of Santa Maria (Protocol No. CAAE: 49198115.2.0000.5346).

RESULTS

Figure 1 shows the frequencies of mother (Topic Sharing) and child (Shared Attention) behaviors of the dyad during the four baseline episodes, and the twelve intervention episodes.

There is an increase in the frequency of interactive behaviors of the dyad after the intervention phase. Shared-attention behaviors in children obtained more than eighty percent increase between the baseline \(f=27; m=6.7\) and the intervention \(f=393; m=32.7\). The maternal topic-sharing behaviors also presented an upward curve between the baseline phase \(f=95; m=23.7\) for the intervention \(f=666; m=55.5\).

There are peaks in frequencies of maternal and infant behaviors between episodes 7 to 9, and 10 to 12. The descriptions of the videos referring to these intervals show that the interaction occurred in a playful way, involving jokes such as “peekaboo”, “run and hug mommy”, “give mommy a kiss” and “tickle”. Such exchanges imply behaviors such as direct eye contact and the use of cue gestures, such as pointing at things, which reflect the sharing of mutual attention concerning the dyad.

Between episodes 9, and 10 and in the interval between 13 and 15, a fall in these frequencies was observed when the mother sought to interact with the child using a ball, which was not an object of interest to the child. Consequently, the mother reduced her requests as the child moved away from the interaction, reciprocally reflecting the decrease of these behaviors.

The frequency of each maternal behavior that composes the socio-communicative skills is presented together in Figure 2.

nt topic-sharing subcategories in the intervention phase were comments \(f=381; m=31.8\), Hand Gestures \(f=180; m=15\) and Questions \(f=68; m=5.6\). The reports of the videos show how fast the mother was to develop sharper skills in order to engage the child in interactive games throughout the interventions, using initiatives such as pertinent questions or comments that acted as reinforcement for the engagement with the child. Hand Gestures, in turn, began to be used more frequently by the mother, following the instructions to draw the child’s attention to objects of interest using the act of pointing at things.

It is important to note that the increase in the frequency of these maternal behaviors in the intervention phase comes with the upward curve of the infant behaviors of shared attention in this same phase, which are presented separately in Figure 3.

Among the behaviors of Shared Attention, directing the Gaze to the mother’s face obtained an important frequency increase in the intervention phase \(f=112; m=11.2\), as well as the child’s smile \(f=105; m=10.2\). It is important to highlight the fact that these behaviors are of a nonverbal nature, manifested here because the child has not developed verbal language.

The reports on the intervention videos show that the frequency of these behaviors seems to be related to the type of activity and the playful resources that the mother uses when she plays with her child. Games such as “peekaboo” or “poke and fright” were the central theme of the episodes in which the Smile category appeared more frequently, as well as the flailing movement of legs and arms as a sign of excitement.

The results of the intervention on parent empowerment are presented in Figure 4.
There is an increase in the general level of empowerment from the pre- to the post-intervention phase. Before starting the PII, the parents scored a total sum of 30 points on the empowerment scale ($M=2.5; SD=1.5$) and, at the end of the intervention, this score rose to 54 ($M=4.5; SD=0.52$). The dimension of empowerment that presented the greatest increase was safety in parental ability to help in the development of their child (item 2). Such increase is no surprise since the item directly addresses how capable these parents feel about making decisions in order to support their child by following the received orientations. In this sense, it

**Figure 1.** Frequency of socio-communicative skills of the dyad.

**Figure 2.** Frequency of maternal topic-sharing behaviors.
seems that the guidelines helped these parents better understand not only child development, but also how they can help these children develop the skills that are deficient in autism. It is observed that statements 1, 3, 4 and 6 were classified on the likert scale as “completely false” before the orientations, whereas at the end of the intervention, they began to be considered as “mostly true”. These questions involved respectively
issues concerning the following statements: 1) When I come up against problems concerning my son/daughter, I deal with them very well; 3) I know what to do when problems arise with my son/daughter 4) I believe that my family’s life is under control; and 6) I believe I can solve problems with my son/daughter when they happen. These assertions address essential points of the parental empowerment construct, as they deal specifically with the acquisition of dominance and control over their lives and the child’s development to achieve the goals shared during the orientations. In a sense, the results showed that the parents’ perception of empowerment increased after the beginning of the orientations.

DISCUSSION

The aim of this study was to assess the effects of a parent-implemented intervention on the socio-communicative abilities of the mother and autistic child, as well as to verify the influences of this intervention on parent empowerment. Results show that the intervention had a positive effect on the socio-communicative abilities of the mother and child. Such positive effect was observed by an increase in the frequency of topic-sharing and shared-attention behaviors of the dyad after the beginning of the orientations. In addition, it was observed that the level of parent empowerment was significantly higher after the intervention than before it.

This result is in line with what the literature that investigates this mode of intervention has shown. A systematic review on Parent-Implemented Interventions (PII) on autistic children, aged between one and six years, showed that studies reported gains in the children’s communicative abilities, in the maternal interactive style, and in parental knowledge. In addition there was a decrease in maternal depression (McConachie & Diggle, 2007). In fact, the PII not only cares about the instrumentalization of parents during their performance in the intervention but promotes access to information about autism so that they act as mediators directly with their child.

Despite the fact that parental involvement in the implementation of intervention strategies for children with autism has a history of more than four decades (Schopler & Reichler, 1971), PII has been predominantly evaluated by means of parent-centered variables (e.g., increased skills, confidence, well-being and stress reduction) or child-centered variables (e.g., socio-communicative skills, engagement in interaction). The present study results in more knowledge in the area by corroborating the gains in the communicative abilities of the mother-child dyad, and especially by highlighting the benefits of parental empowerment.

The perception of parent empowerment implies that they feel more confident in dealing with the demands of their children’s education, enabling them to evaluate and access health and education services with greater confidence and autonomy. Therefore, it is a broad construct, capable of including several indirectly related variables previously investigated in a PII, such as promotion of self-esteem, well-being, knowledge in autism and specific skills for the intervention. Considering the relevance of the challenges that autism poses to families, empowerment takes prominence by triggering parental resilience resources, such as optimism and self-efficacy, strengthening the abilities of the parental duo to remain physically and emotionally adapted in stressful situations. Therefore, when verifying the influences of PII on parental empowerment, in addition to its importance in the context of families of people with autism, it is suggested that this variable be considered as an inherent part of the measures of effectiveness in studies on interventions.

It is also noteworthy that the use of the autoscopy methodology proved especially appropriate for this purpose by providing a space for self-observation by parents and technicians combined with the observation of behaviors by parents and children during the intervention videos. The discussions resulting from these meetings ended up refining parental strategies, some of which were already present in the parents’ repertoire, when they were adapted to the objectives of the intervention. In addition, new strategies based on the orientations given by the professionals were proposed.

In fact, the present intervention aimed to acquire parameters on child development and autism in order to make it possible for parents to develop and use their own customized strategies for their child. Dunst points out that, in the different approaches for work on families, the model of co-responsibility implies a situation in which they “create opportunities for families to exercise existing capacities or to develop new skills” (Dunst, 2000, p. 12). By enabling parents to build intervention strategies for their child, it is possible for them to feel safer and able to collaborate in the development of their child (Dunst & Trivette, 1996; Jones & Passey, 2004).

Caution is recommended in the interpretation of these results, and some limitations of the study should be taken into consideration. The choice of a single case study, despite the encouraging results, is still a preliminary evidence of the intervention. Moreover, a measurement of the orientations given to parents was not performed, making it impossible to verify their frequencies between baseline and intervention in order to identify how faithfully these orientations were actually followed in the intervention and, consequently, whether they were responsible for the effects on socio-
communicative skills.

It is also considered important to propose the expansion of the results of this study, such as using collective orientations to parents by means of group activities. In this modality, parents could equip themselves, in terms of possible strategies, in addition to the fact that only one professional could simultaneously guide several parents, saving time and resources while facilitating their possible use in large-scale public policies.

Finally, it is suggested that studies of this nature can be replicated with a larger number of participants as a means to obtain greater data reliability. Likewise, the data obtained by this study can be used in order to disseminate the benefits that family-centered intervention can bring to the development of people with autism, and consequently to the families’ empowerment process.

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