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Interference of the communicative profile of children with autism spectrum disorders upon their mother's quality of life

Interferência do meio comunicativo da criança com transtorno do espectro do autismo na qualidade de vida de suas mães

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Keywords

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ABSTRACT

Purpose: According to the World Health Organization, quality of life is defined as the perception an individual has on his/her position within the cultural context and the system of values in which he/she is contained. This perception is intrinsically related to the objectives, expectations, patterns, and concerns of such an individual. We know that when a member of a family is assailed by an ailment, the quality of life of all of those who surround him/her suffer a strong impact. One of the great concerns of the families regarding the development of a child with Autism Spectrum Disorder (ASD) is the lack or impairment of the child's speech. Thus, the objective of this study was to analyze the interference of the communicative means of children with ASD upon the quality of life of their mothers. **Methods:** This was a transversal study. The sample was obtained from 41 mothers of children diagnosed with ASD by a multi-disciplinary team: the mothers were divided into two groups: 20 mothers of non-verbal children-GASD-NV; and 21 mothers of verbal children-GASD. We applied the WHOQOL-Bref questionnaire to score and analyze the quality of life of these mothers. **Results:** There was no significant difference in the maternal perception related to the domains that reflected the quality of life which we compared between these two groups of mothers. In both groups, we observed high indexes of dissatisfaction. **Conclusion:** We verified that the quality of life of the mothers of children with ASD was affected regardless of the communicative means used by the child.

Descritores

Transtorno Autístico
Qualidade de Vida
Comunicação
Linguagem
Fonoaudiologia

RESUMO

Objetivo: A Organização Mundial de Saúde define a qualidade de vida como a percepção que o indivíduo tem de sua posição na vida dentro do contexto cultural e do sistema de valores nos quais ele está inserido. Ela está intrinsicamente relacionada aos objetivos, expectativas, padrões e preocupações deste indivíduo. Sabe-se que, quando um membro da família é acometido por alguma doença, a qualidade de vida de todos ao seu redor sofre forte impacto. Uma das grandes preocupações das famílias em relação ao desenvolvimento da criança com Transtorno do Espectro do Autismo (TEA) é a ausência da fala. Sendo assim, o objetivo deste estudo foi analisar a interferência do meio comunicativo da criança com TEA na qualidade de vida de suas mães. **Método:** Trata-se de um estudo transversal. A amostra foi constituída por 41 mães de crianças diagnosticadas, por equipe multidisciplinar, com TEA que foram divididas em dois grupos: 20 mães de crianças não verbais - GTEA-NV e 21 mães de crianças verbais - GTEA. Para a análise da qualidade de vida das mães, aplicou-se o questionário WHOQOL-Bref. **Resultados:** Não houve diferença significante na percepção materna acerca dos domínios que refletem a qualidade de vida na comparação entre os grupos de mães. Em ambos os grupos, observamos índices elevados de insatisfação. **Conclusão:** Verificamos que a qualidade de vida das mães das crianças com TEA esteve afetada independentemente do meio comunicativo utilizado pela criança.

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INTRODUCTION

The concept of quality of life in the health area is understood at the interface of health and the disease as a continuous process related to economic, socio-cultural, psychological, and lifestyle aspects[1]. According to the World Health Organization, we can define it as the individual's perception of his position in life within the cultural context and the value system in which he is inserted. Quality of life is also intrinsically related to the individual's goals, expectations, standards, and concerns[1].

We know that when a family member has some illness, the quality of life of everyone around him suffers a strong impact. For example, the Autism Spectrum Disorder (ASD), which is characterized by severe impairments in the areas of interaction and social communication and a restricted and stereotyped repertoire of interests and activities[2]. As it is a lifelong and severe neurobiological condition, possibly emotional overload and constant concerns about the care of the child with ASD may impact the quality of life of family members, especially mothers[3-6].

The absence of speech is one of the major concerns of families in the development of the autistic child. A considerable number of children with ASD are unable to use verbal communication due to the severity of the condition[2].

Several authors have highlighted the importance of assistance for the child and the families. This is due to the severe disturbance in the relational dynamics that is installed as a result of the impairment in the mental and emotional development of the child, which limits the creation and maintenance of situations of reciprocity between them and their families[3-6]. The family's commitment to treatment expands the therapeutic goals in the home context, providing greater synchronicity and, communicative and social contingency, between the child and his interlocutors. As it empowers the family, it reduces their emotional burden[3-6].

The study aimed to analyze the interference of the communicative environment of the child with Autism Spectrum Disorder in the quality of life of their mothers. This study hypothesizes that the absence of verbal communication by the child with ASD interferes negatively with the quality of maternal life by adding greater concern and emotional overload to family members.

METHODS

All parents or guardians were aware of the methodological procedures of the study and signed the Informed Consent Term approved by the Research Ethics Committee of the Federal University of São Paulo (CEP 5505/2017).

The sample had 41 mothers of children with Autism Spectrum Disorder evaluated and diagnosed by a multidisciplinary team, according to the DSM-5 criteria[2].

The inclusion criteria were the child's ASD diagnosis. The exclusion criteria were the presence of neurological changes, malformations, and/or associated genetic syndromes, physical, auditory/visual, and/or motor disabilities in the child; and/or the mother's refusal to answer the questionnaires proposed in the study.

These mothers were between 29 and 57 years old, with a mean age of 42 years and 7 months (SD = 7.02). Regarding the level of education of the mothers, 46.3% said they had completed high school; 43.9%, completed higher education; 7.3%, completed elementary school; and 2.4%, technical education. As for the classification by socioeconomic level, 51.2% of the families belonged to class C, followed by 34.2% belonging to class B, 7.3%, to class A and 7.3%, to class D.

The children were between 2 and 12 years old with an average age of 5 years and 6 months and had an average education level of 35 months (SD = 26.9). Seventy-eight percent (78%) of the children were male and 22%, female.

Regarding the children's communicative environment, 48.8% were classified as non-verbal as they produced only vocalizations and/or isolated words; and 51.2% were classified as verbal as they emitted juxtaposition of words (necessarily one of the words, verb) or phrases in the period of speech-language assessment.

As for the children's cognitive profile, the average intellectual quotient index was 64.59 (SD = 23.06), as seen by the application of the Weschler Intelligence Scale - WISC III[7].

Procedures

The mothers or guardians answered to the following instruments through an interview:

- An abbreviated version of the WHOQOL-Bref[1] instrument: It is an abbreviated Brazilian version, translated into Portuguese[1], to measure the quality of life of individuals. It has 26 questions with physical, psychological, social relationships, and environmental domains;
- Autism Behavior Checklist[8]: It is a list of 57 non-adaptive behaviors divided into five areas: sensorial, the use of body and object, relational, language, and personal-social, measuring the severity of the autistic behaviors;
- ABEP Socioeconomic Scale[9]: The basic concept of this classification is to discriminate people socioeconomically through information about their education and the possession of certain "comfort items", such as a television, refrigerator, radio, car, and housekeepers. The number of items is taken into account rather than simply assigning points according to the presence or absence of each item. The sum of the points obtained would include the person interviewed in classes A, B, C, D, or E.

We formed two groups to assess the interference of the communicative medium in the quality of maternal life:

Verbal Group: 21 mothers of children whose communicative profile was characterized by the predominance of emission of the juxtaposition of words and/or phrases in the initial period of speech-language assessment.

Non-verbal group: 20 mothers of children whose communicative profile was characterized by the predominance of vocalization emission and or minimum emission of words in the same period of speech-language assessment.

Statistical method

We initially performed descriptive analyzes of all variables of interest in the study. The Mann-Whitney test compared the numerical variables between groups. The significance level of 0.05 was considered.

RESULTS

Table 1 shows the distribution of sociodemographic information; severity of behavioral atypia and intellectual quotient of the total sample of children and by groups: non-verbal and verbal.

Table 2 shows the quality of life of the total sample of mothers and by groups: non-verbal and verbal, according to the WHOQOL-Bref domains.

There was no statistical difference in the average age of mothers of non-verbal children and the mothers of verbal children (p = 0.132; 41 years and 5 months, 43 years and 8 months, respectively).

We also identified homogeneity of the groups regarding the time and level of education of the mothers, with 38.1% of mothers in the group of non-verbal children and 43.9% of the verbal group reporting having completed higher education; 40% of the non-verbal group and 52.4% of the verbal group with complete high school.

The predominant socioeconomic level of the families was class C (50% of the non-verbal group and 47.6% of the verbal group), although it varied at all levels, in both groups.

Regarding the total sample of children, the mean age was 5 years and 6 months, with no significant difference between the groups (p = 0.215). There was no statistical difference in education level, with 38.5 months in the non-verbal group and 32.7 for the verbal group (p = 0.685), with a predominance of enrollments in regular schools in both groups.

The total values of non-adaptive behaviors obtained through the application of the Autism Behavior Checklist[8] were also similar in both groups, with 80.8 in the verbal group and 69.7 in the non-verbal group (p = 0.171).

There was no significant correlation between the domains of quality of life with the levels of education in the mothers, socioeconomic status of the families, or with the total values of the Autism Behavior Checklist[8].

DISCUSSION

In the quality of life analysis of the total mothers interviewed, we found that the maternal perception showed high levels of dissatisfaction in all domains, confirming the great impact in the families with the diagnosis of Autism Spectrum Disorder in children, especially in mothers who are the potential caregivers[3-6].

The questions related to the environment had the least positive answers. These data reflect the families' concern in the financial resources to guarantee the child's access to health care, education, and leisure services; which can further intensify parental stress[10-15].

There are important barriers in Brazil imposed by the health system, from limited access to evaluation, diagnosis, treatment services in public sectors, as well as the very high cost of quality private services. These barriers will negatively impact families, generating constant parental stress[15].

Table 1. Sociodemographic data; behavioral atypia and intellectual quotient of the total sample and by groups: non-verbal and verbal

Social-demographic data		Total Mothers	NVG	VG	Mann-Whitney test (p)	Result
Maternal age (months)	Mean	42.73	41.55	43.86		
	Median	42	40.5	43	0.132	NV = Verbal
	SD	7.02	7.99	5.93		
	N	41	20	21		
Child's age	Mean	5.68	6.2	5.18		
	Median	5.25	5.67	5.09	0.215	NV = Verbal
	SD	2.31	2.57	1.95		
	N	41	20	21		
Child's education level (in months)	Mean	35.56	38.5	32.76		
	Median	36	36	36	0.685	NV = Verbal
	SD	26.92	29.94	24.11		
	N	41	20	21		
ABC	Mean	75.03	80.84	69.76		
	Median	76.5	82	66	0.171	NV = Verbal
	SD	23.54	16.21	27.97		
	N	41	20	21		
IQ	Mean	64.59	61.6	67.43		
	Median	65	61.5	72	0.082	NV = Verbal
	SD	23.06	22.36	23.9		
	N	41	20	21		

Caption: NVG = Non-verbal children group; VG= Verbal children group; NV= Non-verbal; SD = Standard Deviation; N = Number of Individuals; ABC = Autism Behavior Checklist; IQ = Intelligence Quotient

Table 2. Quality of life of the total mothers and by groups: non-verbal and verbal, according to WHOQOL-Bref domains

WHOQOLBref domains		Total Mothers	NVG	VG	Mann-Whitney test (p	Result
Physical	Mean	61.9	64.85	59.1		
	Median	50	69	50	0.247	NV = Verbal
	SD	18.78	18.85	18.73		
	N	41	20	21		
Psychological	Mean	55.68	55.85	55.52		
	Median	50	56.5	50	0.979	NV = Verbal
	SD	24.76	23.21	26.73		
	N	41	20	21		
Social relationships	Mean	62.17	60.35	63.9		
	Median	56	56	56	0.522	NV = Verbal
	SD	23.07	25.47	21.02		
	N	41	20	21		
Environment	Mean	50.83	50.95	50.71		
	Median	50	50	50	0.979	NV = Verbal
	SD	21.85	23.05	21.38		
	N	41	20	21		

Caption: NVG = Non-verbal children group; VG= Verbal children group; NV= Non-verbal; SD = Standard Deviation; N = Number of Individuals

Several studies with families of children with ASD have pointed out to the high risk of mothers suffering from physical and emotional fatigue, depressive symptoms, and anxiety resulting from everyday concerns and the need for intensive management of the child's behavioral atypia[10-15].

This study hypothesized that the absence of verbal communication would negatively impact the mothers' quality of life; however, we found that the child's communicative environment did not directly interfere, that is, when comparing the rates obtained in the interviews with the mothers of both groups of children, we obtained alarming dissatisfaction data.

These results show the importance of valuing coping strategies, emotional support for families, regardless of the severity of symptoms or the communication condition of the child affected by ASD[3-6,10-15].

However, the sample size may have reduced the potential for statistical treatment and should be a limitation of the study. We suggest that, in subsequent studies, in addition to the sample increase, the application of instruments to assess symptoms of anxiety and depression, for example, in families, should also be considered.

CONCLUSION

Mothers reported high rates of dissatisfaction in all domains of the subjective assessment of the quality of life.

The child's communicative environment did not directly interfere with the quality of maternal life, showing the importance of valuing coping strategies, emotional support for families, regardless of the communication impairments and the child's severity level.

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Author contributions

GM was responsible for the collection, tabulation of data, and preparation of the manuscript; MI collaborated with the data tabulation; MR, SCC, and JP collaborated with the final elaboration of the manuscript; ACT supervised the collection, collaborated with the data analysis and was responsible for the design of the study and general guidance on the stages of execution and final elaboration of the manuscript.