

Caring for children with autism spectrum disorder and the relationship with the social determinants of health from the perspective of caregivers

A sobrecarga do cuidado da criança com transtorno do espectro autista e a relação com os determinantes sociais da saúde na visão dos cuidadores

La carga del cuidado de niños con trastorno del espectro autista y la relación con los determinantes sociales de la salud desde la perspectiva de los cuidadores

Suelen Bernardo Guckert¹ 

Aline Mara de Oliveira¹ 

Aline Megumi Arakawa Belaunde¹ 

Abstract

Purpose: To verify the possible relationship between the children with Autism Spectrum Disorder caregiver's burden with the Social Determinants of Health **Methods:** Descriptive exploratory qualitative study carried out with caregiver's of children up to 12 years old who have the Autism Spectrum Disorder diagnosis and were undergoing treatment in a Specialized Rehabilitation Center. Data collection was

¹ Universidade Federal de Santa Catarina, Florianópolis, SC, Brazil.

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AMAB: study design; methodology; data collection; draft of the article and critical review; guidance and supervision.

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AMO: draft of the article and critical review.

Email for correspondence: arakawa.aline@ufsc.br

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carried out with triggering questions, through individual interviews, which were recorded for later analysis. Data were analyzed qualitatively according to Content Analysis, in thematic modality. **Results:** The main caregiver's are the children's mothers, who dedicate full time to the child's needs and, some of them need to reconcile this care with domestic tasks, work activities and personal life. These caregiver's presented reports of tiredness, stress, helplessness feelings, unpreparedness and guilt, that reflect on the burden experienced. The possible causes of the caregiver's burden are related to the Social Determinants of Health and could be avoided or minimized if government agencies turned their attention to these aspects, such as access to health, education and leisure. **Conclusion:** The caregiver's burden could be reduced if health promoting actions were carried out in favor of these people, both those who provide care and who receive it, in this case, the children.

Keywords: Speech-Language and Hearing Sciences; Caregivers; Social Determinants of Health; Autistic Spectrum Disorder.

Resumo

Objetivo: Verificar a possível relação entre a sobrecarga dos cuidadores de crianças com Transtorno do Espectro Autista com os Determinantes Sociais da Saúde. **Métodos:** Estudo do tipo descritivo exploratório de caráter qualitativo realizado com os cuidadores de crianças de até 12 anos de idade que possuem o diagnóstico de Transtorno do Espectro Autista e que estivessem em tratamento no Centro Especializado em Reabilitação, tipo II. A coleta de dados foi realizada com questões disparadoras, por meio de entrevistas individuais, que foram gravadas para posterior análise. Os dados foram analisados de forma qualitativa de acordo com a Análise de Conteúdo, na modalidade temática. **Resultados:** As principais cuidadoras são as mães que se dedicam em período integral às necessidades da criança e algumas precisam conciliar esse cuidado com as tarefas domésticas, as atividades laborais e a vida pessoal. Essas cuidadoras apresentaram relatos de cansaço, estresse, sentimento de desamparo, despreparo e culpa, que, por sua vez, refletem na sobrecarga vivenciada. Os possíveis causadores da sobrecarga dessas cuidadoras estão relacionados aos Determinantes Sociais da Saúde e poderiam ser evitados ou minimizados se órgãos governamentais voltassem seus olhares a esses aspectos, como acesso à saúde, educação e lazer. **Conclusão:** A sobrecarga dos cuidadores poderia ser reduzida se ações promotoras da saúde fossem efetivadas em prol de quem oferece o cuidado, como quanto quem o recebe, neste caso, as crianças.

Palavras-chave: Fonoaudiologia; Cuidadores; Determinantes Sociais da Saúde; Transtorno do Espectro Autista.

Resumen

Objetivo: Verificar la posible relación entre la carga de los cuidadores de niños con Trastorno del Espectro Autista y los Determinantes Sociales de la Salud. **Métodos:** Estudio descriptivo exploratorio de carácter cualitativo realizado con cuidadores de niños de hasta 12 años que tienen el diagnóstico con Trastorno del Espectro Autista y que se encontraban en tratamiento en el Centro de Rehabilitación Especializada, tipo II. La recolección de datos se realizó con preguntas desencadenantes, a través de entrevistas individuales, las cuales fueron grabadas para su posterior análisis. Los datos fueron analizados cualitativamente según Análisis de Contenido, en modalidad temática. **Resultados:** Los cuidadores principales son madres que se dedican tiempo completo a las necesidades del niño y algunas necesitan equilibrar este cuidado con las tareas domésticas, actividades laborales y vida personal. Estos cuidadores presentaron relatos de cansancio, estrés, sentimientos de impotencia, falta de preparación y culpa, que, a su vez, reflejan la sobrecarga vivida. Las posibles causas de sobrecarga de estos cuidadores están relacionadas con los Determinantes Sociales de la Salud y podrían evitarse o minimizarse si las agencias gubernamentales se enfocaran en estos aspectos, como el acceso a la salud, la educación y el ocio. **Conclusión:** La carga de los cuidadores podría reducirse si se realizaran acciones de promoción de la salud a favor de quienes brindan cuidados y quienes los reciben, en este caso, los niños.

Palabras clave: Fonoaudiología; Cuidadores; Determinantes Sociales de la Salud; Trastorno del Espectro Autista.



Introduction

The Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by symptoms such as difficulties with communication, socialization and feeding, restricted interests and repetitive and/or stereotyped movements. An autistic child may present all or only two of the symptoms and the severity of the symptoms also varies. Due to the challenges associated with ASD, children with this disorder often require significant caregiver support to navigate daily life and various social contexts.^{1,2}

A caregiver is an individual who provides care and support to another person who is unable to independently perform daily living activities, partially or fully. This need for support that the individual needs may be due to a birth disability (when the person is born with the disability) or acquired disability (when the disability is caused by an illness or injury)^{1,3}.

The primary caregiver for a child with ASD is typically the mother, who, in turn, stops carrying out other activities to dedicate herself exclusively to the child's needs. Considering the symptoms, caregivers can become overwhelmed by giving up their needs (and self-care) when faced with daily challenges to understand and help the child³.

In order to minimize the difficulties faced by these families in their daily lives, children and caregivers can receive care from specialized professionals, receive support from people in the health and education sectors, and access leisure environments that meet the needs of both adults and children. Ideally, these places and services should be in line with the Social Determinants of Health (SDH) and linked to social and community networks, health services, education, and cultural and environmental conditions².

Considering the proximal determinants, health promotion strategies aimed at caregivers can be developed, expanding the provision of services to the public and strengthening the participation of these caregivers in discussions and issues relevant to ASD, reducing social inequities⁴.

For the treatment of people with ASD, some cities have specialized health and education services, such as rehabilitation centers, associations and support groups. In theory, the caregiver burden could be reduced if these services were available to this population; however, specialized services

are not widely available and, when they are, they have difficulty meeting all the demand directed at them, resulting in low resolution and lack of assistance^{1,3}. Given the significant burden experienced by caregivers of children with ASD, this study aimed to investigate the factors contributing to caregiver overload.

Methods

This qualitative, descriptive, and exploratory study investigated the experiences of caregivers of children aged 12 and under with Autism Spectrum Disorder (ASD) receiving treatment at a specialized rehabilitation center. The study was conducted as part of a master's thesis in Speech-Language Pathology at the Federal University of Santa Catarina (UFSC) and was approved by the University's Human Research Ethics Committee (HREC) under reference number 5,309,482.

The present study included children's guardians diagnosed with ASD, who were receiving assistance at CER type II and who voluntarily agreed to participate in the study. The exclusion criteria adopted were withdrawal during the interview or the impossibility of scheduling the interview, which did not occur in this study. The participants were individually invited to join in the research through face-to-face meetings. All caregivers signed the Free and Informed Consent Form (FICF) and received a copy of it.

All the data collection was carried out between May and June 2022, after scheduling interviews and carried out individually by the researcher, in a private and quiet environment, lasting approximately 30 minutes. It began with a dialogue clarifying the research proposal and, subsequently, the search for sociodemographic information from caregivers such as: age, gender, income, occupation, education and access to health services.

From this, the following guiding questions were used for the dialogue: 1) What is your daily routine with the child like? How do you experience the advantages and disadvantages of caring? 2) Who can you count on to help you look after the child? What about your family? What about places? 3) What is it like to provide care with your income? 4) What are the first warning signs to seek diagnosis and treatment? 5) What is the easiest and most difficult aspect of interacting with the child? Has this situation changed over time?

The interviews were recorded with a cell phone to be transcribed in full and saved in an online file storage and synchronization service, encrypted and with unique access by the researchers in order to maintain data confidentiality.

The sociodemographic data were described in an Excel® table and the interviews were transcribed into a Word® document for later analysis using Content Analysis, which according to Minayo⁵, consists of three stages, the first referring to pre-analysis, followed by exploration of the material and finally, the treatment of the results obtained and their Interpretation.

The caregivers were coded by the initial letter corresponding to the research group “C” and the interviews were marked by a numerical code in Arabic numerals, in ascending order, successively. The interviews were closed according to data saturation.

The SDH were analyzed considering the model developed by Dahlgren and Whitehead⁶ based on the levels of social conditions that emerged in the

participants’ statements. This model was employed as a foundational framework given its comprehensive exploration of determinative factors, spanning from the individual to the macro factorial level.

Results

Sociodemographic characterization of research participants

For this study, 11 caregivers of children with ASD were interviewed, being 10 of them female and 1 male. The degree of kinship of these caregivers with the children was predominantly maternal, as shown in Table 1. In addition, the average age of the participants in this study was 34.63 years (minimum 26 years and maximum 62 years of age), with an average monthly family income of R\$ 2,621.45, the vast majority of occupations are housewives or self-employed, and three (27.27%) of the caregivers have higher education, as shown in Table 1.

Table 1. Characterization of the study participants/caregivers

Caregiver	Caregiver's gender	Child's gender	Caregiver's age (years)	Child's age (years)	Age when received diagnosis (years)	Income (MW)	Occupation	Education
C1	F	M	31	9	6	1 a 2	Manicure (self-employed)	High School
C2	F	M	52	9	8	1 a 2	Housewife	Incomplete Higher Education
C3	F	M	60	8	7	2	Retired	Not informed
C4	F	M	64	4	3	1	Retired	Incomplete elementary education
C5	F	M	37	5	3	4 a 5	Restaurant manager	Postgraduated
C6	F	M	26	6	5	1	General Services	Elementary Education
C7	F	M		7	2	1	Intern	Higher Education in progress
C8	F	M	26	5	3	1 a 2	Housewife	Incomplete Higher Education
C9	F	M	30	7	3	1 a 2	Manicure (Self-employed)	High School
C10	M	F	27	3	2	4 a 5	Teacher	Graduated
C11	F	M	28	5	2	4 a 5	Housewife	Graduated

Caption: C = Caregiver; F = Female; M = Male, MW = Minimum Wage



The results, in general, presented the perception of caregivers of children with ASD, expressing views regarding daily life, support network, income and aspects related to the diagnosis. These aspects will be presented and discussed in three categories, which, in turn, systematize the problems presented in this study: a) Daily life of the caregiver with the child: the overload can be present in the caregiver and in the person being cared for; b) Strengths and weaknesses in caring for children with autism; c) From warning signs to diagnosis and therapeutic process.

Category 1) Everyday life of the caregiver with the child: the overload can be present in the caregiver and in the person being cared for

The daily life of a caregiver of a child with ASD can be challenging, as they need to balance their duties with caring for the child. As a result, some caregivers choose not to have employment contracts. Maintaining a paid job may be an imminent necessity for others, given the child's demands. One option that some caregivers have found is to work from home, as a freelancer. This way, the caregiver has greater flexibility in adjusting the time dedicated to work activity to the child's needs, as can be seen in the following statements:

"I've just quit my job and I'm working as a manicure at home." (C1)

"In the morning, I try not to be working, when I am, I ask his father to keep an eye on him." (C9)

The children's daily activities include therapy, daycare or school, and other tasks that the caregiver understands to be necessary for the child. In this context, children may feel overwhelmed, as activities can be exhausting, turning moments that should be enjoyable into unpleasant ones. This creates a risk of overload for both the child and the caregiver, an aspect not observed in cases of mild autism.

"In the morning, when he doesn't have therapy, he goes to school. I work in the afternoon, so when I leave my job, I pick him up from school and he still goes to college with me. We try to work out our schedules, so he doesn't miss too many classes either. So it's quite tough, both for him and for me, as I'm a single mother." (C7)

Category 2) Everyday life: strengths and weaknesses in caring for children with autism

This category was divided into two subcategories for better visualization of the results, one to present the strengths and the other to present the weaknesses that caregivers face during their daily life with the child.

Facilities:

According to caregivers, there are some skills that children have developed that have made daily life easier, such as their relationship with the caregiver, (improved) communication, independence in performing tasks, understanding commands and reducing or eliminating inappropriate behavior. These factors listed as easiness can be developed with therapeutic care and/or according to the parents' teachings, helping with family dynamics, as reported:

"He is quite independent; if he wants to drink coffee he goes and gets it. He is very dear, he is very affectionate, and he helps me. He doesn't complain." (C1)

The support network was also defined as one of the facilities that caregivers have, as this network is made up of family members who are willing to help the caregiver. Some statements brought up the role of the partner/husband as another person to make up the support network, in the role of collaborating with the care provided by the mother figure.

"I count on my sister. Then there's only my husband, who helps me a lot when he's home." (C3)

"We have good support. We have both grandmothers, our maternal and paternal grandmothers. We've never had any problems with support... support like that." (C10)

The caregivers' speeches brought up some social facilities considered to be an integral part of the support network, such as schools that have students diagnosed with ASD and the group of parents and/or caregivers that takes place at CER. In this group, activities are carried out collectively with parents and/or caregivers, coordinated by a neuropsychologist and with the participation of therapists from CER, in addition to a WhatsApp® group:

"I depend on the school to be able to work in the afternoon..." (C7)





"We are having lectures here, which help a lot because at the private clinic we didn't have much contact with other mothers. There is also a WhatsApp® group for autistic mothers here in the city." (C11)

Weaknesses:

Several aspects were defined as difficulties for caregivers when faced with symptoms presented in autism, such as crises that can occur more or less frequently, the intensity of the crisis, and situations involving episodes of aggression:

"It got much worse with the pandemic. He wouldn't go out and started having panic attacks. These attacks started to happen once a month and then once a day." (C3)

"He cries a lot, we say "no" and we have to put up with him crying. He had more intense attacks when he went longer without therapy." (C11)

Just as independence was listed as one of the advantages, dependence is related to difficulties, since the child may require more help to carry out their daily activities.

"Today, it is much better! I don't know if it's because of him, it seems like he demands more from us, you know? They want attention, you know." (C2)

Caregivers are concerned about the child's development in all the skills necessary for their full development. In this context, feeding difficulties, selective eating, and delayed language development are also daily challenges faced by caregivers.

"He hardly eats anything. His food is whole-wheat bread with a little ketchup, I heat it up in the sandwich maker and he just eats it." (C3)

"The biggest difficulty I have with him is communication. He doesn't communicate with us at all." (C7)

It is understood that children generally need support to develop their independence and skills; however, caregivers have a proportional demand when the same child requires more time to develop such skills. In this situation, the caregiver gives up their own needs in favor of the act of caring.

"Before, I thought I had given up my life to take care of him. It wasn't what I imagined for myself, but I see that most mothers do this." (C11)

The difficulties faced by caregivers are not always related to the act of caring for the child, but

to other issues related to the family environment: psychological, financial, and emotional aspects, lack of leisure time, and comments from those who are unaware of the disorder.

"In this routine, I think it is more psychological and financial as well." (C5)

"We spend a lot of time at home, because he doesn't like to go everywhere! Sometimes he gets nervous at the mall. People talk, point out, or give advice." (C11)

Children typically attend CER for three to twelve months. Caregivers often express concern about potential regression of skills after discharge from the program.

"And now, when these three months are over, what will we do? He can't be left without treatment! There will be regression. The biggest difficulty today is the (low) number of therapies offered by the health department, you know" (C7)

In the region where the study was conducted, there are few places that offer free services for children with ASD. Some children receive therapy in private services. The cost of other services was mentioned as one of the difficulties in providing this care.

"At the time, we didn't have health insurance; everything was private." (C8)

"When we started here, it was at the same time that we looked for a private neuropediatrician, because there are no neuropediatrician at SUS (Unified Health System)." (C10)

To help with childcare expenses, it can be considered obtaining a benefit provided monthly by the government, but not everyone meets the eligibility criteria or is still in the process of being analyzed.

"He has been receiving the BPC (Continuous Benefit Payment) since last year. We had a struggle. The BPC was denied four times." (C7)

The interviewees reported that they had felt helpless, without guidance and support from other entities or public bodies, and that the CER was the only place for support.

"I think some psychological support, because at home I'm responsible for everything. Then everything becomes overwhelming when night falls." (C2)



"I go to therapy once a week, and that has helped me." (C5)

Category 3) From warning signs to diagnosis and therapeutic process

The warning signs when a child is suspected of having autism can be observed by people around the child, such as caregivers, family members, health and education professionals. These signs may become apparent in early infancy or may take longer to manifest. Throughout this diagnostic process, there is a long journey, a series of recommended assessments and exams that can make the process slow.

"Not looking into the eyes and then the stereotypies. I noticed this when he was ten months old, but the correct diagnosis came when he was six years old." (C1)

"We took him to the pediatrician, and she said it would require some evaluation. So we went from June to January, which was when the doctor confirmed the diagnosis." (C8)

The search to find out why a child has a delay in neurodevelopment or even why they exhibit certain behaviors is tireless, and can generate discomfort and even exclusion experienced by some families, making this process more difficult and painful for the caregiver and the child. After the diagnosis, another concern arises related to carrying out the treatment indicated by the neuropsychiatrist. The other place in the city that also provides care for this group is the Association of Parents and Friends of the Exceptional Children (APAE), the Center for Psychosocial Care for Children and Adolescents (CAPSi) and the Specialized Center for Rehabilitation (CER).

"They didn't accept him at the municipal daycare center, they (the teachers) said he had a problem." (C1)

"He was already a patient at APAE, but when he was six and a half years old they stopped assisting him. He spent about four months without treatment until he was called here at CER, but here it's been only one year." (C7)

After the beginning of the therapeutic process, many families reported noticing significant changes in their child's daily life. Others, despite a short stay at the CER, showed small developmental changes, according to caregivers.

"After he came here, he changed a lot. And so, it's a shame that he can only stay here for a short period of time." (C6)

"I would say that he had small improvements in everything, in all aspects we felt this improvement." (C10)

Finally, in the family context, the diagnosis can be received in different ways. Some people have great difficulty accepting the diagnosis, other caregivers recognize the value of understanding the child's perspective to effectively support their daily needs.

"It was very difficult for me. But then it passed. I thought it wouldn't change anything; in fact, it became much easier, because we know the cause." (C8)

Discussion

It is noteworthy that the participants in this study are, on average, young individuals. Care is no longer provided by older people such as grandmothers, who historically were more present in the child's daily life^{7,8}. In this study, 90.90% of the children were male, corroborating studies in the literature that show a prevalence of autism diagnosis in boys⁹.

In addition to age, another issue related to SDH was the monthly earnings of the interviewees. The monthly income of most caregivers (73%) is up to two minimum wages¹⁰. A study carried out with caregivers of adolescents with autism found a similar condition in which the majority of caregivers had a monthly income below two minimum wages, being classified as low-income people.

Mothers continue to assume the primary caregiving role for most children, but this is not linked to the fact of caring for a child with a disorder, as since ancient times the act of caring has been designated and performed by female people^{11,12,13}, as it can be observed in other studies in which caring for children with neurodevelopmental disorder occurs predominantly by the child's mother^{7,8}.

The factors listed such as the caregivers' age and income as well as children's prevalent gender are also associated with aspects of the SDH, representing individual characteristics, the basis of the model on which this research is based. In the fourth layer of the SDH, there are issues relevant

to the individuals' living and working conditions, in this case, the caregivers' occupation¹⁴.

In this research, only three of them had a formal job and the others were self-employed, housewives, retired and/or interns. When we think about women exercising an exclusive care role for children, it can be inferred that they stopped carrying out other activities to dedicate themselves to the child, giving up their job, academic life, leisure and other duties to which they were dedicated to before motherhood^{7,8,15}.

The higher the person's level of education, the better their understanding of the child's needs, the ease in searching for interventions and services aimed at the child's development, such as early diagnosis and intervention, among other benefits. However, this does not nullify the knowledge that a caregiver with a low education may have about the needs and benefits for autistic children^{7,8}, given that it is experienced by each person in their social dimension, socially and historically constructed.

Among the interviewees, only one was providing care for a female child. This caregiver identified difficulties in communication as the primary challenge associated with their child's nonverbal condition. Corroborating this observation, a separate study indicated that caregivers of female children often experience a superior quality of life compared to those caring for male children⁸.

Parenting is defined as the care provided by a child's primary caregiver, typically a parent or legal guardian. This care encompasses various tasks necessary for a child's upbringing¹⁶. While the responsibilities of childcare are ideally shared among all involved parties, this study reveals that, in practice, caregivers often position the father as a secondary support, rather than an equal partner, in the caregiving process alongside the mother.

This situation can lead to caregiver burnout, even if there is mutual agreement among the parties involved. Caregivers may experience physical, emotional, and psychological exhaustion¹³. The daily lives of these "solo" caregivers can be particularly stressful, with a heavy workload and limited social support.

Parental self-efficacy is positively correlated with the caregiver's level of involvement and satisfaction in the child's interventions¹². Conversely, caregivers burdened by financial and social challenges may experience lower levels of parental self-efficacy. This may be particularly true for mothers

of children with ASD, who often face additional demands and stressors alongside their caregiving responsibilities¹⁷.

To mitigate caregiver burnout, a robust support network is crucial. The well-being of the child and caregiver are inextricably linked¹⁸, influencing interpersonal relationships, care provision, and adaptation to new circumstances. In this study, caregivers identified a lack of support networks as a significant challenge for both them and their children. This finding aligns with previous research, which highlighted difficulties in accessing specialized health services, qualified professionals, and support groups for mothers of children with ASD¹³.

The support network identified by caregivers in this study primarily consisted of family members and social facilities such as health centers, rehabilitation centers, schools, daycares, and clinics¹³. As caregivers dedicate themselves to their child's needs, self-care often takes a backseat. To alleviate this burden, caregivers could benefit from support services that promote both physical and mental health, including strategies for coping with the challenges of caregiving¹⁶.

Caregivers of children with atypical development, such as those with ASD, often face greater demands than caregivers of neurotypical children. To mitigate the symptoms of ASD, intensive therapy is often recommended, requiring hours of weekly therapies and effort from caregivers. This can have a substantial financial, social, and emotional impact¹². A strong support network, as outlined in the third layer of the SDH, can help minimize these social and vulnerability risks¹⁴.

The literature emphasizes the importance of providing health services to train, instruct, supervise, and guide caregivers^{9,19}. Qualified listening, for instance, can be a valuable tool for gathering information about the caregiver's situation and offering support. This approach can help develop strategies to reduce stress, overload, and tension associated with caregiving responsibilities¹⁸.

Support can also be found in face-to-face support groups for parents and caregivers¹⁹. These groups, often coordinated by health services or organized by caregivers themselves, provide opportunities for individuals to connect with others who share similar experiences. Through these interactions, caregivers can gain a sense of community, learn from each other's experiences, and



develop healthy coping strategies for these moments of distress¹⁸.

Given the challenges inherent in establishing in-person support networks, caregivers often seek remote support through social media platforms such as WhatsApp®. These digital exchanges facilitate the sharing of experiences and information, which can mitigate the anxiety, doubt, and uncertainty associated with an ASD diagnosis. Such online communities serve as valuable health promotion tools, fostering a sense of belonging and empowerment among caregivers. Additionally, these platforms can motivate other family members, thereby contributing to positive outcomes for individuals with ASD.

Upon receiving an ASD diagnosis, caregivers often experience a range of concerns and uncertainties, as their idealized expectations for their child may need to be reconsidered^{7,13}. Acceptance of the diagnosis varies among caregivers. Some understand that it can facilitate access to appropriate treatments, while others may undergo a grieving process, experiencing feelings of guilt, fear, and distress. These findings align with previous research^{16,18,19}.

Children with autism often exhibit behavioral challenges, such as communication difficulties, feeding issues, and inappropriate behaviors, which can significantly contribute to family stress^{7,13,19}. Parental disagreements, stemming from differing values, beliefs, and parenting styles, can further exacerbate these challenges¹⁶. However, caregivers who can effectively collaborate and compromise, despite their differences, can create a more harmonious family environment and reduce stress levels.

A primary challenge faced by caregivers of children with ASD is impaired communication. This is often cited as an early indicator of developmental delay, corroborated by various studies^{7,12,18}. Symptoms are frequently perceived around the age of two or three, stemming from delays in language development. Effective communication is essential for individuals to express their needs, interests, and emotions, as well as to share experiences and concerns¹³. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), recognizes language delay or difficulty as a core characteristic of ASD²⁰. Consequently, caregivers often seek professional evaluation and intervention to understand the underlying causes of these behavioral manifestations⁷.

The diagnosis of ASD necessitates a comprehensive assessment conducted by multidisciplinary team¹⁹. Following this initial evaluation, children are typically referred to a medical professional, ideally a neuropediatrician, for a definitive diagnosis¹⁸. Caregivers frequently reported difficulties accessing both the initial assessment and subsequent medical evaluation. Notably, neuropediatricians are not routinely included in the medical teams provided by the Unified Health System (SUS) in the study location. As a result, referrals are required, leading to extended wait times for care.

According to the Dahlgren and Whitehead model⁶ to exemplify the SDH, access to health services is situated in the fourth layer, representing an inherent right of all individuals. Those experiencing social disadvantage are disproportionately exposed to and vulnerable to health risks. Caregivers, as social actors, are uniquely positioned to recognize and navigate these challenges, particularly when facing obstacles in accessing essential health services¹⁴.

Given the limited accessibility of specialized care within SUS, caregivers often find themselves compelled to seek alternative options, including private services. To mitigate the associated financial burden, caregivers may apply for the BPC benefit on behalf of their child. The BPC is a government program that provides a monthly minimum wage to elderly individuals or people with disabilities who demonstrate financial need. Eligibility for BPC is determined based on criteria such as monthly per capita family income, which must not exceed one-quarter of the minimum wage²¹.

The sample population in this study was predominantly male, with only one female participant. This finding aligns with existing research, which suggests a higher prevalence of ASD diagnoses among boys⁹. Boys are often characterized by greater levels of dependency, which may exacerbate the challenges associated with ASD⁷.

It is recommended that formal diagnosis of ASD occur around the age of three. However, early identification and intervention are crucial, particularly when developmental delays are observed, or a family history of ASD exists. Early intervention aims to mitigate the impact of ASD on a child's development²¹. In accordance with the Guidelines for Care for the Rehabilitation of People with Autism Spectrum Disorders, a comprehensive care plan should be developed concurrently with diagnosis. This plan should include recommendations for ap-



appropriate interventions and referrals to specialized professionals, such as speech therapists, psychologists, occupational therapists, physiotherapists, and other relevant experts, tailored to the individual needs of the child¹⁹.

Given this, early detection of ASD is crucial to facilitate timely intervention²². Initiating therapeutic interventions as soon as symptoms emerge is associated with more favorable outcomes compared to delayed interventions. The early years of life represent a critical period for neurodevelopmental plasticity, making early intervention a key factor in improving long-term prognosis²³.

The narratives collected in this research indicate that caregivers identified early signs of ASD in their children. However, significant delays in diagnosis and subsequent intervention were reported. Such delays can have detrimental consequences for both the child and the caregivers.

Primary Health Care teams can play a crucial role in early ASD detection by being vigilant for early signs exhibited by the child or reported by family members. Initial screening can be conducted using validated tools such as the Modified Checklist for Autism in Toddlers (M-CHAT)¹⁹. Throughout the diagnostic and treatment process, it is essential to provide caregivers with accurate information and reassurance. Emphasizing the collaborative nature of care, involving both healthcare professionals and families is crucial in order to go through this journey²⁰.

Healthcare and education professionals must be adequately prepared to support individuals with ASD and their families⁹. To this end, inclusive policies such as the Subsidiary Document for the Inclusion Policy have been implemented. This document provides guidelines for transforming Brazilian public schools into inclusive and high-quality learning environments that value and accommodate the diverse sociocultural and physical-emotional needs of all students²⁴.

In this study, schools were identified as key components of the support network for children with ASD, providing both childcare and family guidance. Conversely, instances where early childhood education institutions refused enrollment due to ASD diagnoses highlighted the potential for exclusionary practices. Such exclusion may stem from a lack of professional preparedness and awareness of the specific needs of children with ASD, as well as inadequacies in current legislation.

To foster a truly inclusive environment, a collaborative approach involving various social segments, including healthcare professionals, is essential. Healthcare professionals can provide valuable support to teachers in managing the unique challenges presented by children with ASD in classroom^{23, 24}.

Families often expect healthcare professionals to possess the knowledge and skills necessary to address their needs. However, many interviewees reported encountering healthcare providers who lacked adequate understanding of ASD. Simultaneously, families themselves may be unfamiliar with the condition, and a diagnosis can significantly disrupt family identity, functioning, and structure. The lack of preparedness among healthcare professionals can contribute to delayed diagnosis and communication, exacerbating the challenges faced by families. These delays can further compound the impact of social stigma associated with mental health conditions, hindering both the seeking of support and acceptance process²².

The research site, located in the Serra Catarinense region, is a central hub for individuals seeking specialized services. The high demand for these services has resulted in significant wait times. Given that the Center of Reference (CER) serves multiple cities within the region, this increased demand is understandable.

This study underscores the critical role of speech-language pathologists in addressing the complex communication needs of individuals with ASD. By focusing on language development, both verbal and nonverbal, speech-language pathologists can contribute to improving social and emotional outcomes. Furthermore, these professionals can provide essential support to parents and guardians, enhancing the overall healthcare network and contributing to public health initiatives²⁵. This study was subject to several limitations. Firstly, challenges were encountered in recruiting and scheduling interviews with caregivers. Future research should aim to increase sample size and ensure gender parity among participants to investigate potential gender differences in caregiver burden. Additionally, exploring the impact of varying levels of autism severity on caregiver burden and quality of life would be a valuable direction for future studies.



Conclusion

The caregiver burden could be alleviated by implementing comprehensive health promotion strategies, providing empathetic and qualified listening services, and offering specialized health services designed to address the unique needs of both the child and the caregiver.

The caregiver burden, resulting from task accumulation, could be alleviated through a strengthened support network. This network could facilitate task sharing and reassignment, leveraging the expertise of specialized professionals and the support of family and friends. Additionally, harmonious intersectoral collaboration among health, education, and social assistance sectors could further contribute to reducing caregiver burden.

Finally, caregivers often experience significant stress, concern, and frustration during the diagnostic process for ASD. From the initial recognition of symptoms to the final diagnosis and subsequent intervention, caregivers may face numerous challenges, including limited access to specialized services. These delays can negatively impact the child's overall development and well-being.

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