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Remote Speech-Language Intervention, with the Participation of Parents of Children with Autism

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Abstract

The question about the possibility of identifying the best therapeutic approach for children with autism spectrum disorder (ASD) has also been discussed in the literature. The intervention should be individualized, in order to involve the current level of development of the child and to identify the profile of the facilities and difficulties of each child. The families are constantly involved in complex and changeable context and are aware of the importance of access and participation to the treatment chosen, since that service delays can directly affect efficacy. In general, studies on language acquisition and development in autism focus on the child's communication, and some analyze the mother seeking to understand how the role of parents and caregivers influences the communication of the children with autism. Observing the importance of the active inclusion of parents in the speech and language therapy of children with ASD, a Distance Speech Therapy Intervention project, was developed that would allow language stimulation of a greater number of children and adolescents with autism.

Keywords: autistic disorder, language, parent child relations, social communication, behavior

1. Introduction

Autism is a global disorder of child development that goes on throughout life and evolves with age.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association [1], the category of Global Developmental Disorders refers

to disorders that are characterized by severe and invasive impairment in various areas of development, such as reciprocal social interaction, communication skills, and the presence of stereotyped behaviors, interests, and activities.

The qualitative impairments that define these conditions represent a deviation from the individual's level of development, which affects their social, educational, and communication adaptation [2].

Autism is considered a behavioral syndrome with multiple etiologies, characterized by deficits in social interaction, visualized by the inability to relate to the other, usually combined with language deficits and behavioral changes. However, the table does not involve all areas of behavior in the same proportion and is considered to cause diffuse impairment [3, 4].

In Brazil, since 2012, a law was approved by the federal government that guarantees the rights of persons with autism: I—dignified life, physical and moral integrity, free personality development, security, and leisure; II—protection against all forms of abuse and exploitation; III—access to health services and actions, with a view to the integral attention to their health needs, including the early diagnosis, although not definitive; the multiprofessional service; adequate nutrition and nutritional therapy; medicines; information that aid in diagnosis and treatment; and access to education and vocational education; to the dwelling, including the protected residence; to the labor market; social security and social assistance.

It is significant to note that all descriptions of children with autism mention important language impairments, especially with respect to their functional aspect. The question of the communication of these children is probably their most important disorder, and the studies on the communication of children with autism that refer to questions related to the functional use of language use parameters based on pragmatic theory [5, 6].

The question about the possibility of identifying the best therapeutic approach for these children has also been discussed in the literature [7]. Research has identified the effectiveness of various therapeutic approaches and draws attention to the fact that any comparison should have information about the family and social context [8, 9].

It is suggested that the intervention should be individualized, in order to involve the current level of development of the child and to identify the profile of the facilities and difficulties of each child [10, 11]. The approaches and strategies can be diverse, but the ultimate objectives are the same: to improve the linguistic, social, and cognitive abilities [12].

These families are constantly involved in complex and changeable context and are aware of the importance of access and participation to the treatment chosen, since that service delays can directly affect efficacy [13].

Families of children with autism always find it difficult to obtain appropriate care [14], including obstacles to where and how to obtain these services, how to pay for them [15], and doubts on how to choose the treatment options [16, 17].

In Brazil, there are no epidemiological studies regarding the prevalence of autism spectrum disorder (ASD) cases, with only an estimated number of it. A 2010 survey [18] reported an estimated number of one million cases of ASD in Brazil. In 2012, it was estimated that there

would be 100,000 people with autism in the city of São Paulo; most of them would still be without diagnosis and/or treatment [19], and a very large necessity to increase the resources available to take care of the large prevalence of autism that exists.

When the family suspects that the child has some disability, they find difficulty in accessing special services, mainly to obtain the diagnosis [20].

The family is extremely important because it helps to include the child with autism in a world where people connect and where he/she does not see himself/herself, where he/she is not, and where he/she finds it difficult to communicate. The interest of the parents reflects in the children security, motivation, and mitigation of possible difficulties. Inclusion should begin at home, accepting the problem, stimulating improvements, and working daily so that the autism picture has a minimum of stereotypies and compromises [21]. It is important that the child is inserted in a stimulating environment of social interaction.

In general, studies on language acquisition and development in autism focus on the child's communication [22–24], and some analyze the mother (caregiver)—seeking to understand how the role of parents and caregivers influences the communication of the children with autism [25, 26].

Parents of children with autism experience greater challenges than families affected by other disabilities when attempting appropriate services [27]. With the recent increase in the incidence of individuals with autism and limited resources, a potential outcome is that many children will not receive the treatment and services they need and deserve. Thus, as research continues on the possible causes of autism, it is equally critical that better models are developed to ensure that interventions are effective and that the majority of individuals actually receive care.

The introduction and development of advanced technologies, widely available to the population, such as the exchange of digital data through Internet, can provide alternatives and supplements for how services and treatments would be provided to those in need [28]. Telehealth is a mechanism that allows individuals to receive support, service, and professional from a distance. This may involve being able of communicating in real time with a health-care professional or interacting with online platforms to learn new information [29]. Technology can be accessed at any time of the day and at any location with low-cost equipment, basic to customize the information relevant to the individual's learning needs and to be shared between different scenarios and people [30]. Several studies involving telehealth have shown promise in teaching. More recently, researchers have used telehealth to train parents of individuals with autism [31, 32]. For example, Hamad et al. [33] trained 51 professionals and family members to perform applied behavior analysis (ABA) procedures, using an online distance-learning course that included narrated slideshows, video examples, and application exercises. Participants significantly increased their ABA knowledge from pre- to post-training and reported a high level of satisfaction with the online course.

In addition to telehealth training for professionals, researchers began experimenting with online modalities to teach parents to implement specific interventions for autism. Currently, a self-directed DVD [34] and the web-based learning program [35] have been associated with increased parental skills in intervention activities.

Observing the importance of the active inclusion of parents in the speech and language therapy of children with ASD, a Distance Speech Therapy Intervention project was developed that would allow language stimulation of a greater number of children and adolescents with autism.

In addition to study the best proposals for intervention for different manifestations, the research has a responsibility to offer resources that can reach the greatest number of people who require the service and at the most appropriate time for them.

2. Purpose

The purpose is to construct a project of effective speech-language intervention that allows the stimulation of the language of a greater number of children and adolescents with autism.

3. Methods

The project of the Distance Speech Therapy Intervention at home by parents and/or caregivers with remote monitoring was composed by four moments for elaboration and verification of its effectiveness. Each one of these phases is further described in **Table 1**.

At the first moment, the therapist’s plans were discussed with the researcher about the activities to be carried out at home with the parents. This should contain the objective of the intervention to be carried out and the proposed activity. Remembering that autism is being part of a broad spectrum with changes in the development of social interaction and language, and such characteristics vary in the typology and severity with which they manifest, the plans made for this research were quite individualized both in the activity to be done such as time and frequency. This moment lasted 2 weeks.

1° moment	2° moment	3° moment	4° moment
<ul style="list-style-type: none">• Therapists plan the activities to be carried out at home with the parents• The patients will still be in weekly care in the service• Lasted 2 weeks	<ul style="list-style-type: none">• The proposal of a distance intervention began to be passed on to the parents, starting with the execution of the activities• The patients will still be in weekly care in the service, and during these visits the therapists questioned the parents some facts• Lasted 4 weeks	<ul style="list-style-type: none">• The interventions occurred with both face-to-face therapies and at home with the parents• The feedback given by the parents to the therapists should be done by some means of communication agreed between them• Lasted 4 weeks	<ul style="list-style-type: none">• The patients no longer attended speech therapies weekly with their therapists; they only received the intervention at home• The feedback given by the parents to the therapists should be done by some means of communication agreed between them• Lasted 6 weeks

Table 1. Phases of the intervention program.

These individual proposals based on an individualized profile of child's characteristics, as well as their needs and family context, will be presented as an example later on.

At the second moment, the proposal of a distance intervention began to be passed on to the parents, starting with the execution of the activities elaborated by the therapists in the first moment of the research. This lasted for 4 weeks.

In these 4 weeks, the patients will still be in weekly care in the service provided by the Laboratory of Speech and Language Pathology Research in Autism Spectrum Disorders, and during these visits, the therapists questioned the parents some facts such as if the activities were performed; If some day was not possible or difficult to perform the activity; what the parent and/or caregiver thought of the proposed activity; how was the activity and if they played together; and if any difficulty was found with the proposed activity.

After these 4 weeks, in the third moment, just as in the second moment the interventions occurred with both face-to-face therapies and at home with the parents but the feedback given by the parents to the therapists should be done by some mean of communication agreed between them. The same questions asked at the second moment should be answered by the parents during this contact. This will also last for 4 weeks.

In the fourth moment of the research, the patients no longer attended speech therapies weekly with their therapists; they only received the intervention at home during the execution of the games with their parents.

During the 6-week period, the therapists made contact with the parents by means of the best or more easily available communication previously determined (email, telephone, Skype, Whatsapp). In these contacts, besides clarifying doubts and discussing the child's performance during the activities, the parents answered the questionnaire described, aiming to improve the next phases of the program.

The evaluation of the functional communication profile was used to verify the effectiveness of the project. The evolution of participants pragmatic performance was evaluated at the beginning and at the end of 2 years, the first one in which the Distance Speech Therapy Intervention project was not applied and the second one in which the participants in the project.

The work was referred to the Ethics Committee for Research Projects Analysis and was approved under the Protocol 1.057.800. Everyone responsible for the individuals involved signed the consent form.

Participants were 40 parents of children with ASD with ages between 6 and 17 years, and in this phase they received just the intervention at home, with the parents as mediators. They were instructed to perform play activities that have been planned and discussed with them before the onset of the program.

Inclusion criteria were the children had to have a diagnosis within the autism spectrum disorders determined by a psychiatrist and/or a neurologist according to the DSM-IVtr (ref) and/or ICD10(ref); parents/caretakers had to have a functional level of literacy and be able to contact the speech-language pathologist (SLP) weekly through Skype, Whatsapp, or telephone.

4. Results

Partial results show that among the five items of evaluation of the Functional Communication Profile analyzed, Communicative Space, Interactivity, Communicative Acts Per Minute, Communicative Functions, and Interactive Communicative Functions, the only item that showed the greatest progress with a statistically significant difference in the year that the distance intervention occurred was the item Interactive Communicative Functions. It authorizes to affirm that the participation of parents in the intervention process and the family environment provide more interactivity of the people with ASD (Table 2).

The hypothesis that by participating in a speech at a distance intervention process held at home by parents and/or caregivers of children with ASD, with remote monitoring, would be presented where developments in functional use of language, becoming more interactive, can be confirmed.

The data showed that the participants, despite having shown evolution in the development of the functional profile of communication in 2 years observed, showed greater evolution in Communicative Functions Interactive item in the year received stimulation at home by their parents and with your remote monitoring therapist’s speech-language pathologists.

In general, studies on language acquisition and development in autism focus on the communication of the child [19, 22, 26], and some analyze the dyad mother (caregiver)-child, seeking to understand to what extent the role of parents and caregivers influences the child with autism [19, 25].

These results suggest that the participation of parents during the intervention process combined with daily stimulation occurring in the home environment increases the interactivity and sociability of the participants.

This proposal of speech-language intervention with remote follow-up allowed the inclusion of other family members besides the parents. Only 11 children had always had the same adult as play partner during all the activities. However, except for one child, the other adults were close family members. The other adult was a neighbor that had very close contact with the child.

Results indicate that only 40% of the parents/caretakers conducted the activities proposed every day. Among those who skipped the activities a few days, 22.5% did so during the weekends, 12.5% did so due to adult’s previous appointments, 10% reported that the child was sick, and another 10% that the child refused to participate.

Number of interactive communicative functions expressed	T1 and T2	T3 and T4
% subjects that evolved	40	68
p-Value	0.02*	
*≤ 0.05		

Table 2. Proportion of participants with improvement in both periods (ANOVA).

The parents/caretakers of 35% of the participant children reported that the activities were difficult in at least one of the weeks of the program and 5% felt they were repetitive.

Behavioral problems were also reported as reasons for the difficulties in conducting the proposed activities. Attention impairments were described by 30% of the parents/caretakers, as well as anxiety during the activity and tantrums at the end of it.

5. Conclusions

These data highlight the importance of parents to the development of intervention programs that include the families by providing detailed information about the child's development, discussing doubts and exchanging experiences. Speech-language pathologists should encourage and provide guidance to parents and caretakers to take more active roles in providing communication environments that are appropriate to children with ASD and allow successful interactive experiences.

The participation of parents is important for the accomplishment of a Distance Speech Therapy Intervention project, either by providing accurate information about the child's development, accepting doubts, and understanding requests or by inviting them to participate as agents of the language process.

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