

Ingrid Ya I Sun¹
 Fernanda Dreux Miranda Fernandes²

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Correspondence address:

Ingrid Sun
 Rua Cipotânea, 51, Cidade Universitária,
 São Paulo (SP), Brasil, CEP: 05360-000.
 E-mail: ingrid.sun@usp.br

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Communication difficulties perceived by parents of children with developmental disorders

Dificuldades de comunicação percebidas pelos pais de crianças com distúrbio do desenvolvimento

ABSTRACT

Introduction: The child's inclusion in his/her social-cultural context is very important to his/her adaptation and well-being. The family has a major role as a facilitator of this process. Therefore the difficulties of these families in communicating with children with communication disorders are an important issue to be assessed in order to support orientations to families. **Purpose:** The present study aimed to identify and compare communication difficulties perceived by parents of children with Down Syndrome (DS), Autism Spectrum Disorders (ASD) and Specific Language Impairment (SLI). **Methods:** Information was gathered with the use of a questionnaire with 24 questions regarding the perception of parents about their child communication disorders and the difficulties they identify. The questions were divided into four domains: 1 - Parents' personal difficulties; 2 - Parents' impression about themselves regarding their child; 3 - Parents' impressions about other persons' reactions to their child and 4 - Parents' impression about their child. Sixty parents were the subjects of this study: 20 had children with DS, 20 with SLI and 20 with ASD. All children had ages between 6 and 12 years. **Results:** It was possible to observe that there was significant difference between the parents of ASD children with those of DS and SLI on the second, third and fourth domains. **Conclusion:** The questionnaire is effective to the identification of the communication disorders of ASD children based on their parents' reports but not to other developmental disorders.

RESUMO

Introdução: A inserção da criança no contexto sociocultural é de grande importância para a sua adaptação e bem-estar, e a família desempenha um papel primordial como mediadora desse processo, tornando as dificuldades familiares com a comunicação da criança com distúrbios de linguagem um importante aspecto a ser estudado para basear as orientações familiares frequentemente oferecidas a essa população. **Objetivo:** O presente estudo visou identificar e comparar as dificuldades na comunicação percebidas por pais de crianças com Síndrome de Down (SD), com Distúrbio do Espectro do Autismo (DEA) e com Distúrbio Específico de Linguagem (DEL). **Métodos:** As informações foram colhidas a partir da aplicação de um questionário com 24 questões fechadas envolvendo a percepção dos pais a respeito da comunicação de seu(a) filho(a) e das dificuldades identificadas. Essas 24 questões foram divididas em quatro domínios: 1 - Dificuldades pessoais dos pais; 2 - Impressão dos pais sobre eles próprios em relação aos seus filhos; 3 - Impressões a respeito das atitudes dos outros em relação à criança e 4 - Impressão dos pais em relação aos seus filhos. Participaram desta pesquisa 60 pais, sendo 20 de crianças com SD, 20 de crianças com DEA e 20 de crianças com DEL; todos com idade entre 6 e 12 anos. **Resultados:** Foi possível observar que houve diferença significativa entre o grupo de pais de crianças com DEA com SD e DEL nos domínios 2, 3 e 4. **Conclusão:** O questionário é efetivo para a identificação das dificuldades de comunicação das crianças portadoras de DEA a partir de dados colhidos com seus pais e/ou cuidadores, mas não para os outros distúrbios de desenvolvimento.

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(1) Department of Speech Language Pathology and Audiology, Physical Therapy and Occupational Therapy, School of Medicine, Universidade de São Paulo – USP – São Paulo (SP), Brasil.

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INTRODUCTION

The factors involved in the process of language development have been the subject of controversies and the topic for different researches. The social and cognitive issues are, sometimes, considered prerequisites and, at other times, considered to be aspects affected by language⁽¹⁾, this being an important matter to be considered in the study of language development.

Because of the process of socialization, children expand their vocabulary, not only as to the number of words but also as to the complexity of the concepts used. Most important in this process is that language, once acquired, becomes an instrument not only of thinking but also for the regulation of behavior itself⁽²⁾.

In general, the first effective bond in development is established by the parents and/or caretakers, and it will be responsible for giving meaning to the vocalizations. At first, these vocalizations do not have communicative intent⁽³⁾ but are of great importance, as they constitute the basis for non-verbal language, which, in turn, contributes to the development of the child's sociocognitive abilities⁽⁴⁾.

However, there are disorders that affect language directly and, consequently, the effectiveness of communication and social interaction themselves. Among the most frequent disorders are autism spectrum disorders (ASD), specific language impairment (SLI), and Down syndrome (DS). It is relevant, therefore, to search for more information on the language aspects of these pathologies, aiming at the improvement of the communicative development of the affected individuals.

Autism is a development disorder characterized by qualitative deviations in language, social interaction, and cognition. According to the World Health Organization, in the International Classification of Diseases⁽⁵⁾, autism is a syndrome present since birth, manifesting before 30 months of age, presenting abnormal responses to visual and auditory stimuli, as well as difficulties in communicative interactions⁽⁶⁾. Several studies search deeper into the communication and language abilities of children with autism in pursuit of a pragmatic development analysis of the functional aspects of language. It is known that the alteration on language development of these children with ASD involves, beyond the formal aspects of language, socio-cognitive and communicative factors⁽⁷⁾. Thus, in cases of autism, language disorders characterize the clinical situation and constitute a diagnosis criterion⁽⁸⁾.

SLI is defined as a language impairment not related to hearing loss, cognitive development and speech mechanics alterations, extensive development disorders, neurosensorial alterations, or any other pathology that may justify this difficulty⁽⁹⁾.

The noticeable linguistic characteristics of SLI are difficulty with receptive and/or expressive language, the first being, usually, less affected; late acquisition of the first words; and problems in the discrimination of phonemes and in forming sentences due to morphosyntactic difficulty. The areas of phonology, semantics, syntax, and pragmatics are affected at different levels, the pragmatic one being a consequence of the linguistic difficulty, different from autism. Thus, in SLI, the language alterations define the disorders, differentiating children

with ASD from those with DS, because, in ASD, children present a deficit in communication, social abilities, and cognitive abilities⁽¹⁰⁾ and, in DS, the cognitive and physical areas present more relevant alterations.

DS is a result of the trisomy of chromosome 21, and it is considered the main genetic cause of mental disability⁽¹¹⁾. The cognitive development of children with DS is higher than the language development and their comprehension is better than their oral production. They present impairments in memory, attention, speech intelligibility, probably related to muscle hypotonia, and in pragmatic skills⁽¹²⁾.

According to Bissoto⁽¹³⁾, the late language development, the lower recognition of grammar and syntactic rules of the language, as well as their difficulties in speech are characteristics of DS. Besides, several studies have been proving that children with DS feel more difficulty in keeping up with spoken instructions, especially if they involve multiple information or consecutive commands/orientations, because the perception of phoneme sequences and their morphosyntactic components are affected by otitis conditions. This difficulty may, however, be minimized if these instructions are followed by gestures or pictures referring to the instructions given, for their visual-spatial short-term memory is less affected by the condition. Thus, in DS, language alterations are a result of cognitive deficits.

The proper insertion of the child in their sociocultural context is of great importance for their adaptation and well-being, and the family plays a key role in this process as a mediator⁽¹⁴⁾, which turns the familiar difficulties with the child's communication, due to language disorders, into an important aspect to be studied, so then the guidance often offered to this population may be based on scientific evidence.

OBJECTIVE

To identify and compare the difficulties in communication related by parents of children with DS, ASD, and SLI, aged from 6 to 12 years.

METHODS

Subjects

Sixty parents took part in this research, being 20 children with DS, 20 with ASD, and 20 with SLI; all of them aged between 6 and 12 years.

All participants signed the informed consent, approved by the ethics committee of the institution (protocol no. 365/10).

Material

A questionnaire was developed by Balestro⁽¹⁵⁾ about the perception of parents on their children's communication and the difficulties reported in this process (Appendix 1).

The development of this questionnaire is intended to "produce a material addressed to parents of children with ASD, not based on the symptoms which characterize the

condition, but based instead in the perspective of the care taker” (p. 3)⁽¹⁵⁾.

The questionnaire consists of 24 closed questions divided into four domains:

- Domain 1: Parents’ attitudes toward their child (green)
- Domain 2: Parents’ impressions about themselves regarding their child (yellow)
- Domain 3: Parents’ impressions about other people’s reaction/acceptance to their child (blue)
- Domain 4: Parents’ impression about their own child (pink)

The answers are statements regarding the informer’s agreement, from the options “agree completely,” “agree,” “disagree,” and “disagree completely.”

Procedures

The researcher applied the questionnaire as an interview, reading each one of the 24 statements, clarifying, and registering possible doubts.

This study used the Student’s *t*-test, a statistical test that uses statistic concepts to whether reject a hypothesis or not, setting the significance level at 0.05 (or 5%).

RESULTS

From the sample of parents of children with ASD who answered the questionnaire, 15% had complete college degree, 10% had incomplete college degree, 25% had complete high school degree, 15% had incomplete high school degree, 10% had complete elementary education, 20% had incomplete elementary education, and 5% were illiterate.

From the sample of parents of children with SLI who answered the questionnaire, only 5% (1 subject) had complete college education, 45% had complete high school education, 15% did not completed high school, and 35% had incomplete elementary education.

From the sample of parents of children with DS, 20% had a college degree, 45% completed high school, 15% completed elementary school, and 20% did not complete elementary school.

The average age of children was around 8 years and 5 months to 9 years and 8 months. The disposition by gender evidences the profile of each diagnosis, with a prevalence of boys especially in ASD cases, as it is also shown in literature.

With the Student’s *t*-test, the answers from the different groups of questions were compared to all four domains in the questionnaire, as shown in Chart 1. In the comparison between the domains, no significant differences were observed in none of the groups, as shown in Chart 2.

Domains 2, 3, and 4, which approach parents’ perception on themselves, on the society, and on their own child, respectively, distinguish parents of children with ASD from parents of children with DS and SLI, but not these two last ones from one another. We may also observe that the possibility of distinguishing parents of children with ASD from parents of children with DS is higher in domain 2, regarding the perception of parents as to their own difficulties.

Chart 1. Student’s *t*-test comparing the answers of different groups of questions in relation to the four domains of the questionnaire

p<0.5	1 x 2	1 x 3	1 x 4	2 x 3	2 x 4	3 x 4
ASD	0.722	0.256	0.542	0.234	0.614	0.598
DS	0.235	0.457	0.220	0.682	0.920	0.556
SLI	0.960	0.949	0.721	0.892	0.711	0.504

Caption: ASD = autism spectrum disorders; DS = Down syndrome; SLI = specific language impairment

Chart 2. Comparison of the answers in the four domains

Comparison of the answers referring to domain 1 (parents’ attitudes toward their child) in the different groups (Student’s <i>t</i> -test)			
	ASD	DS	SLI
ASD	1	0.927	0.309
DS	0.899	1	0.412
SLI	0.309	0.412	1
Comparison of the answers referring to domain 2 (parents’ impressions about themselves regarding their child) in the different groups (Student’s <i>t</i> -test)			
	ASD	DS	SLI
ASD	1	0.012*	0.013*
DS	0.012*	1	0.836
SLI	0.013*	0.836	1
Comparison of the answers referring to domain 3 (parents’ impressions about other people’s reaction/acceptance to their child) in the different groups (Student’s <i>t</i> -test)			
	ASD	DS	SLI
ASD	1	0.046*	0.018*
DS	0.046*	1	0.745
SLI	0.018*	0.745	1
Comparison of the answers referring to domain 4 (parents’ impression about their own child) in the different groups (Student’s <i>t</i> -test)			
	ASD	DS	SLI
ASD	1	0.037*	0.017*
DS	0.037*	1	0.898
SLI	0.017*	0.898	1

Caption: ASD = autism spectrum disorders; DS = Down syndrome; SLI = specific language impairment

DISCUSSION

The first set of questions, which approach parents’ attitudes toward their child, was the only domain that did not show significant difference among the participant groups.

It is possible to observe that the parents who took part in this research, in face of the individual difficulties of their child, in general search for information on how to adapt the best to the situation.

In the second group of questions, regarding parents’ impressions on themselves, there was a significant difference between the group of children with ASD and the groups with DS and SLI, evidencing the sensation parents of children with ASD have of being incapable of dealing with the communication difficulties their children have.

The language of the child with autism has peculiarities and does not evolve the same way as that of other children’s. According to Loveland et al.⁽¹⁶⁾, the language of the child with

autism is rigid and stereotyped, and its content is used in limited contexts. In general, the communication characteristics of the child with autism do not allow quality interactions, considering that, for decades, it was believed that those children had no communicative intent.

Studies^(17,18) have been pointing to the relevance of the difficulties in functional language presented by these children, taking into account their interactional abilities and enhancing the possibilities of real and spontaneous speech interactions⁽¹⁹⁾.

The third group of questions, which regard the reaction of other people toward manifestations of their children, also evidences significant difference between parents of children with ASD and the ones of children with DS and SLI.

Some authors consider autism as a neurodevelopment disorder in which there is subjacent organic brain dysfunction. The symptoms of these disorders may manifest in several ways, such as intolerance to changes, self-aggression and aggression to others, hypersensitivity, and difficulty in understanding social rules⁽²⁰⁾. These characteristics, in general, are little accepted by society and by other members of the family, causing major discomfort on parents within social situations.

More and more the needs and the quality of life of children with autism have been investigated along with the possible implications for their psychological well-being⁽²¹⁾ and, among other behaviors, one may observe the formulation of strategies, by the parents, to adapt their child to social rules⁽²²⁾.

As to DS, we may observe a high number of educational initiatives, which aware and educate society about the characteristics of this disorder, leading to greater familiarity of this population to the situation.

By definition, children with SLI present two or more committed language areas, at the same time they present absence of physical, sensorial, neurological, psychiatric, and intellectual disabilities. Therefore, these children acquire and adjust strategies, as needed⁽²³⁾.

Finally, the fourth domain, under the impression of parents about their own child, also presented a significant difference between parents of children with ASD and the ones of children with DS and SLI, which is a reflection of the singular difficulties of each disorder.

As approached in the beginning of this study, children with SLI present alterations strictly in the area of language, with heterogeneous manifestations. The problems of children with SLI remain, affecting social, behavior, and educational/learning skills⁽²⁴⁾. However, one of the diagnosis criteria of SLI is the absence of intellectual deficit, enabling them to better adapt to society.

As for the children with DS, many authors argue on the lack of “harmony” between language and cognitive development, because one area is directly related to the other to develop. Besides the physical aspects, such as generalized muscle hypotonia and cardiomyopathy, DS is considered to be the main cause of genetic mental disability, being the most studied genetic pathology since 1866 and, consequently, the most well known and accepted one by the society⁽²⁵⁾.

ASD, in turn, is a development disorder that strikes three areas: language, cognition, and social interaction. None of them

being secondary to the others, but every one of them being relevant to the clinical condition. In addition to the language and cognition alterations, the social aspects of autism have been systematically studied and referenced to by caretakers. In the research conducted by the author of the questionnaire, specifically applied to parents of children with ASD⁽¹⁵⁾, the domain referring to the perception of parents in relation to the society was the most prominent one. The quality of life of the child with autism is strongly influenced by the way by which difficulties are understood⁽²⁶⁾. And the “family suffers social pressure when there is an element which does not correspond to the social expectations” (p. 44)⁽¹⁵⁾.

Therefore, it is important that the professional dealing with these children understands the relevance of intervening for such, in an attempt of empowering parents into dealing with their child’s specific difficulties, no matter if language, cognition, or social adaptation ones.

CONCLUSION

The objective of this study was to identify and compare the difficulties in communication reported by parents of children, between 6 and 12 years of age, with DS, ASD, and SLI. On the basis of the presented results, it was possible to observe that there was a significant difference in the matters of communication between the parents of children with ASD and the ones of children with DS and SLI in the domains referring to the attitudes of parents toward their child, the impressions of parents about their own child and about society’s reactions to their child. These elements provide important information concerning which are the main areas in need for attention, with family guidance proposals directed to parents of children with these different clinical conditions. The proposal of the analysis of a data set, which reveals significant results, demands, however, considering that the data regarding a group may not reflect exactly the situation of each of its components. This way, individualized guidance may benefit from the individualized applying of this questionnaire.

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Appendix 1. Questionnaire survey: Balestro⁽¹⁵⁾

Subject No: BD: ___/___/___

Age:

Age of the Mother: School education:

Age of the Father: School education:

Age of the care taker /Position in the family: School education:

Gender: F () M ()

Diagnosis:

Place:

	Agree completely	Agree	Disagree	Disagree completely
I don't know how to react to some behaviors of my child				
I have difficulties in communicating to my child				
I'm under the impression that people don't understand what my child wishes to communicate				
I have difficulties in communicating to my child when we are alone				
I'm under the impression my child does not understand what I say				
I have difficulties in communicating to my child when other people are present				
I take all the objects my child points to				
I have difficulties in playing with my child				
I'm under the impression people mock my child when him/her wish to communicate something				
I have difficulties in understanding what my child wants				
I'm under the impression my child does not understand what other people say				
I have difficulties in understanding what my child feels				
I always talk to my child, even if he/she does not talk to me				
I don't know how to act when my child doesn't understand me or when I don't understand him/her				
I'm under the impression people avoid my child				
I don't feel comfortable in public places with my child				
I notice my child says things that have nothing to do with the moment and/or subject				
I worry about my child's future				
I cannot teach new things to my child				
I feel bad when my child does not initiate communication				
I notice that other people strange my child				
I feel bothered with my child's apathy/uneasiness				
I'm under the impression my child has too few friends				
I would like to have more information on how to communicate with my child				