Questionnaire about communicative difficulties perceived by parents of children of the autism spectrum

Questionário sobre dificuldades comunicativas percebidas por pais de crianças do espectro do autismo

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ABSTRACT

Purpose: To develop a questionnaire to the assessment of communicative difficulties perceived by parents and/or caregivers of children on the autism spectrum in relation to their children. **Methods:** The specific aspects addressed by the questionnaire derived from the literature and from the author's clinical experience in specialized services. The questions were organized according to different domains and responses registered on a Likert-type scale. It was performed a pilot study with 40 parents, 20 parents of individuals with Autism Spectrum Disorder and 20 parents of children without complaints of language as a way to verify the applicability of the questionnaire construction and their usefulness in identifying the specific difficulties of the target population. Was calculated the level of agreement of the issues and the results of the groups were compared (Student T Test). **Results:** The questionnaire was developed in order to cover the fundamental aspects of interpersonal relationships, both within the communicative and social domains. It was divided into 24 multiple choice questions covering four areas and an open question, with space to parents report something they consider important and that has not been asked. The study allowed testing the understanding of the instrument and the statistical analysis indicated that 19 questions showed difference. **Conclusion:** The questionnaire identified differences in perception and attitude of parents of children with autism spectrum disorders and children without complaints of language in relation to communication difficulties with their children. Thus, it was proved useful to assess these difficulties in a larger group of individuals.

Keywords: Autistic disorder; Speech language and hearing sciences; Communication; Language; Family

INTRODUCTION

The value of parents' perception, attitude and involvement towards their child's development has been object of several studies in the last couple of years[1,2]. One study points out that there is a clear association between parent/child bond and adequate social, behavioral and communicative development [1].

The communication disorders of individuals with Autism Spectrum Disorders (ASD) include symptoms that vary from lack of speech in children older than 3 years, the presence of peculiar traits as echolalia, pronoun reversal, out of context

discourse or lack of facial expression to the sudden loss of speech[2-4]. These disorders are frequently mentioned as one of the parents' first concerns[3].

Another fundamental issue regarding ASD is the parents' perception about their child's acceptance by other people. Some studies have shown that stigmatization may lead to depression, reduced self-esteem and social isolation. The impact on the family dynamics may produce negative results to the communicative process[5,6].

A literature review[7] about the last 5 years in three journals that focus specifically on autism (Journal of Autism and Developmental Disorders, Focus on Autism and other Developmental Disorders, and Autism) has shown that the number of studies about families with ASD children is very small. It wasn't expected due to the impact of the ASD child on the family's dynamics and also to the importance of family's participation on the diagnostic, intervention and education processes. Some topics are more frequently mentioned: emotional demands, support groups and quality of life, characterization of families and family members and parents' perspectives about their child and the intervention processes. Even considering that most of these studies deal with more than one topic, the number of papers about intervention with families or with their systematic participation is very low[7].

Some intervention proposals reported good results based on specific orientation to parents directed towards improving parents-child interaction[8,9], improving communicative abilities[10] and reducing inadequate behaviors[11].

A recent research about orientation to mothers of ASD children aimed to investigate the interference of systematic and specific instructions conducted in short periods of time. The results have shown that these instructions improved not only the children's communicative environment but also to the familiar understanding about each child's abilities and inabilities[12].

Most of the therapy programs report the importance of having parents and other family members involved in the intervention process[1,2]. These issues have been approached in some countries and it is possible to find instructional manuals to parents published in different languages[13,14]. These manuals however do not refer to previous studies about the difficulties reported by the parents to whom the orientations are proposed. They are based on characteristic symptoms, without mentioning the heterogeneity of their combination and severity[14].

Therefore, a number of questions about communication continue unanswered. The main proposal is that, based on parents' perception it will be possible to understand and intervene in the most relevant points regarding the communication difficulties on an individualized basis. It should be considered that other people's attitudes and behaviors regarding ASD child's behavior will probably influence the communication of both parents and child also on individualized way[15,16].

This way it is possible to perceive the need of tools that assess the issue of parents' perception and attitudes regarding their communicative difficulties with their ASD child.

In order to build a questionnaire some authors[17,18] point out that health services must know what are the necessities of the population to which the actions are destined. It is recommended that the researcher conduct a previous study and propose a new questionnaire only if it represents a real evolution regarding the already existing protocols, including important aspects that were not included previously. Questionnaires have been considered a key-tool in gathering precise and qualified information[18].

The aim of this study was to build a questionnaire that could be used with a large number of individuals to the identification of the difficulties perceived by parents and/or caregivers of ASD children when communicating with them.

METHODS

Ethical aspects

This research was analyzed by the institution's ethic committee and approved with the number 0687/09. All participants of the pilot study signed the approved consent form.

Building the questionnaire

Even with the recent diagnostic technical progress, clinical data are the golden-standard to the identification of ASD children and the professional's clinical experience is fundamental to the comprehension of the clinical features[19-21]. Therefore the identification of questions and issues to be included had as main criteria the authors' clinical experience. This experience was used to select the most relevant data identified on a literature review about the last 5 years about ASD's family issues (communication, stress and emotional difficulties)[7].

The questionnaire's form was based on a study[22] about the perception of parents of communication disordered children that included question about stigmatization, prejudice by themselves, other children, other adults and family members. These issues were organized in blocks of questions.

Three basic rules[17,23] were used to propose the questions:
- do not formulate questions before studying the research issues (problems and purposes);
- maintain the focus on the research theme; and
- ask yourself the question "why I am making this question?" and answer it in the perspective of the resolution of the central problem.

Therefore, the first step while building a questionnaire is the identification of the specific aspects to be assessed.

The main concern was the identification of paternal perceptions about the quality of their communication with their ASD child, independently of their concrete disorders, their diagnostic and objective characteristics. Hence, the questionnaire's purpose was not to describe the characteristics of the child's communication. The focus was totally aimed towards the caregiver's perspective about the impact of these difficulties on the various situations of social interaction.

A Likert-type scale model was used in the final format of the questionnaire[24]. This proposal allows the determination of the agreement or disagreement level with a statement. We adopted a four-level format comprised by the alternatives: totally agree, agree, disagree and totally disagree.

This format has been used, with modification in various studies in the field of health[25,26].

Questions about social-demographic issues were also included (place of residence, gender, age, order of birth and informant's instruction level).

Application of the questionnaire on a pilot study

As a way to verify the applicability of the questionnaire and its use to the identification of specific difficulties of parents of ASD children, it was applied to two groups of caregivers.

The first group consisted of 20 parents and/or caregivers of ASD children with ages between 2 and 10 years, attending a specialized language service. The second group involved 20 parents and/or caregivers of children without complain or history of language disorder with ages between 1 and 3 years. These parents were approached on a public place and asked about their child's language development, when any complain or doubt was identified, it was suggested that they take the child to a speech-and-language service and the questionnaire was not applied. The authors aimed to evaluate if it would be possible to use the questionnaire with a wide range of individuals with different cultural and educational backgrounds. That is why the interviews were conducted on a public place, without any previous social demographic criteria.

One of the purposes of the pilot study was to verify if the questions were easily understood, if their order produced any bias and eventually to change the wording or phrasing if necessary. To avoid the interference of informant's literacy abilities and aiming to guarantee clarity and comprehension of the questions, the researcher read the questions during an individual interview. This study considered "caregiver" the adult that performs the maternal/paternal role in their absence. If the informant was the caregiver the researcher used the name of the child during the interview instead of the expression "your son/daughter".

The analysis of the answers was based on the agreement level, that is, the disagreeing answers were not specifically analyzed.

To compare the answers of both groups of parents the t-Student test was used, presuming different variances. The significance level was 0.5%.

All questions are presented in Chart 1.

RESULTS

The questionnaire was divided in four domains and Chart 1 presents the questions and their respective domains.

The first domain – regarding the parents and/or caregivers' impressions about their children – has a larger number of questions because they focus specifically the issue of parents' social and communicative profile from their own perspective. Since it is the main focus of the research there are 12 questions being eight about communication and four about social abilities and comprising 50% of the questionnaire.

The other three domains – parents' perception about other people's acceptance of their child; parents' attitudes regarding their child and parents' impression about their child – were divided in two groups of questions, two communicative and two social on each domain.

The questions were distributed aiming to balance the themes and their order of distribution interspersed one question of the first domain with the other (Appendix 1).

Table 1 shows the demographic data of participants of both groups.

The participants didn't present any difficulties to answer any item of the questionnaire and therefore no chance was proposed.

Table 2 shows the statistical descriptive and inferential analysis regarding the comparison of both groups.

The groups were compared according to the agreement level in each question. The inferential analysis has shown differences in 19 of the 24 questions (except questions 7, 10, 12, 13 and 24).

DISCUSSION

The questionnaire is a mean for collecting information about the communicative profile a given dyad and/or family and not a test that aims to produce some kind of response. It was built in order to obtain general and individual information about the communication with ASD children.

Some studies suggest that to obtains better understanding about the parent's view of the communicative process it is necessary to value their roles as communication partners because they interact with their child based on their values and beliefs, which are the base of the meaning assignment to other people's actions[1,5,12,15].

Determining the difficulties profile of caregivers allows the consideration that their perception interferes on the communicative process and their attitudes lead to the valorization or depreciation of their roles on the dyadic communication[1,2,5]. That is the reason why the questions of the first domain (parents and/or caregivers' impressions about their children) constitute half of the questionnaire and eight of them refer to communication issues and four refer to social issues.

In each domain were included reaffirmation questions, focusing the same points under different perspectives. The purpose of this kind of rephrasing is to confirm the quality of the answers to the questionnaire[17,18,23].

In Table 2 it can be noted that the questions 10, 12 and 24 of the first domain didn't present statistical differences between the groups. It confirms literature data referring to the parents' willingness to communicate with their child[13,15,27]. Questions 10 and 12 deal with the child's desires and feelings and the answers reflect the children's developmental level. In typical development the verbal mean is the main communicative channel and the use of verbal expression regarding feelings and desires begin after the second year of life. After the third year more complex terms appear reflecting the child's larger understanding about his/her interlocutor's mind. In the case of parents and/or caregivers of ASD children the communication functionality may be tampered with in its most basic level, as the expression of feelings (by any means)[2]. Different reasons may explain the similar responses by parents of both groups. On the first case, it is the temporary stage of development, on the second, a persistent difficulty. Even if caregivers, in several cases, may learn how to understand requests, desires and feelings, it will never reach the detail degree desire by the families[29]. Question 24 reflects the parents' unanimous desire to learn more about their child development.

On the second domain (parents' perception about other people's acceptance of their child) questions 3 and 9 refer to communication issues and questions 15 and 21 to social issues. Recent studies[5,6] have attributed to labeling by other people an important role in hampering the social and psychological functioning of children and their caregivers. Some researches(6,7) also conclude that the stigma is reinforced by society and that its effects are not easily overcome by the coping attitudes adopted by the affected persons and their families.

Questions 1 and 19 have their focus on the social issues of the third domain (parents' attitudes regarding their child). The questions 7 and 13 that refer to the communicative issues of this domain didn't reveal statistical differences between the groups. Both questions have an implicit ambiguity with opposing means for each group. In normal development answering to the child's initiatives is a natural attitude by parents. Parents of ASD children often receive instructions telling them to pretend they didn't understand the child as a mean of obtaining more complex initiatives.

It is considered that parents that "read", "translate", "tell"

Chart 1. Distribution of the four domains

Objective	Question
1st domain: parents'/caregivers' impression about themselves regarding their child	
General perception about their difficulties to communicate with their child. Regardless of the communicative context of cognitive–linguistic abilities of the dyad.	I have difficulties communicating with my son/daughter.
Perception about communicative difficulties with the child on a dyadic situation.	I have difficulties communicating with my son/daughter when there are just the two of us.
Perception about communicative difficulties with the child specifically in the presence of other persons..	I have difficulties communicating with my son/daughter when there are other persons in the same room.
Perception about interactive difficulties during play situations regardless of the symbolic level of the play and/or the time spent in it.	I have difficulties playing with my son/daughter.
Perception about difficulties to understand child's communicative intent regardless of the context or the communicative means.	I have difficulties to understand what my son/daughter wants.
Includes organic perception (cold, hunger, pain…) as well as emotional perception (sadness, joy, frustration…)	I have difficulties to understand what my son/daughter feels.
Includes situations where the adult feels unable to understand verbal and non-verbal clues provided by the child or situations where he feels unable to make himself understood.	I don't know what to do when my son/daughter doesn't understand me or when I don't understand him/her.
Includes familiar and unfamiliar public places regardless of the cause of stress (physical distance, embarrassment...)	I am not at ease with my son/daughter in public places.
Refer to the perception of future expectations about independence, self-sufficiency and social relationships in the absence of the adult.	I worry about my son's/daughter's future.
Includes the perception of initiatives, by any means or with any purpose (ask, comment, get attention, show displeasure..).	I get upset when I notice my son/daughter doesn't initiate communication.
Refer to the adult's uncomfortable feeling regarding the child's behavior.	I get upset with my son's/daughter's apathy or agitation.
Refer to the desire to obtain more information or instructions about the communication process.	I would like to receive more information about how to communicate with my child.
2nd domain: parents' perception about other people's acceptance of their child	
General question about the perception of the child's communication process with another partner, regardless of the communicative context or of the cognitive-linguistic abilities of the participants.	I feel that other people do not understand what my son/daughter wants do express.
Refer to the caregiver's perception about other person's responses/reactions of their child's communicative initiatives.	I notice that some people make fun of my son/daughter when he/she tries to express something.
Involves the caregiver's perception of other person's withdrawal from their child.	I have the impression that people avoid my son/daughter.
Involves the perception by the caregiver of a feeling of awkwardness and/or discomfort by other persons when near their child.	I notice that people think my son/daughter is strange.
3rd domain: parents' attitudes regarding their child	
How does the caregiver sees his/her ability to understand and answer to the child's behavior, regardless of their appropriateness.	I don't know how to act with some of my child's behavior.
How the caregiver responds to the child's primitive communication initiatives.	I reach the objects that my son/daughter points to.
How the caregiver reports his/her role during a dyadic interaction.	I always talk to my son/daughter even if he/she doesn't talk to me.
How the caregiver refer to his/her role as the child's tutor on any task.	I can't teach new things to my son/daughter.
4th domain: parents' impressions about their child	
How the caregiver perceives the child's abilities to understand him/her.	I have the impression that my son/daughter doesn't understand what I say.
How the caregiver perceives the child's ability to understand what other persons say.	I have the impression that my son/daughter doesn't understand what other people say.
If the caregiver perceives expressions used out of context.	I notice that my son/daughter speaks things that are not adequate to the moment or the context.
How the caregiver perceives the child's relationships with other children.	I have the impression that my son/daughter has few friends.

Table 1. Description of the study's sample

	Parents and/or caregivers of normally developing children	Parents and or caregivers of ASD children
Gender		
Male	9	16
Female	11	4
Instruction level		
Fundamental	4	3
Medium	7	8
Superior	9	9
Age of parents		
Minimum	24	23
Maximum	51	65
Median	38.35	43
Age of children		
Minimum	1	2
Maximum	3	10
Median	1.95	6.35

and attribute meaning to their child's actions and reactions may be producing a positive influence[10,11] to their child development and adaptation. However, parents that do not perceive/recognize their child's difficulties, for not being able to discriminate behavior subtleties may produce the opposed influence without perceiving it[2].

On the fourth domain, about the parents' impression about their child's communication and socialization it was considered that there are three questions about communication and just one about social aspects. This is due to the question 17 "I notice that my son/daughter speaks about things that are not appropriate to the moment and/or subject". Although there is a specific mention to a communicative behavior, the focus of the question is the environmental/social repercussion of this behavior. This way, in this domain, questions 17 and 23 refer to social aspects and questions 5 and 11 involve communicative issues.

It is important to mention that in the social aspects were included issues that are relevant to the communicative process as, for example, means; interaction; behavioral, emotional and cognitive issues, as proposed in the literature[22-25].

These four domains may be understood as two aspects of social relationships. The first and third domains represent the personal (what I think about my communicative interaction with my son/daughter) and interpersonal levels (how I act with my child) of the dyadic relationships. The second and fourth domains represent the parents perception about the interaction between their child and society. The second domains places its focus on the society's attitudes towards the child and the fourth domains inverts the focus and consider it from the individual's perspective[22,25].

The different domains place their focus on parents and/or caregivers on different roles, representing different levels of relationship, placing them as partners on a dyadic relationship with their child and as symbolic bearers of the culture[27].

With the pilot study it was possible to verify how the four domains and interconnected. However, even considering that the answers allowed identification of the domains that showed more difficulties, their interpretation will depend on each individuals reality[12].

As this is a questionnaire and not a test the psychometric variables such as judgment agreement and reliability do not apply.

The analysis if the questionnaire (Appendix 1) does not intends a number that differentiates one subject form another, but to know the difficulties perceived by parents and/or caregivers. It may allow that the instructions eventually provided to be based on individualized information and not on common sense and preconceptions[12].

The pilot study has shown that most of the questions were adequate to identify specific difficulties of each group. Parents of normally developing children sometimes considered some questions strange since they were designed to obtain information about ASD children that were frequently older.

Although this study had attained its purpose, one of its limitations refers to the inclusion of the children without language complaints or disorders. Since the focus was placed

Table 2. Comparison between parents of normally developing children and of ASD children

	Question	Mean G1	Mean G2	p-value		Question	Mean G1	Mean G2	p-value
Domain 1	2	2.5	1.45	<0.001*	Domain 2	3	3.6	1.6	<0.001*
	4	2.2	1.05	<0.001*		9	2.95	1	<0.001*
	6	2.65	1.4	<0.001*		15	2.95	1	<0.001*
	8	2.1	1.15	<0.001*		21	3.5	1	<0.001*
	10	2.5	2.1	0.078	Domain 3	1	2.85	1.8	<0.001*
	12	2.55	2.1	0.072		7	2.3	2.5	0.25
	14	3	1.25	<0.001*		13	3.7	3.95	0.096
	16	2.3	1	<0.001*		19	2.1	1.05	<0.001*
	18	3.9	4	<0.001*	Domain 4	5	2.5	1.4	<0.001*
	20	3.1	1	<0.001*		11	3.05	1.5	<0.001*
	22	2.8	1.2	<0.001*		17	3.25	1.25	<0.001*
	24	0.45	0.26	0.2			3.5	1.4	<0.001*

* Significant values (p≤0.05) – Student t test

on the families with children on the first stages of language development, their ages were considerably different from the ASD children.

CONCLUSION

The questionnaire was build according to the directions proposed by several authors. Its application has shown to be useful in identifying specific communicative difficulties. It has also shown to be useful in providing a basis to instruction to parents and/or caregivers. The presented questionnaire also allows the analysis of the singularity of the symptoms and their meaning to the family context.

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RESUMO

Objetivo: Elaborar um questionário para o levantamento de dificuldades comunicativas percebidas por pais e/ou cuidadores de crianças do espectro do autismo em relação a seus filhos. **Métodos:** Os aspectos específicos abordados no questionário foram identificados a partir da literatura e da experiência clínica das autoras em dois serviços especializados. As questões foram organizadas segundo diferentes domínios e as respostas registradas numa escala tipo Likert. Foi realizado um estudo piloto com 40 pais, 20 pais de crianças do espectro do autismo e 20 pais de crianças sem queixas de linguagem, como forma de verificar a aplicabilidade do questionário construído e sua utilidade na identificação de dificuldades específicas da população alvo. Foi calculado o nível de concordância das questões e os resultados dos grupos foram comparados entre si (teste t Student). **Resultados:** O questionário foi desenvolvido de maneira a abranger aspectos fundamentais para o relacionamento interpessoal, tanto no âmbito comunicativo quanto social. Foi dividido em 24 questões fechadas que abrangem quatro domínios; e uma questão aberta, com espaço para que os pais relatassem algo relevante e que não tenha sido perguntado. O estudo possibilitou testar a compreensão do instrumento e a análise estatística indicou que 19 questões apresentaram diferença. **Conclusão:** O questionário elaborado identificou diferenças na percepção e atitude de pais de crianças do espectro do autismo e de crianças sem queixa de linguagem, em relação às dificuldades de comunicação com seus filhos. Dessa forma, mostrou-se útil para o levantamento dessas dificuldades em um grupo maior de indivíduos.

Descritores: Transtorno autístico; Fonoaudiologia; Comunicação; Linguagem; Família

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Appendix 1. Questionnaire about communicative difficulties

Date:__/__/__		BD: __/__/__	Region:		Gender: F ( ) M ( )		
Age of mother: School level:					Age of caregiver: School level:		
Age of father: School level:					Position in the family:		
Diagnosis:							
	Question	Completely agree	Agree	Disagree	Completely disagree		
1	I don't know how to act with some of my child's behavior.						
2	I have difficulties communicating with my son/daughter						
3	I feel that other people do not understand what my son/daughter wants do express.						
4	I have difficulties communicating with my son/daughter when there are just the two of us.						
5	I have the impression that my son/daughter doesn't understand what I say.						
6	I have difficulties communicating with my son/daughter when there are other persons in the same room.						
7	I reach the objects that my son/daughter points to.						
8	I have difficulties playing with my son/daughter						
9	I notice that some people make fun of my son/daughter when he/she tries to express something.						
10	I have difficulties to understand what my son/daughter wants.						
11	I have the impression that my son/daughter doesn't understand what other people say.						
12	I have difficulties to understand what my son/daughter feels.						
13	I always talk to my son/daughter even if he/she doesn't talk to me.						
14	I don't know what to do when my son/daughter doesn't understand me or when I don't understand him/her.						
15	I have the impression that people avoid my son/daughter.						
16	I am not at ease with my son/daughter in public places.						
17	I notice that my son/daughter speaks things that are not adequate to the moment or the context.						
18	I worry about my son's/daughter's future.						

19	I can't teach new things to my son/daughter.				
20	I get upset when I notice my son/daughter doesn't initiate communication.				
21	I notice that people think my son/daughter is strange.				
22	I get upset with my son's/daughter's apathy or agitation.				
23	I have the impression that my son/daughter has few friends.				
24	I would like to receive more information about how to communicate with my child.				