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Brief communication

Communication difficulties perceived by mothers of children with suspected autism spectrum disorder during social distancing

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ABSTRACT

Purpose: to characterize the perception of mothers of children at risk for Autism Spectrum Disorder about their children's communicative difficulties, and to investigate possible changes after intervention based on brief guidance by telemonitoring.

Methods: eight mothers of children aged 32 to 45 months with suspected Autism Spectrum Disorder undergoing diagnostic investigation participated. The Communicative Difficulties Questionnaire was used, applied before and after intervention based on a brief telemonitoring guidance. The inferential analysis used the Wilcoxon rank test, at a significance level of 5%.

Results: comparison between the two moments did not indicate statistically significant difference. However, there were changes in qualitative analysis. In domain 1, a change in mode was observed in two questions. Initially, in domain 2, a disagreeing mode was seen, which after the intervention evolved to agreeing about the feeling of other people avoiding/bullying their children. In domain 3, the question "I take all objects that my child points to" changed from agreeing to disagreeing (62.5% to 25%), and the question "I can't teach my child new things" had no change in mode, only a reduction of agreement (50% to 25%). In domain 4, there was a reduction in agreement, with no change in mode.

Conclusions: the mothers perceived communicative difficulties and daily challenges in dealing with their children. Despite the lack of a statistical difference, qualitatively subtle changes were observed in the perceptions of difficulties, after the intervention.

Descriptors: Autism Spectrum Disorder; Communication Disorders; caregivers; Child development; Language Development

INTRODUCTION

Developmental impairments may be present in the first year of life of children with Autism Spectrum Disorder (ASD), manifested by the lack of eye contact, social smile and interaction responses[1]. According to current diagnostic criteria, these children will have persistent deficits in social communication and restricted, repetitive patterns of behavior, interests or activities[2].

With regard to communication, deficits include impairments related to facial expression, shared attention and communicative intention, delay in producing first words, presence of echolalia and, in some cases, speech regression. Even children with ASD who develop verbal language have difficulties in communicative functionality and impairment of pragmatic competence[2].

Thus, communication deficits are an important challenge for the development of these children and impact the family dynamics[3]. The search for a diagnosis, in most cases, begins when parents start to notice impairments in their children's development, in behaviors that preclude communication, interaction or the accomplishment of daily life activities[4].

In some children, the clinical signs of this disorder are present early. In other cases, the characteristics only become evident with the increase in communication demand, which can delay the diagnosis and the access to intervention programs and family guidance[5].

Longitudinal research shows that responsive parenting behaviors reliably predict subsequent gains in communication skills in children with ASD. Research also shows that the participation of mothers in intervention processes of their children with ASD increases the frequency of topic sharing and shared attention of the dyad, indicating positive effects on the socio-communication skills of mother and child[5].

Intervention programs have been developed to train parents and caregivers as mediators in the process of stimulating their children. These therapeutic intervention proposals consider strategies aimed at increasing the parents' awareness of their role in their children's development[6].

By guidance and the development of intervention programs that include families, the speech therapist can provide parents with conditions to assume more active roles in establishing appropriate communication environments for children with ASD, which provide successful interactive experiences[7].

However, the social distancing required during the COVID-19 pandemic, the family dynamics of many homes have changed. Some family members had to perform their work activities at home, others had their salaries reduced or lost their jobs. Also, the deprivation of social experiences emerges as a risk factor that may have potentiated or triggered difficulties in development, since this is influenced by biological, environmental and socioeconomic factors, which are necessary for a harmonious development[8].

In the initial period of the pandemic, services considered as non-essential or elective, which did not fit into urgency and emergency, such as outpatient speech therapy rehabilitation, were interrupted[8]. As a result, many children and families who were starting a process of investigation or diagnostic intervention did not have face-to-face assistance.

From this perspective, this study aimed to characterize the perception of mothers of children at risk for Autism Spectrum Disorder about their children's communication difficulties, and to investigate possible changes after intervention based on a brief guidance by telemonitoring.

METHODS

This study is part of a larger project approved by the Institutional Review Board of Onofre Lopes University Hospital, Brazil, as determined by Resolution N. 466/13 of the National Health Council, report n. 4.204.936. All mothers who agreed to participate signed a Free Informed Consent Form.

The study was conducted in partnership with the City Specialized Rehabilitation Center (CER). The selection of participants was conducted in September 2020, based on the CER screening, and all children were on a waiting list to continue with the diagnostic investigation process with a multidisciplinary team because they had clinical signs suggestive of ASD. The inclusion criteria for families included having children aged at least 2 and a half years, besides having access to a smartphone or computer with internet. In total, the study was conducted on eight mothers of children aged 32 to 45 months.

Regarding the socioeconomic level of families, classified according to the Brazil Criterion[9], categories B1, B2 and C1 were the most frequent, with 25% of occurrence each, ranging from B1 to D-E. Regarding the educational level, 75% of mothers had completed high school, 12.5% had completed elementary school and 12.5% had completed higher education.

To respond to the study objective the mothers were interviewed using the Questionnaire on Communication Difficulties (QCD)[10], whose purpose is to list the difficulties perceived by parents and/or caregivers of children with ASD in communicating with their children. The questionnaire is an instrument for collecting information to obtain the profile of the communicative style of each dyad and/or family, rather than a test that aims to achieve a result and encourage a certain reaction by questions. It was constructed to address personal information and general issues involved in the autism spectrum[10].

The QCD is composed of 24 closed questions, whose answers can vary between four possibilities: completely agree – when there is dominant agreement; agree – when there is agreement, although not all the time; disagree – when there is disagreement, although not all the time; strongly disagree – when there is dominant disagreement. A score is assigned to each answer, ranging from 3 points (completely agree) to 0 points (completely disagree).

Its questions are divided into four domains: (1) mothers' perception of themselves in relation to their children; (2) mothers' feelings regarding people's acceptance of their children; (3) mothers' actions with their children; and (4) mothers' perception of their children.

The questionnaire was applied by the first author by a telephone call at two different times. The first application (pre-intervention) was performed immediately after the initial interview with the family and face-to-face assessment of children. The second application (post-intervention) occurred after a three-month interval. During this period, the mothers participated in an intervention based on parental guidance. The intervention was conducted by a speech therapist and a neuropsychologist in virtual sessions. To ensure the blinding of researchers, individuals in charge of the intervention did not have prior contact with the QCD responses, and the content addressed was not based on the questionnaire.

The mothers' responses at both moments were tabulated and classified according to the QCD[10] proposal. The final score could range from 0 (all answers completely disagree) to 72 points (all answers completely agree).

Statistical analysis was performed on the SPSS software at a significance level of 5%. The descriptive analysis of answers considered both the mode (most frequent answer) in each question and the percentage of total agreement (sum of only the answers completely agree and agree) in both moments. The inferential analysis used the non-parametric Wilcoxon rank test to compare the scores in each domain and in general at the two moments of application.

RESULTS

The descriptive analysis indicated that most questions had concordant answers. In domain 1, two questions had a change in mode, and in the question regarding difficulties to communicate with the child when there are other people in the same environment, the mode was agree and changed to disagree, besides having a reduction in total agreement (62.5% to 50%). In question "I do not feel comfortable in public places with my son", the mode changed from completely agree to agree, with initial agreement of 62.5% and final agreement of 75%.

Although there was no change in mode, the questions "I have difficulty playing with my child" and "I don't know how to act when my child doesn't understand me or when I don't understand him" had a reduction in total agreement. Conversely, the question "I am bothered by my child's apathy/agitation" had an increase in this parameter (Table 1).

In domain 2, questions related to the impression of other people bullying or avoiding the child had an initial mode of disagree and then changed to agree; in both cases, the total agreement increased. Conversely, the question related to the perception of estrangement only changed in mode, which was agree and changed to completely agree (Table 1).

In domain 3, the question "I take all the objects that my child points to" changed from agree to disagree, with a reduction in total agreement from 62.5% to 25%. The question "I can't teach my child new things" did not change in mode, but also had reduced agreement from 50% to 25%. Finally, in domain 4, only the question regarding inadequacy had a reduction in agreement, without change in mode (Table 1).

Table 1. Mode of response and percentage of total agreement in the two moments of application of the Communicative Difficulties Questionnaire

Domain	Question	Mode 1st moment	Mode 2nd moment	Total agreement 1st moment (%)	Total agreement 2nd moment (%)
1	I don't know how to deal with some of my child's behaviors	Agree	Agree	62.5	62.5
	I have difficulty communicating with my child when we are by ourselves	Disagree	Disagree	25	25
	I have difficulties communicating with my child when there are other people in the same environment	Agree	Disagree	62.5	50
	I have difficulty playing with my child	Agree	Agree	75	62.5
	I have difficulty understanding what my child wants	Agree	Agree	87.5	87.5
	I have difficulty understanding what my child feels	Agree	Agree	87.5	87.5
	I don't know how to act when my child doesn't understand me or when I don't understand him or her	Fully agree	Fully agree	75	62.5
	I am uncomfortable in public places with my child	Fully agree	Agree	62.5	75
	I am concerned about my child's future	Fully agree	Fully agree	100	100
	I am upset when I notice that my child does not initiate communication	Disagree	Disagree	37.5	37.5
	I am bothered by my child's apathy/agitation	Agree	Agree	62.5	75
	I would like more information on how to communicate with my child	Fully agree	Fully agree	100	100
2	I have the impression that people do not understand what my child wants to communicate	Fully agree	Fully agree	87.5	87.5
	I have the impression that people make fun of my child when he or she wants to communicate something	Disagree	Agree	37.5	50
	I have the feeling that people avoid my child	Disagree	Agree	25	50
	I notice that others consider my child strange	Agree	Fully agree	62.5	62.5
3	I don't know how to act with some of my child's behaviors	Fully agree	Fully agree	87.5	87.5
	I take all objects that my child points to	Agree	Disagree	62.5	25
	I always talk to my child, even if he or she does not talk to me	Fully agree	Fully agree	87.5	87.5
	I cannot teach my child new things	Disagree	Disagree	50	25
4	I have the impression that my child does not understand what I say	Agree	Agree	87.5	87.5
	I have the impression that my child does not understand what other people say	Agree	Agree	87.5	87.5
	I notice that my child says/does things that have nothing to do with the moment and/or subject	Disagree	Disagree	50	37.5
	I have the impression that my child has few friends	Fully agree	Fully agree	87.5	87.5

Comparison between the two moments of application of the QCD did not indicate statistically significant difference in any of the four domains or in the overall score (Table 2).

Table 2. Comparison between scores on the Communicative Difficulties Questionnaire in the two moments of application

Variable	Moment	Minimum	Maximum	Median	Interquartile interval		p value
Domain 1	1	19	28	22.5	19.3	26.5	0.260
	2	18	28	24.0	20.5	26.5	
Domain 2	1	2	11	6.0	5.3	7.0	0.131
	2	2	10	7.0	6.0	10.0	
Domain 3	1	6	9	8.0	6.3	8.8	0.705
	2	6	10	8.0	6.3	8.8	
Domain 4	1	6	10	8.0	7.0	9.8	0.854
	2	3	11	8.5	7.3	9.0	
General	1	38	56	43.5	38.8	50.8	0.258
	2	36	54	46.5	40.0	53.8	

* statistically significant difference ($p<0.05$) – non-parametric Wilcoxon rank test

DISCUSSION

The results of this study characterize the perception of mothers of children at risk for Autism Spectrum Disorder regarding their children's communication difficulties, besides comparing whether this perception has changed after an intervention based on brief guidance by telemonitoring.

Analyzing the results in the two moments of questionnaire application, it can be observed that the mothers' answers referred to difficulties in dealing with their children and the challenges of daily life at the first moment, but after intervention fewer difficulties were identified. However, there was no statistical difference in the general score and in the domains between moments. If, on the one hand, the inferential analysis indicates that the intervention had no effect on this sample concerning the mothers' perception, on the other hand, it is important to consider that the instrument used has a much more qualitative nature, even using response categories[10]. It should also be mentioned that no studies were found in the literature discussing the analysis of the questionnaire score; rather, only its use is discussed when comparing populations[11]. Therefore, considering its more qualitative nature, the descriptive analysis is valid to investigate the particularities of each moment of questionnaire application.

Analysis of the first domain, which represents the personal level and refers to what mothers perceive in the communication relationship with their children, showed that, before intervention, most mothers agreed that they felt difficulties in communicating with their children in front of other people, and after the intervention there was a reduction in agreement. Also in this domain, the same pattern was observed in relation to the difficulty in conducting games with their children and in not knowing how to act with the child in the presence of understanding difficulties. This finding reinforces the hypothesis that parental guidance, even brief, can benefit the interaction of the mother-child dyad. Specific guidance to parents can provide strategies for the development of their children and offer help to deal with difficulties[12].

The answers referring to not feeling comfortable in public places with their children had an increase in full agreement. This finding could be justified by the fact that children with ASD can present externalizing behaviors[13], which can be quite challenging. Alike similar studies, it is possible that, over the course of guidance, these mothers became more attentive to such behaviors and had greater perception of their difficulties in dealing with these challenges[10,11,14].

The results of the second domain reinforce this finding, since post-intervention there was an increase in agreement regarding the feeling of other people avoiding or bullying their children. Even though the families were initially in social isolation (due to the COVID-19 pandemic), most mothers did not remind observing people's strangeness. This information shows that, after being questioned, mothers may have started to reflect and observe, in a more directed and attentive manner, the behaviors of their children and

how other people act in relation to these behaviors or difficulties[10,11,14].

The third domain, which is related to the action towards how their children communicate, also suggests that mothers benefited from the intervention; in this case, due to reduction in the interpretation that pointing to something is enough to have their demands met and the difficulty to teach new things to their children. These mothers demonstrate that they understand how their actions can influence their children's communication performance, either positively or negatively[6,15].

The fourth domain showed high agreement levels in both moments, without significant changes. However, the reduction of agreement about the inadequacy of actions or speeches of their children for some situations may also reflect a better understanding of ASD. It is also possible that, due to social distancing, these families may have reduced the diversity of interaction contexts[8], which would reduce the possibilities of such behaviors.

This information points to the fact that the guidelines have promoted more changes in the way through which the mothers observe their communication relationships with their children and in their attitudes towards the communication difficulties that their children present, rather than in the manner through which they perceive that other people observe their children and their own impressions about them.

Since this study was developed during the first year of the COVID-19 pandemic, it is important to stress some limitations. These include the small sample size, the absence of a control group and the restricted time between questionnaire applications. However, even if these limitations may compromise the generalization of results, it is possible to identify critical points for intervention aimed at families of children with communication difficulties. Similar studies are still scarce, but it is noted that investing in parental guidance strategies can provide gains, especially when mothers are still awaiting diagnosis or intervention for their children.

In summary, this study brings contributions to clinical practice, since it is important for speech therapists to understand how mothers of children with communication difficulties perceive and face the communication.

CONCLUSION

Mothers of children at risk for Autism Spectrum Disorder demonstrated to perceive the difficulties of their children to communicate, besides their own attitudes towards these difficulties. The inferential analysis did not identify a statistically significant difference between the pre- and post-intervention moments, yet the qualitative analysis suggests that intervention based on virtual parental guidance has the potential to modify the mothers' perception. Such modification contributes to the understanding of how their actions can influence, positively or negatively, the communication performance of their children.

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