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Information and Impression Regarding ASD Questionnaire Answered by Foreigners Living in Brazil

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Abstract

Autism Spectrum Disorders (ASDs) constitute a group of disorders characterized by changes present at early ages and manifesting in the areas of development of communication, behavior, and interpersonal relationship. Because ASD significantly affects communication and the social skills, all multicultural context needs to be better investigated. There is an urgent need to understand the impact of migratory process, bilingual environment exposure on the language development of children with ASD. The present study aims to present the results of 657 foreign residents in Brazil that answered an online questionnaire to know the consolidated information about ASD. Participants from 23 countries responded to the survey. Bolivia and Argentina were the countries with the highest number of participants. The present study found that 100% of the participants have heard of autism. About 80.6% of the sample had a family member with autism. The sociodemographic diversity identified in this study reflects the sociocultural diversity present in Brazil, besides reinforcing the importance of considering this population when thinking about strategies and behaviors directed at individuals with ASD.

Keywords: Autism Spectrum Disorder, knowledge, lay beliefs, survey

1. Introduction

Autism Spectrum Disorders (ASDs) constitute a group of disorders characterized by changes present at early ages and manifesting in the areas of development of communication, behavior, and interpersonal relationship. Early diagnosis and intervention are essential for the prognosis [1]. The Centers for Disease Control and Prevention (CDC) estimate the prevalence

of ASD to be 1 in 68 children [2]. The Diagnostic and Statistical Manual, Fifth Edition (DSM-5) [3], provides criteria to diagnose ASD. The two sets of criteria involved are related to social communication deficits and restricted, repetitive patterns of behavior, interests, or activities. The social and language difficulties characteristic of ASD make the speech therapist participation indispensable in any action for ASD.

Studies on language in ASD highlight that the greatest difficulty of these individuals is related to the functional use of language. Language skills are certainly the greatest perceived difficulties in individuals with ASD [4].

The pragmatic aspects of language involve specific communication skills, deficits in nonverbal communication, and difficulties adjusting behavior according to various social contexts, which includes language adjustment for different listeners. The characterization of language in the pragmatic perspective considers the relationship established between interlocutors, the communicative context, and the sociocultural elements involved [5].

For the communication to be effective, the interlocutor must be able to use the language in each situation appropriately, to understand social cues used in each context. This pragmatic competence includes verbal and nonverbal communication skills, besides considering the social understanding and the communicative context in which the communicative exchanges are carried out [5, 6].

Because ASD significantly affects communication and the social skills, all multicultural context needs to be better investigated. There is an urgent need to understand the impact of migratory process, bilingual environment exposure on the language development of children with ASDs.

In recent years, the world has experienced a great migratory movement. In 2015, the Department of Economic and Social Affairs (UN DESA) [7] registered the mark of 244 million international immigrants, an increase of 41% over the year 2000. The number of immigrants totaled 3.3% of the global population in 2015, while in 2000, they totaled 2.8%.

Some studies have pointed out the importance of investigating autism in an international setting considering all the cultural, social, and language implications involved in a migratory process [8–11].

Within this scenario, Brazil is characterized as a country of continental dimensions, with a territory of more than 8 million km² and with an estimated population of more than 206 million inhabitants. Many are the indexes that point to the existing inequality within the country as well as to the difficulties imposed by its size and diversity. Faced with this reality, there are very few population data, especially in terms of communication aspects, as well as access to specialized assessment and intervention programs. However, it is possible to know that just as in the world Brazil has also received many international immigrants. In 2015, there were 1,847,274 regular immigrants according to the statistics of the Brazilian Federal Police [12].

Cultural, social, and linguistic diversity needs to be considered when focusing on ASD diagnosis and intervention. Therefore, systematized research regarding the degree of knowledge and information that the population has about autism can contribute to the construction of a body of evidence that bases the decision making regarding proposals of intervention directed to those with ASD [13, 14].

This premise originated a study [15] that had for its purpose the elaboration and application of an online questionnaire to know what the consolidated information that the Brazilian population has on the subject of autism. A total of 5000 people answered the survey of whom 657 were foreign residents in Brazil.

The participation of foreigners was not predicted by the study. None of the instruments used (invitation, questionnaire, and instructions) were elaborated in another language or with any additional resources that facilitated the participation of nonfluent citizens in Portuguese. As the participation of foreigners was not objective of the study, the information collected from the participants did not contemplate sufficient data to characterize the foreign participants. However, the spontaneous participation of 657 foreigners (13% of all study participants) reveals the urgent need to understand the particularities of this population and establish proposals for specific attention and care for them.

The present study aims to present the results of this group of foreigners, considering the particularities and importance in the deepening of the reflection at world level.

Immigration is an important phenomenon all over the world today. The results described in this chapter involve the participation of professionals and family members of children with ASD from 23 different countries. This certainly helps to increase the knowledge of how much this population has of information and impression regarding ASD. This better characterization and understanding becomes paramount for the different realities of countries that receive any kind of immigration phenomena.

2. Methods

An authorization was obtained from the Ethics Committee for Research of the host institution (protocol number: 954.385), which authorized the study and agreed with the request to waive the use of the free and informed consent term.

A total of 657 people participated in this study, who were willing to respond to a digital questionnaire composed of closed questions written in Portuguese. These people were contacted to participate in the survey by invitation received by e-mail or by publication in social network. The two invitations were also written in Portuguese. Each participant could forward the invitation to whom it considered pertinent. There was no way to identify the respondent or the device used to complete the questionnaire. As there was an exemption from the consent form, only completed questionnaires were considered, with the understanding that if the person answered all the questions and sent the answers she agreed to participate in the study. Completion of the questionnaire was done only in digital media because it was part of the study to consider the efficiency of this medium as a research tool.

A total of 4600 e-mails were sent per month at regular intervals throughout the 18-month period in which the questionnaire was available on the web. During this period, there was also 1 weekly publication in social networks, inviting to participate in the study.

The questionnaire was self-explanatory allowing to be answered in an autonomous way. The instrument contained five parts, the first involved information about the participant. The second block of questions sought to know if the participant already had some contact with the topic autism and how was given this contact. The third part of the instrument addressed the participant’s knowledge about the etiology, signs, and symptoms of autism. The fourth part of the instrument sought to investigate the participant’s knowledge about the variability of the symptoms of individuals with ASD. The last part of the questionnaire had as an objective to know from the perception of the participant which professionals are essential for the monitoring of the autistic individual.

Of the 5000 completed questionnaires, only 657 were considered for this study because they were answered by non-Brazilian citizens.

3. Results

3.1. Sociodemographic profile

The predominant age group of the participants was between 30 and 39 years of age, of the feminine gender, and of the race declared as white. The informant family income was between R\$1000.00 and R\$3000.00—equivalent to US\$ 300.00 and 900.00 per month (**Table 1**).

Demographic information	Classification	N	%
Age group	18–29 years old	208	31.7
	30–39 years old	256	39.0
	40–49 years old	146	22.1
	50–59 years old	34	5.2
	Over 60 years old	13	2.0
Genre	Male	105	16.0
	Female	552	84.0
Race	White	410	62.4
	Yellow	105	16.0
	Brown	96	14.6
	Black	36	5.5
	Indigenous	10	1.5
Monthly household income	Less than US\$300	89	13.5
	Between US\$300 and US\$900	226	34.4
	Between US\$900 and US\$1800	177	26.9
	More than US\$1800	57	8.7
	Did not know	0	0.0
	Was not able to inform	108	16.5

Note: The data marked in bold represent the most frequent occurrences

Table 1. Description of the 657 participants in the study.

All study participants attended school. The majority completed higher education (25.9%) and the smallest part had postgraduation (4.3%) (**Table 2**).

Participants from 23 countries responded to the survey. Bolivia and Argentina were the countries with the highest number of participants (17.2 and 14.8%, respectively) (**Table 3**).

Level of education	Classification	N	%
	Elementary school	85	13.0
	Complete primary education	120	18.3
	High school	122	18.5
	Incomplete higher education	132	20.0
	Complete higher education	170	25.9
	Postgraduate studies	28	4.3

Note: The data marked in bold represent the most frequent occurrences

Table 2. Level of education of the 657 participants.

Country of origin	N	%
Bolivia	113	17.2
Argentina	97	14.8
Japan	79	12.0
China	54	8.2
Colombia	43	6.5
USA	37	5.6
Paraguay	33	5.0
Uruguay	29	4.4
Netherlands	28	4.3
Jordan	24	3.7
Lebanon	20	3.0
Spain	19	2.9
Haiti	16	2.4
Portugal	14	2.2
Greece	11	1.7
Italy	11	1.7
Peru	9	1.4
Indonesia	8	1.2
Germany	7	1.1
Belgium	2	0.3
Israel	1	0.2
Cuba	1	0.2
Chile	1	0.2

Note: The data marked in bold represent the most frequent occurrences

Table 3. The country of origin of the 657 participants.

3.2. Information about how the participant had access to the topic autism

All participants knew the term “autism” (100%). Most of them have an autistic individual in the family (87.8%) (Tables 4 and 5).

3.3. Information about what the participant knew about autism

The answers given to questions about the participant’s knowledge about autism were categorized (Table 6). The percentage of occurrence was less than 10% only in the question about the contagion, and in seven questions, the answers were between 40 and 50% (Table 7).

3.4. Information about what the participant identifies as specific characteristics of an autistic person

The highest concordances as to the characteristics of autistic individuals are the difficulties of communication (77.2%) and do not answer to the name when called (74.1%) (Table 7).

3.5. Information on what professionals are indispensable for the care of an autistic individual

The professionals who presented the highest concordance as essential for the treatment of an autistic individual were: Neurologist (98.9%), Neuropediatrician (96.5%), Specialized Teacher (89.3%), Psychiatrist (89.3%), and Speech therapist (85.8%) (Table 8).

Means of access	N	%
TV	87	13.2
Desktop	116	17.7
Family	577	87.8
Website	398	60.6
Note: The data marked in bold represent the most frequent occurrences		

Table 4. Means of access to the autism theme of the 657 participants.

Means of contact	N	%
Mother	343	52.2
Father	72	11.0
Family	114	17.4
Professional	128	19.5
Note: The data marked in bold represent the most frequent occurrences		

Table 5. How the contact with the autistic individual occurred by the 657 participants.

Knowledge about autism	Yes		No	
	N	%	N	%
Is autism a disability?	427	65	230	35
Is autism a psychological state?	105	16	552	84
Is autism a social condition?	265	40.3	392	59.7
Is autism a disease?	321	48.9	336	51.1
Is autism an illness that you are born with?	287	43.7	370	56.3
Does autism have genetic origin?	81	12.3	576	87.7
Is autism hereditary? Do you move from a mother/father to a child?	67	10.1	590	89.9
Does autism have a cure?	390	59.4	267	40.6
Is autism contagious?	21	3.2	636	96.8
Is autism a rare disease?	104	15.8	553	84.2
Is autism an acquired illness?	227	34.5	430	65.5
Are there different types of autism?	301	45.8	356	54.2
Environmental factors cause autism?	157	23.9	500	76.1
Are there medications for autism?	201	30.6	456	69.4
Is there an exam that detects autism?	97	14.8	560	85.2
Is the cause of autism known?	147	22.4	510	77.6
Is the cause of autism determined?	169	25.7	488	74.3
Is autism a consequence of emotional trauma?	187	28.5	470	71.5
Is autism a developmental disorder?	301	45.8	356	54.2
Vaccine causes autism?	294	44.7	363	55.3

Note: The data marked in bold represent the most frequent occurrences

Table 6. What the participant knows about autism.

Specific characteristics	All		Many		Some		None	
	N	%	N	%	N	%	N	%
Isolation	361	55	158	24.1	43	6.5	5	0.9
Aggressive behaviors	66	10.4	183	27.85	251	38.2	157	23.89
Difficulty in social life	93	14.15	426	64.84	138	21	0	0
Do not make eye contact	154	23.43	207	31.5	152	23.13	144	21.91
Do not talk	257	39.11	354	53.88	36	5.47	10	1.52
Eye contact changed	216	32.87	194	29.52	158	24.04	22	3.34
Difficulty in communicating	507	77.16	134	20.39	16	2.43	0	0
Specific physical characteristics	150	22.83	4	0.6	3	0.45	410	62.4
Intellectual deficit	121	18.41	267	40.63	154	23.43	25	3.8

Specific characteristics	All		Many		Some		None	
	N	%	N	%	N	%	N	%
Special skills	132	20.09	232	35.31	187	28.46	106	16.13
Sleep disorders	60	9.13	163	24.8	69	10.5	365	55.55
Hearing compromised	29	4.41	110	16.74	320	48.7	198	30.13
Food difficulties	14	2.13	321	48.85	292	44.44	30	4.56
Visual impairments	170	25.87	0	0	0	0	487	74.12
Respiratory distress	28	4.26	160	24.35	0	0	469	71.38
Difficulty playing	187	28.46	274	41.7	196	29.83	0	0
No response when called by name	487	74.12	0	0	20	3.04	150	22.83
Absence of affection, affection for anyone	39	5.93	204	31.05	287	43.68	127	19.33
Repetition of phrases, decontextualized words (echolalia)	150	22.83	150	22.83	205	31.2	152	23.13
Can be independent, take over the conduct of one's life	63	9.58	143	21.76	152	23.13	299	45.5
Behavior of waving, swinging, turning, or staring	354	53.88	8	1.21	11	1.67	284	43.22

Table 7. What the participant knows about the autistic person.

Essential professional	N	%
Neurologist	650	98.9
Neuropediatrician	634	96.5
Specialized teacher	587	89.3
Psychiatrist	587	89.3
Speech therapist	564	85.8
Pediatrician	509	77.5
Psychologist	460	70.0
Psychopedagogue	398	60.6
Nutritionist	354	53.9
Occupational therapist	325	49.5
Psychomotrist	201	30.6
Physical educator	125	19.0
Geneticist	109	16.6
Physiotherapist	107	16.3
Dentist	0	0.0

Note: The data marked in bold represent the most frequent occurrences

Table 8. Professionals essential to care for an autistic person.

4. Discussion

The study involved participants from 23 countries. Among the 23 countries, 10 countries are Spanish-speaking or Portuguese speaking, and 13 countries with more different languages, such as Greece, Lebanon, and Jordan. Unfortunately, the study did not provide information on participants' level of proficiency in Portuguese. Therefore, it is only possible to suppose that participants from Spanish-speaking countries had less difficulty answering the questionnaire than participants from countries with languages more distant from Portuguese. Another hypothesis to be considered is the possibility of participants using a digital tool as a resource to translate the questionnaire into their native language.

The present study found that 100% of the participants have heard of autism, and the level of autism awareness can be considered as high. The high level of awareness reported in the present study reflected the fact that 80.6% of the sample had a family member with autism. Women (84%) and mothers (52.2%) of autistic children mainly answered the questionnaire. These data suggest that the care of children with ASD is still responsibility of women, mothers, and professionals working with children with ASD.

Another aspect to be considered is the high level of education of the participants. This fact should have contributed to the study access and the possibility of responding to the questionnaire.

The low family income declared by the participants points to possible difficulties faced by foreigners, difficulties in adapting to different realities and culture.

Generally, the immigration process involves difficulties for social, school, and work adaptation. These difficulties can be hard hit by the presence of an autistic child who requires more care and closer and systematic follow-up in social and communication situations.

Many studies have investigated the information that the general population or specific groups have about autism. The autism knowledge in a health care setting [16], experiences of autism diagnosis [17], lay beliefs, and the role of cultural values [18]. A general population survey assessed autism awareness, knowledge about autism, and perceptions about autism interventions in Northern Ireland using a digital instrument and had similar results to those found in this study [19].

Other studies investigating language aspects of autistic children in bilingual [20–23], multicultural environments [24, 25], specifically with minority groups [26], of immigrants [27] reported aspects like those observed in this study. One study [10] was found that involved research into autism awareness and knowledge about autism specifically in foreigners.

The great migratory movement observed worldwide reflects in the growing ethnic and cultural diversity of the Brazilian population. This reality brings new challenges for professionals working in the field of health and education. Based on what is already happening in other countries [25], it is necessary to establish public proposals that guarantee the access of this population to basic services through culturally appropriate strategies. Specifically, the speech

therapist must improve instruments and procedures that are efficient to distinguish what is characteristic of social adaptation, which is part of the heritage of culture, the native language, and what is really a communication disorder.

About ASD, it is necessary to ensure that all children have equal access to quality and early diagnosis. Speech-language assessment should be sensitive enough to distinguish cultural differences from communication disorders characteristic of ASD.

The speech pathologist has a responsibility to enhance knowledge about the social media profile characteristic of ASD, to strengthen information about the initial characteristics of ASD, and to improve early detection. The speech therapist should engage in the dissemination and awareness of the ASD by strengthening access to information and care for all by reducing social disparities.

5. Conclusion

The sociodemographic diversity identified in this study reflects the sociocultural diversity present in Brazil, besides reinforcing the importance of considering this population when thinking about strategies and behaviors directed at individuals with ASD. It is important to emphasize that all participants in the research were linked to people with autism or family ties or working with this population.

Since it was not the focus of the original study, it is not possible to know the exact situation of foreigners in Brazil, whether they are temporary workers, residents, or refugees. The fact is that regardless of the condition in which these people meet, the unique condition of the ASD mobilizes them to seek information and help. In this sense, the Internet becomes a very important tool because it allows reducing the sociocultural and linguistic distances that can so much impact the acquaintanceship of these people.

Social isolation and stigmatization may be intensified by economic, social, and linguistic difficulties in addition to limited awareness of autism.

Regardless of the condition of life, parents play a crucial role in the early identification and treatment of ASD. Their cultural beliefs about development and disability can influence the proximal processes and decisions about caring for their children.

Care must be taken to ensure that situations experienced by foreigners, such as social isolation, language difficulties, cultural diversity do not interfere with the diagnosis of ASD.

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