



SUPPORT NETWORK FOR FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER¹

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ABSTRACT

Objective: to identify the social support network for families of children with Autism Spectrum Disorder (ASD). **Methods:** descriptive study with a qualitative approach, with the participation of 22 family members of children with ASD. Data collection was conducted through semi-structured interviews between August 2018 and March 2020. Statements were transcribed and submitted to content analysis, with the support of the WebQDA[®] software. **Results:** the following categories and subcategories emerged: family support (elements of family network, restricted network, and network functions) and community support (services used, material support and services, community resources, cognitive guide and advice). **Final Considerations:** the family support network is restricted and weakened due to limited support from the extended family or other community members. In addition, barriers were identified in the access to health services and social assistance resources ensured by law for people with ASD, revealing the importance of the role of multidisciplinary teams in connecting the care network, with a view to strengthening the families, becoming agents for the protection of rights and expansion of the network for the child with ASD and their family.

Keywords: Autism Spectrum Disorder. Child Health. Social Support. Family.

INTRODUCTION

Estimates show that one out of 54 children lives with Autism Spectrum Disorder⁽¹⁾, which is characterized by alterations in the child's brain development that affect communication, social interaction, and behavior. In the area of social communication, the child may present deficits in social-emotional reciprocity, failure in establishing conversations, reduced sharing of interests, emotions, or affect, and deficits in initiating or responding to interactions⁽²⁾.

In social interaction, there may be difficulties in making friends and sharing imaginative play, as well as lack of interest in peers. The behavioral area is characterized by restricted or repetitive motor

movements, use of objects, or speech. There are highly restricted interests that are abnormal in intensity or focus, such as strong attachment to or preoccupation with unusual objects, and hyperreactivity or hyporeactivity to sensory input⁽²⁾. This condition generates demands for specialized care, causing families to organize themselves to meet them and to require social support for childcare.

Social support networks are relationships between people who are connected by affective bonds, in which subjective and objective exchanges occur and make them real, favoring the access to goods and services, information, and social interactions⁽³⁾. Through networks, it is possible to obtain social, emotional, cognitive, and

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financial support, which are factors that contribute to human development and fulfill the person's needs to interact with others. Moreover, they provide the comfort of belonging to a group and of being loved, conditions that are considered important for the maintenance of self-esteem⁽⁴⁾.

The forms of social network support identified in the scientific literature are: 1) Social companionship, 2) Material support and services, and 3) Cognitive guide and advice⁽³⁾. Social companionship comprises sharing pleasurable social activities, such as going to the movies, dancing, having dinner, shopping, praying or other leisure activities. In addition, it involves mutual emotional support through positive attitudes, understanding, sympathy, encouragement, and support⁽³⁾.

Material support and services relate to provision, collaboration, physical help, financial aid, or specialized services, as in the case of the health sector. In this type of social support, new connections take place with people and networks, family or community, favoring its expansion. The third form of social support, cognitive guide and advice, refers to sharing personal and social information⁽³⁾.

Social support for families of children with ASD is important, as the child presents characteristics related to persistent deficits in social communication, behavior, and social interaction⁽⁵⁾. Thus, upon the commitment and limitations imposed by the child's condition, the family faces the challenge of adjusting plans and expectations for the future, as well as the need to adapt to the intense dedication and provision of care to the child's specific needs⁽⁶⁾.

Thus, families may have difficulties in providing full assistance for the child's health needs, which is why they need support from the community, social organizations and the state to minimize or solve them⁽⁷⁾, and support networks are essential for such provision.

In this context, the support of professionals in understanding, respecting, and meeting the child's specific care needs is essential. In addition, it is important to assist the family in adapting to the new care context. However, according to a study, mothers take on more responsibility, which is associated with higher levels of parental distress and can influence the family dynamics⁽⁸⁾.

Family members report several changes in their

functions and roles to take care of the child with autism, such as changing their working hours to adjust them to the child's health care; intense dedication in teaching daily activities, such as using the bathroom, dressing, eating, among others; managing the attention to other family members, such as siblings of the child with autism⁽⁹⁾.

The union among family members is intensified in order to meet the child's needs, nonetheless, they report a lack of support from extended family members, financial difficulty, and hindered access to specialized public health services⁽⁷⁾.

In view of the above, considering the context of a family of a child with autism, there is a need for further studies on this subject, given the importance of the social support network to help overcome the challenges that will inevitably arise throughout life⁽¹⁰⁾.

In this scenario, this research seeks to answer the following guiding question: what is the social support network like for families of children with Autism Spectrum Disorder?

Based on the results of this study, we expect to produce information about the relational and affective bonds of the families and their sources of support, and thus to contribute to the planning of care that meets their needs. This research aimed to identify the social support network for families of children with Autistic Spectrum Disorder.

METHOD

This is a descriptive research with a qualitative approach, carried out in a Center for Specialized Child Health Care (CAESI) and two Education Centers (EC), both public facilities, located in the city of Curitiba of the Brazilian state of Paraná. Twenty-two family members of children diagnosed with Autism Spectrum Disorder participated in this study. Participants who considered themselves a family member, whether blood-related or not, who lived in the same household and provided care to the child with autism were included.

The eligibility criterion adopted was to be a family member of children aged between four and ten years diagnosed with Autism Spectrum Disorder. This age range was chosen considering that the diagnosis of Autism Spectrum Disorder occurs more frequently after 36 months of age⁽¹¹⁾,

and the age limit for the study is due to the period of childhood according to the World Health Organization⁽¹²⁾. The exclusion criterion established was being an underage family member.

The sampling process began with the completion of a list of potential study participants, containing the eligibility criteria presented earlier. Pre-selection was carried out differently at each site due to the organization of each service.

At the Center for Specialized Child Health Care (CEASI), pre-selection took place 48 hours before the appointment, where 44 children were pre-selected through medical records. Among them, 26 were excluded for not meeting the age inclusion criterion, and seven family members selected did not show up for the appointment. It was not possible to reschedule the interview with those family members due to the periodicity in which the appointments take place.

In one of the educational institutions, the list of enrolled children with a diagnosis of Autism Spectrum Disorder was used for pre-selection. Among them, 16 family members were pre-selected, out of which four were excluded for being outside the established age range and one did not show up on the date scheduled for the interview. There were no refusals to participate in the study.

In the initial sample, there were 60 family members, out of which 30 were excluded for being outside the age range and eight were excluded for not showing up on the date of the interview or appointment. It is worth mentioning that in one of the institutions there were twin brothers. Therefore, we obtained a final sample of 22 family members of 23 children diagnosed with Autism Spectrum Disorder.

Data collection was conducted through semi-structured, on-site, audio-recorded interviews, with an average duration of 30 to 40 minutes, between the months of August 2018 and March 2020. The data collection instrument was composed of sociodemographic data about the families and the children with Autism Spectrum Disorder, as well as 11 questions that sought to identify the social support network used by the families. The participants' speeches were identified by letters according to the site of study: the Specialized Center for Child Health Care (CEASI) and the Education Center (EC), as well as by numbers in the sequential order of interviews, in order to

preserve anonymity and confidentiality. This study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist for presenting its research report.

For data analysis, the statements were fully transcribed and typed into a Microsoft® Word document. The Web Qualitative Data Analysis Software (WebQDA®) version 3.0 was used to help organize the data⁽¹³⁾. The tool was chosen because it is an online operating system, which enabled interaction and sharing of data between the researchers throughout the analysis process. Following the analysis of statements, categories and subcategories were established according to the content analysis method⁽¹⁴⁾.

This research was conducted according to required ethical standards and approved by the Research Ethics Committee of the Health Sciences Department of the Federal University of Paraná, under Opinion No. 2.327.633/2017, and Certificate of Ethical Appraisal Submission No. 73197617.0.1001.0102.

RESULTS

The characterization of family members showed that 20 (91%) were female and two (9%) were male. The participants were aged between 25 and 50 years, and years of education ranged from five to 16. Regarding marital status, 16 (73%) were married, four (17%) were single, one (5%) was divorced, and one (5%) was widowed. In relation to the participants' occupation, three (13.6%) did not respond, nine (41%) were full-time caregivers of the child, and 10 (45.4%) worked in other activities. The participants' family incomes ranged from one to 20 minimum wages, with a predominance of one minimum wage.

As for the characterization of the children, the ages ranged from four to nine years. Sixteen (71%) were male and seven (30%) were female. Among the 23 children diagnosed with Autism Spectrum Disorder, nine (39%) had a comorbidity associated with the disorder, with a mean age of 2.5 years at the time of diagnosis. All children were enrolled in the educational system, 21 (91.3%) attended public schools and two (8.7%) attended private schools.

Two categories emerged from data analysis: 1) Family Support and 2) Community Support. Both

indicated how family members felt about the support they received. A total of 385 codes from the interviews were analyzed in the WebQDA software, out of which 130 comprised the Family Support category and were distributed into

subcategories. The second category, Community Support, was composed of 255 codes which were distributed into subcategories, as presented in Table 1. The Services Used subcategory showed the highest number of codes (178).

Table 1. Categories and number of codes per category and subcategories extracted from WebQDA®.

Categories	Number of Codes	Subcategories	Number of Codes
Family support	130	Elements of family support network	22
		Network functions	77
		Restricted network	31
Community support	255	Services used	178
		Community resources	09
		Material support and services	54
		Cognitive guide and advice	14

Source: Research data (2021)

The categories, subcategories and respective statements that represent them are shown below.

Family Support

In the subcategory of elements of family support, the speeches expressed that the mother, the main caregiver, receives support from family members for the care of the child with the disorder, but in a restricted manner, from the members of the nuclear family, according to the following statements:

It's just me, I'm the only one who takes care of him (CEASI-2).

I'm the only caregiver (EC-4).

It's only me and my wife (EC-10).

Me, my husband and my daughter (CEASI-6).

Among the narratives in the restricted network subcategory, some family members stated that they did not receive help in the daily care of the child, as shown in the statements:

It's very hard for us to get people from our own family to help us with him (CEASI-2).

I don't have the participation of the family, it's only me (CEASI-9).

Unfortunately, I have no help from anyone (EC-05).

Less frequently, a smaller portion of the interviewees mentioned the extended family as an element of the support network, according to the speeches:

My mom, my aunt and my grandmother (EC-7).

My in-laws, they help a lot (EC-8).

Regarding the subcategory of network functions performed by the extended family, the participants' reports indicated social companionship, material support and services:

We try to have family time, going to restaurants, going cycling (CEASI-1).

I feel that my family helps me, they're always with me, they're my support network (EC-7).

He helps me in caregiving, and also in the things that he needs (CEASI-4).

Although she [stepmother] is not the mother, she picks her up from school[child], gives her lunch, and spends the rest of the day with her (EC-10).

My ex-husband pays for his[child] health insurance (CEASI-01).

Community support

Community support constituted the subcategory of services used for specialized health care and education that the children need due to the characteristics of the disorder, as observed in the following statements:

The list is long: speech therapist, psychologist, physical therapist, pediatrician, neurologist, ophthalmologist, otolaryngologist, gastroenterologist, and endocrinologist (EC-05).

I only take him to the health clinic, I don't take him

anywhere else (EC-10).

We started to get closer after we started attending APAE, he [child] started to have more contact (EC-01).

Despite using certain formal services, participants expressed difficulty in obtaining access to them:

This institution is the one that helps me the most, you know (EC-6).

I go to hospitals that are covered by the health insurance (EC-8).

After visiting the health clinic, we tried, kept trying, and after a year and a half we were able to get it (CEASI-8).

The insurance didn't want to provide it at first, they were very resistant; then there were injunctions from other families, and we got access to a clinic specialized in therapies for autism (CEASI-1).

The community resources that families resorted to were identified, such as associations and non-governmental organizations:

In my hometown there is a non-governmental organization, I helped create it; and I also participate in another non-governmental organization here (CEASI-5).

I attended an association, where they also offered counseling about autism (CEASI-1).

I participate in two groups, one that is the [support group's name], and there's a smaller one for mothers (EC-03).

The families mentioned material support and services related to public policies. However, they face difficulties in accessing them:

He has the social assistance benefit, which we were able to get (CEASI-5).

He takes the bus, that little blue one (EC-1).

The transit pass they have (EC-9).

We get medication at the health clinic, the Health Unit (EC-7).

I still couldn't get it, because the National Institute of Social Security is tedious, it's slow, they don't want to provide it, but he has the right to it (EC-8).

They have the right to a transit pass, which I also couldn't get (CEASI-8).

Regarding cognitive guide and advice, it was possible to note that the families use the Internet as

a source of information, as well as live transmissions performed by health professionals. The participants, however, recognized that not all information available on the Internet is reliable, as shown in the statements:

There's a website about autism, there's a lot of information there, and what you can't find there you can search on Google, because it's the only way (CEASI-8).

I watch many lives with Doctor [professional's name]; after I discovered him, I started to do more research about autism (CEASI-4).

There are things that you can't take into consideration on the Internet (CEASI-10).

DISCUSSION

Faced with the impact of the diagnosis, each family adapts differently to the attention demanded and the emotions that the new condition arouses among family members in a systemic way⁽¹⁵⁾. The mother, the primary caregiver of the child with autism, participates in a social support network, and receives restricted help from the child's father, sister, aunt, and grandparents.

The bond with the extended family was minimal, which is common in families of children with Autistic Spectrum Disorder according to the scientific literature, as in this condition there is a withdrawal by the extended family and, consequently, a feeling of helplessness, since the support network is reduced to nuclear family members⁽⁷⁾. From this perspective, a greater involvement of network members can contribute to reducing the work overload, stress, and other psychosocial repercussions encountered in the family's life⁽¹⁶⁾.

The functions performed by elements of the social support network are essential for the protection of families experiencing a chronic condition⁽³⁾. Among the functions that the network elements can take on in the context of family relationships, this study highlights social companionship, material support and services. The union among family members is thus highly important in the care of the child and in the members' adaptation to the disorder, providing mutual support among the network elements and a greater concern for the child's needs⁽⁷⁾.

The mother of the child with autism relies on

the social network through a health and social assistance team, which, however, is not always helpful, according to the reports of difficulties in accessing the right to healthcare and social benefits. The chronicity of ASD and the extent of its characteristics cause families to resort to a variety of health services and to require specialized multidisciplinary care. Therefore, social support through access to health policies in Brazil is important for the health care demands of children with the disorder. In contrast to the rights of families and children with autism, the literature shows that families struggle to access services that provide specialized assistance for the child⁽¹⁷⁾.

Accordingly, professionals have difficulty in their daily practice to integrate the families' social support network and strengthen the necessary assistance for the continuity of care through an effective connection between different intersectoral services^(18,19).

Regarding the specificities of children with autism, Law No. 12,764⁽²⁰⁾ of December 27, 2012, discusses their rights, from diagnosis to rehabilitation through specialized services. The law foresees the full access to health services, including early diagnosis, multiprofessional care, adequate nutrition/nutritional therapy, medicines and information that assist in the diagnosis and treatment of the child with ASD. In addition, the law⁽²⁰⁾ established the right of access to education and vocational training; to housing; to the labor market; to social security and social assistance.

In this context, the difficulties faced by families can be minimized with the support of professionals in the areas of health, social assistance and education, as well as with the articulation of an assistance network for children with autism and their families⁽²¹⁾. The connection between family and professionals must be based on a relationship of commitment to the rights of the family and the child.

Access to a specialized education network is important for the child to achieve the development of their talents and physical, sensory, intellectual and social skills according to their characteristics, interests, and learning needs⁽²²⁾.

Material support is a crucial source of assistance to the families. The literature and the results of this study indicated that families struggle to access social assistance resources, however, children with ASD must be protected and cared

for⁽²⁰⁾ through programs and benefits for children with ASD and low-income families, if applicable. The professionals who assist these families are part of the social support network and are significant sources of information and support to guide them.

In addition to social support from government entities, associations and support groups for parents are also valuable resources in the community context⁽²¹⁾. Such spaces are used for the exchange of experiences between parents/caregivers, emotional support, material support, source of information about the disorder, exchange of experiences about therapies for children, indication of professionals to assist the child, and source of information on how to obtain social support through government subsidies⁽¹⁷⁾.

Other than informal and formal (professional) information sources, families obtain guidance on the Internet, which provides them with the opportunity to learn more about the condition of the child with Autism Spectrum Disorder. The tool is an alternative in the search for answers to their questions and needs⁽⁷⁾, as the digital sphere provides families with the autonomy to resort to the information they need at any time⁽¹⁷⁾.

The Internet searches include research about the characteristics of ASD, its causes and signs, prognosis, the child's behavior, aspects surrounding therapy/treatment, the right to health and education, social rights, future expectations, among others⁽²³⁾.

Although the Internet is used as an information source, it could become problematic due to the abundance of unreliable information⁽²⁴⁾. It is thus important to point out that the sources of information used by families have become a new demand for healthcare professionals. Additionally, informal sources do not replace the guidance of a professional specialized in the field of the disorder.

The sample size is a limitation of this study, as it prevents the generalization of the study findings.

This research provides data to promote actions that can improve the access to community resources to support the demands of families of children with autism.

FINAL CONSIDERATIONS

Family social support was restricted in the context of this study, as the mother, the child's

primary caregiver, receives support from few extended family members. The multidisciplinary social support network was not always helpful, since the study indicated difficulties in the access to health and social assistance policies guaranteed by law for people with ASD.

The disorder requires families to create and seek strategies to live with this new dynamic, so that they can accept this context, overcome the difficulties, and live in a functional way.

This demonstrated the importance of the

multidisciplinary team in articulating the support network, becoming agents for the protection of rights and expansion of the network, as its structure and connections define how much the resources will be attained for the strengthening of families.

Therefore, we consider that the results of this study can contribute to an advance in the strengthening and organization of actions, since it enables the recognition of the social support network.

REDE DE APOIO ÀS FAMÍLIAS DE CRIANÇAS COM TRANSTORNO DO ESPECTRO AUTISTA

RESUMO

Objetivo: identificar a rede social de apoio das famílias de crianças com Transtorno do Espectro Autista (TEA). **Métodos:** trata-se de uma pesquisa descritiva, abordagem qualitativa, com a participação de 22 familiares de crianças com TEA. A coleta de dados ocorreu por meio de entrevista semiestruturada, entre os meses de agosto de 2018 e março de 2020. Os depoimentos foram transcritos e submetidos à análise de conteúdo, com apoio do *software WebQDA®*. **Resultados:** emergiram as seguintes categorias e subcategorias: apoio familiar (elementos da rede familiar, rede restrita e funções da rede) e apoio comunitário (serviços utilizados, ajuda material e de serviços, recursos comunitários, guia cognitivo e de conselhos). **Considerações Finais:** a rede de apoio familiar evidencia-se restrita e fragilizada devido ao suporte limitado da família extensa ou de outros membros da comunidade. Além disso, foram identificadas lacunas no acesso aos serviços de saúde e recursos de assistência social assegurados por Lei às pessoas com TEA, revelando a importância do papel da equipe multiprofissional em articular a rede de atenção, com vistas ao fortalecimento das famílias, transformando-se em agentes de proteção aos direitos e ampliação da rede da criança com TEA e sua família.

Palavras-chave: Transtorno do Espectro Autista. Saúde da Criança. Apoio Social. Família.

RED DE APOYO A LAS FAMILIAS DE NIÑOS CON TRASTORNO DEL ESPECTRO AUTISTA

RESUMEN

Objetivo: identificar la red social de apoyo de las familias de niños con Trastorno del Espectro Autista (TEA). **Métodos:** se trata de una investigación descriptiva, con abordaje cualitativo, con la participación de 22 familiares de niños con TEA. La recolección de datos se realizó por medio de entrevista semiestructurada, entre los meses de agosto de 2018 y marzo de 2020. Los relatos fueron transcritos y sometidos al análisis de contenido, con el apoyo del *software WebQDA®*. **Resultados:** han surgido las siguientes categorías y subcategorías: apoyo familiar (elementos de la red familiar, red restricta y funciones de la red) y apoyo comunitario (servicios utilizados, ayuda material y de servicios, recursos comunitarios, apoyo cognitivo y de consejos). **Consideraciones finales:** la red de apoyo familiar se evidencia restricta y fragilizada debido al soporte limitado de la familia extensa o de otros miembros de la comunidad. Además, se identificaron lagunas en el acceso a los servicios de salud y recursos de asistencia social asegurados por Ley a las personas con TEA, revelando la importancia del papel del equipo multiprofesional en articular la red de atención, a fin de fortalecer a las familias, transformándose en agentes de protección a los derechos y ampliación de la red del niño con TEA y su familia.

Palabras clave: Trastorno del Espectro Autista. Salud del Niño. Apoyo Social. Familia.

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