

## ORIGINAL ARTICLE

# Information needs for parents of children with autism spectrum disorder: a qualitative study

### HIGHLIGHTS

1. Parents of children with autism need information support.
2. Children's rights stood out among parents.
3. Virtual communities complement teaching and learning for parents.
4. Virtual communities reveal gaps in autism care.

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### ABSTRACT

**Objective:** To map the different information needs of parents of children with autism spectrum disorder about their health condition in virtual communities. **Method:** This qualitative study covers 2022 and 2023, using a thematic content analysis approach and social network analysis in virtual media. The study included three Brazilian virtual communities aimed at parents of children with autism. **Results:** The posts were organized into "Assessment of children with suspected autism" and "Interventions for children with autism". **Final considerations:** The primary information needs are related to children's rights, behavior, and signs of autism. The study contributes to forming public health, educational, and social policies and recognizing virtual communities with the potential to strengthen care, prevention, and health promotion actions to support the families of autistic children.

**DESCRIPTORS:** Autism Spectrum Disorder; Family; Access to Information; Internet access; Social Support.

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## INTRODUCTION

The number of people with Autism Spectrum Disorder (ASD) has increased considerably in recent decades. According to the *Autism and Developmental Disabilities Monitoring (ADDM) Network* report published by the US Centers for Disease Control and Prevention (CDC), the prevalence of ASD among 8-year-olds was 27.6 per 1,000 in 2020, which corresponds to approximately one in 36 children. This figure represents an increase compared to the 2018 study, which indicated a prevalence of 23.0 per 1,000 (1 in 44), marking an increase of around 20% in two years<sup>1</sup>. ASD is characterized by alterations in children's brain development that affect social interaction, communication, and behaviour<sup>2</sup>.

Identification of ASD not only changes the child's standard of living but also has a direct impact on family dynamics. Faced with the need to reorganize their routine and adapt to new demands, families face daily challenges and need an informational support network to support their decisions about care<sup>3-4</sup>.

In this context, the *American Academy of Pediatrics (AAP)* points out that the management of ASD involves both assessment and intervention. Assessment takes place in two stages: screening, level 1, to identify risk, or level 2, for confirmation, followed by diagnostic investigation. Once the diagnosis has been confirmed, different intervention strategies are recommended, including pharmacological and non-pharmacological approaches, for which families need to be adequately advised of the benefits and risks<sup>5</sup>.

In addition to professional assistance, the search for information in support networks has proved fundamental for parents of children with ASD. Among the main spaces offering support are virtual communities, which allow for exchanging information, socializing with other families in the same situation, and sharing strategies for dealing with daily challenges<sup>6</sup>.

Despite the importance of the support network, studies show significant gaps in parents' knowledge about ASD, especially during the diagnosis period. These difficulties are exacerbated by the impersonal attitude of some health professionals, who often fail to establish a proper dialog and provide fragmented information. As a result, families feel helpless and without guidance on how to deal with conditions<sup>7-9</sup>.

Faced with this reality, many parents turn to informal sources for information about the disorder, with virtual communities being one of the leading alternatives. On these platforms, they find emotional support and quick explanations about symptoms, therapies, medication side effects, and recommended professionals. Easy access to this information helps families feel better prepared to face the challenges of daily care<sup>4</sup>. In addition to searching for information, participating in virtual groups allows parents to acquire shared experiences, strengthening their confidence in making decisions and managing the condition<sup>10</sup>.

Considering this, this study aimed to map the different information needs of parents of children with Autism Spectrum Disorder about their health condition in virtual communities.

## METHOD

### Type of study

This qualitative study uses a thematic content analysis approach and social network analysis in virtual media, which used the *Consolidated criteria for reporting qualitative research* (COREQ) to guide the reporting of findings<sup>11</sup>. Thematic content analysis emphasizes using categories to describe a group's conceptions, experiences, or attitudes towards a phenomenon, allowing the data to be qualified in the light of one or more theoretical concepts<sup>12</sup>.

Social network analysis involves mapping the interactions between independent units, making behavior patterns and interactions in specific groups visible in a virtual environment (in this case, Facebook®).

### Research team and reflexivity

The research team consisted of professionals with experience in qualitative research and public health, ensuring familiarity with the methodologies adopted. Reflexive practices were adopted throughout the data collection and analysis process, ensuring that the team's involvement and perceptions did not unduly influence the results. No relationship was established between the researchers and the participants since the posts analyzed were publicly accessible, which minimized interpretation bias.

### Selection of participants

The study participants were considered indirectly since the analysis focuses on public posts in Facebook® virtual communities related to autism spectrum disorder. There was no active recruitment or direct interaction between the researchers and the members of the groups.

### Study scenario

The study scenario comprised the three virtual communities with the most participants and posts on the Facebook® platform aimed at parents of children with autism spectrum disorder. The following criteria included the groups: open communities (with no need for the researcher to be identified, to allow for dynamic observation and data collection), with public posts in Portuguese to discuss ASD, with the highest number of participants and posts. Communities of commercial or institutional origin were excluded.

### Data collection

The data was collected manually from the posts made in the selected communities covering 2022 and 2023. The posts were extracted and organized in spreadsheets, forming a textual corpus that served as the basis for the analysis. Information such as the number of reactions and shares was not considered. This was because identifying the content of the posts was deemed sufficient to recognize the themes in which the information needs of parents of children with ASD about their health condition were apparent in the virtual communities studied. Therefore, the focus was on analyzing the textual content of the posts, enabling the identification of themes related to parents' information requirements about ASD.

The data was organized using thematic content analysis, which aims to identify patterns or trends, also understood as themes, relevant to the description and understanding of a data set. To this end, the identification process includes segmentation, categorization, synthesis, and reconstruction stages. The themes identified through these procedures are essential dimensions or aspects of the data analyzed, indicating patterns of response, meaning, or idea<sup>13</sup>. As the analysis included all the posts in the defined period, data saturation was not a criterion for stopping the collection.

## Data analysis

The thematic analysis began with reading and familiarization with the collected data. The publications were reviewed and categorized based on an AAP theoretical model on care strategies for children with autism, resulting in two main categories: "Assessment of children with suspected autism" and "Interventions for children with autism."

When a post contained more than one type of message, the excerpts were separated and coded according to their purpose and content. To identify information needs, only messages whose purpose was coded as 'doubt' were analyzed since these directly reflect the participants' information demands. This strategy was adopted because an analysis of the 'information needs' construct in literature<sup>14</sup> shows that needs are generally expressed as questions. Messages with other purposes, such as reports or guidance, were disregarded for this purpose.

## Ethical aspects

This study followed Resolution 510/2016 of the National Health Council, which exempts approval by an Ethics Committee for research with public data and without identifying participants. The posts analyzed were taken from open virtual communities, ensuring no private or identifiable information was used. The speeches were paraphrased without altering their meaning to preserve the authors' anonymity. The source of the posts was cited, ensuring methodological integrity and compliance with ethical guidelines.

## RESULTS

A total of 2,144 messages were identified for coding. Of these, 1,372 were directly related to doubts about the disorder, representing around 64% of the data collected. The 1,372 classified posts were organized into two categories: a) Assessment of children with suspected autism; b) Interventions for children with autism. Four subcategories emerged from the first category: "Characteristics of the disorder", "Behavior of the child with ASD", "Signs of ASD," and "Diagnosis of the child with ASD", totaling 50.4% of the textual corpus. The second category gave rise to three subcategories: "Rights of children with ASD", "Access to resources", and "Prospects", totaling 49.6% of the text corpus (Chart 1).

**Chart 1.** Topics in which information needs on autism spectrum disorder were identified in the virtual communities. Iguatu, CE, Brazil, 2024

Themes	Total messages
Category 1: Assessment of the child with suspected autism.	691
Characteristics of the disorder	110
Behavior of the child with ASD	246
Signs of ASD	196
Diagnosis of children with ASD	139
Category 2: Interventions for children with autism.	681
Rights of children with ASD	365
Access to resources	171
Prospects	145

Source: The authors (2024).

As shown in Chart 2, the virtual communities need to identify the sub-themes associated with each ASD topic.

**Chart 2.** Themes and sub-themes in which information needs on autism spectrum disorder were identified in the virtual communities. Iguatu, CE, Brazil, 2024

(continue)

Themes	Sub-themes	Total messages
Characteristics of the disorder	What it is	15
	Frequency of cases	12
	Causes	31
	Possible cures	52
Behavior of children with ASD	Behaving in undesirable ways	16
	How to reduce inappropriate behavior	27
	Rewards for dealing with your child	20
	Using reinforcers	23
	Dealing with tantrums and frustrations	47
	Extinguishing challenging behavior	52
	How to teach new skills and behaviors	61
Signs of ASD	What the spectrum means in ASD	26
	Severity levels of ASD	35
	Changes in communication	37
	Sensory changes	42
	Changes in relationships/interactions	56
Diagnosing a child with ASD	How it's done	47
	Tests to be carried out early diagnosis	33
	Early diagnosis	59
Rights of children with ASD	Health plans	53
	Priority in care	62
	Considered a person with a disability	42
	Social programs and benefits	65
	Combating stigma	63
	Labor market and social security	38
	Educational, housing, and transportation rights	42

**Chart 2.** Themes and sub-themes in which information needs on autism spectrum disorder were identified in the virtual communities. Iguatu, CE, Brazil, 2024 (conclusion)

Themes	Sub-themes	Total messages
Access to resources	Therapies	44
	Teaching strategies/resources for obtaining information	54
	Available services	73
Prospects	Prognosis	19
	Risk of having another child with ASD	47
	Concern about who will look after the child in the absence of parents	37
	What the family can do to think about the child's future	42

Source: The authors (2024).

In the posts, the participants accessed the virtual environment to express their doubts, possibly solve them, or obtain some kind of guidance on how to proceed in caring for their children with ASD, especially considering that this condition significantly impacts family members' routines. This can be seen in Chart 3.

**Chart 3.** Themes and posts about information needs on autism spectrum disorder identified in virtual communities. Iguatu, CE, Brazil, 2024 (continue)

Themes	Posts about information needs
Characteristics of the disorder	<p><i>Why are cases of autism increasing so much these days? (Post 144)</i></p> <p><i>Is there a vaccine that could be associated with autism? (Post 11)</i></p> <p><i>Will our child ever be cured of autism? (Post 832)</i></p>
Behavior of children with ASD	<p><i>My son has level 1 autism, but contrary to what I usually read, he is not selective about eating. He overeats, asks for food at relatives' houses, eats his meal, then goes to his grandfather's plate, and even asks for fruit. Is this common, or could it be a compulsion? (Post 303)</i></p> <p><i>How do your children usually react during dental appointments? (Post 62)</i></p> <p><i>We've been trying to wean him off the toilet for eight months, taking him to the bathroom every 30 to 60 minutes, but he only goes in his clothes. Does anyone have any tips to help with this process? (Post 87)</i></p>
Signs of ASD	<p><i>When a child doesn't speak, does this indicate that they are at autism level 2? (Post 910)</i></p> <p><i>Is it common for a seven-year-old autistic child not to be able to read? (Post 601)</i></p> <p><i>What do you do to calm your child down during an autism crisis? (Post 59)</i></p>

**Chart 3.** Themes and posts about information needs on autism spectrum disorder identified in virtual communities. Iguatu, CE, Brazil, 2024 (conclusion)

Themes	Posts about information needs
Diagnosing a child with ASD	<p><i>Which doctor is responsible for assessing and reporting a diagnosis of autism? (Post 71)</i></p> <p><i>I have a one-year-old and a three-month-old baby, and I'm suspicious. How did you notice the first signs of autism in your child? (Post 205)</i></p> <p><i>Is there a specific test to diagnose autism, apart from behavioral observation? (Post 88)</i></p>
Rights of children with ASD	<p><i>Can people who receive the Continuous Cash Benefit work without losing the benefit? (Post 157)</i></p> <p><i>Does ICD F84.0 guarantee access to the Continuous Cash Benefit, as provided for in the Organic Law on Social Assistance? (Post 515)</i></p> <p><i>I put my son in school. Is he entitled to be accompanied by a professional? (Post 92)</i></p> <p><i>Are parents of autistic children entitled to reduced working hours? (Post 396)</i></p>
Access to resources	<p><i>Has anyone experienced side effects when using risperidone? (Post 122)</i></p> <p><i>How do I get the autism therapies offered by the Unified Health System? (Post 83)</i></p> <p><i>How do I get the sunflower cord for my son? (Post 1017)</i></p>
Prospects	<p><i>If you already have an autistic child, is there a greater chance of having another child with the same diagnosis? (Post 235)</i></p> <p><i>Who will look after our child if we are no longer here? (Post 69)</i></p> <p><i>What can we do today to ensure a better future for our autistic children? (Post 441)</i></p>

Source: The authors (2024).

## DISCUSSION

The first category dealt with the need for information on the "Assessment of the child with suspected autism", made up of four subcategories, entitled "Characteristics of the disorder", "Behavior of the child with ASD", "Signs of ASD" and "Diagnosis of the child with ASD", which refer to the need for information on specific aspects of the process of suspecting autism up to the discovery of the diagnosis itself, totaling 50.4% of the text corpus.

Concerning the characteristics of autism spectrum disorder, families should receive information about behavioral changes, manifested by mania, excessive attachment to routines, repetitive actions, a strong interest in specific things, and difficulty imagining; deficits in communication, characterized by repetitive use of language and difficulty initiating and maintaining a dialogue; deficits in social interactions, such as maintaining eye contact, understanding facial expressions, expressing emotions, and making friends; and sensory alterations, such as sensations of smells, tastes, textures, sounds, lights, and colours<sup>2,15</sup>.

Knowing this information is essential for the child's family members, as they often experience stressful situations because they are unable to cope with or understand the development of children on the autism spectrum. Family members need to recognize what causes disruptive behavior, such as self-injury, aggression, and excessive stereotyping in children with ASD<sup>16</sup>.

After receiving a diagnosis of the disorder, the family members of these children feel helpless, distressed, and eager for information; they, therefore, need emotional and informational support to answer questions about the disorder and other aspects involving the child with this condition. To participate effectively in the child's treatment, these parents require informational support regarding the educational role they should play<sup>17</sup>. In this context, professionals are key to encouraging families with the information they need to care for their children.

There is no cure for ASD and no specific drug treatment to date. Still, various intensive behavioral interventions have significantly improved the development of diagnosed children, especially when combined with early detection<sup>2</sup>. Scientific evidence suggests that ASD can be caused by genetic and environmental factors and/or stressful events during pregnancy<sup>2,15</sup>.

In this study, families and friends reported finding it difficult to accept their child's behavior, which caused the family to become socially isolated. These families' social isolation may be due to the population's lack of understanding of the disorder, which often manifests itself through people's discriminatory attitudes<sup>18</sup>. The stigma experienced may be related to lack of knowledge, judgment, rejection, and support. These situations happen at school, in the community, and with family and friends. Sensitization and awareness-raising work should also be focused on these places<sup>18</sup>.

The second category dealt with "Interventions for children with autism". It gave rise to three subcategories: "Rights of children with ASD", "Access to resources," and "Prospects", totaling 49.6% of the text corpus. This category dealt with elements relating to the moment after diagnosis and the implications for caring for children with autism.

The study revealed a significant number of questions regarding the rights of children with ASD. It is worth noting that, in Brazil, Federal Law No. 12,764, of December 27, 2012, determined that people with ASD are considered people with disabilities for all legal purposes, reiterating the right to health for people with ASD from diagnosis to rehabilitation with specialized services<sup>19</sup>.

The law deals with access to comprehensive health actions and services, including early diagnosis, multi-professional care, adequate nutrition/nutritional therapy, medication, and information to help diagnose and treat children with ASD. In addition, the same law deals with the right to access education and vocational training, housing, the job market, social security, and social assistance<sup>19</sup>.

Studies<sup>7,20</sup> have shown that families have difficulties in accessing specialized health care services, as well as weaknesses in the implementation of public policies relating to the care of people with ASD and the line of care for people with ASD and their families in the SUS psychosocial care network. This directly interferes with the supply of trained professionals and comprehensive and adequate care for the individual and their family.

Due to this fragility, the journey between one service and another or between one city and another causes delays in diagnosis, the experience of various obstacles, and anxiety about the difficulties encountered<sup>20</sup>. These issues imply suffering for the

family and the child's prognosis. It is known that identifying the disorder and starting interventional measures early, such as behavioral therapies or sensory integration approaches, allows for a better developmental prognosis. This is mainly based on the needs of each child because the manifestations of ASD are different for each one<sup>21</sup>.

Parents need to know information about the educational resources available, especially the Brazilian Law for the Inclusion of People with Disabilities, Law No. 13.146, of July 6, 2015, which considers any refusal of enrollment by a public or private school to be a crime of discrimination and guarantees rights to vocational education for people with disabilities<sup>22</sup>.

The three most common themes among the participants' questions were "Rights of children with ASD," "Behavior of children with ASD," and "Signs of ASD." The topic of "Rights of children with ASD" was the predominant doubt among the participants in the virtual communities analyzed. The most prominent sub-theme was 'Social programs and benefits,' which discussed the difficulties faced in accessing the right to health and government social benefits.

This result may be related to the impact of the chronicity of ASD and the extent of its characteristics, which makes families resort to various health services and seek specialized multidisciplinary care<sup>4</sup>.

Financial support is an essential source of support for parents. The literature and the results of this study show that families have difficulties accessing social assistance resources; however, children with the disorder should be protected and ensured through programs and benefits aimed at 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 educate them<sup>23</sup>.

Families of autistic children seek information in the digital environment, including informal sources such as blogs, WhatsApp®, virtual communities and websites, which have been connecting individuals with common interests, functioning as spaces for exchanging information, demands and support among their users, and are also capable of influencing people's daily lives and attitudes towards autism<sup>23</sup>. Freely available information raises concerns about its reliability and the extent to which families are critical when accessing this material. This context creates a new demand for society, as it is unknown what impact content from informal sources can have on people's health.

This proposition is based on other antecedents, such as access to information and the Internet, given the predisposition to critical thinking due to not taking the reports transmitted in health institutions for granted.

This new demand on professionals and society refers to the need to learn how to guide family members' research into the digital technologies available, advise them on how to evaluate the sites they are researching, safety issues, and the veracity of the information, and use this knowledge to improve healthcare and the professional patient relationship<sup>24</sup>.

In this context, nursing is gaining ground in caring for fragile children and families who need support and guidance in the direction to take<sup>3,17</sup>. It is worth pointing out that informal sources do not replace the recommendations of professionals qualified in the field of ASD but are intended to be consolidated as complementary sources in the teaching-learning process for parents of children with ASD.

Nursing professionals should pay attention to the uniqueness of individuals and their respective needs, providing comprehensive, quality care that meets all the care demands of autistic people and their families, helping to strengthen and expand relational ties. However, the support offered by professionals is fragmented, discontinuous, and disproportionate to covering all the family's needs<sup>4,17</sup>.

The study's limitation was that it did not analyze closed-group posts. Thus, the discussions analyzed may not represent the totality of interactions in the autism scenario.

## FINAL CONSIDERATIONS

It was found that the primary information needs are related to children's rights, behavior, and signs of ASD. It stands out that the information needed on the rights of children with ASD concentrated the most significant interest among parents in the virtual communities analyzed.

The virtual communities investigated proved to be essential support strategies, offering informational support to parents in the practical experience of caring for a child with ASD. Parents turned to these spaces to meet their information needs, which allowed them to identify the most relevant content, contributing to the decision-making process regarding their children's health.

The study's findings indicate that virtual communities can highlight gaps in care support and stand out as strategic sources of information for parents. These results suggest the need to develop interventions and public health, education, and social assistance policies that recognize this phenomenon, taking advantage of its potential to strengthen care, prevention, and health promotion actions. They also highlight the importance of organizing intersectoral initiatives to improve the coordination of support services for families of children with ASD.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Alencar DC**; Drafting the work or revising it critically for important intellectual content - **Alencar DC, Sousa Neto AR, Ibiapina ARS, de Oliveira JD**; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Alencar DC, Sousa Neto AR, de Oliveira JD**; All authors approved the final version of the text.

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