

Review article

Health literacy among caregivers of children with autism spectrum disorder: scoping review

Letramento em saúde de cuidadores de crianças com transtorno do espectro autista:
revisão de escopo

Alfabetización en salud de cuidadores de niños con trastorno del espectro autista: revisión de alcance

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Abstract

Objective: to map the literature on the health literacy (HL) of caregivers of children with autism spectrum disorder (ASD). **Methods:** scoping review conducted between January and February 2024 and updated in August 2025, across six databases and the gray literature. Data were extracted (“data charting”) using a JBI-adapted form, followed by a basic descriptive analysis. The protocol was registered in the Open Science Framework (OSF). **Results:** of the 741 records identified, 4 met the inclusion criteria and were included in the review. Caregivers of children with ASD experience barriers to accessing and understanding health information, which hampers decision-making. **Conclusion:** caregivers’ HL remains underexplored, and investigating it is essential to inform interventions that improve the quality of pediatric care.

Descriptors: Health Literacy; Caregivers; Autism Spectrum Disorder; Child Care; Scoping Review

Resumo

Objetivo: mapear a literatura relacionada às condições de letramento em saúde (LS) de cuidadores de crianças com transtorno do espectro autista (TEA). **Método:** revisão de escopo, realizada entre janeiro e fevereiro de 2024 e atualizada em agosto de 2025, em seis fontes de dados e literatura cinzenta. Os dados foram extraídos por meio de formulário adaptado da JBI e, em seguida, procedeu-se à análise descritiva das informações obtidas. O protocolo foi registrado no *Open Science Framework*. **Resultados:** das 741 publicações identificadas, quatro atenderam aos critérios de inclusão e compuseram a revisão. Cuidadores de crianças com TEA enfrentam fragilidades no acesso e na compreensão de informações de saúde, o que prejudica a tomada de decisões. **Conclusão:** o LS desses cuidadores permanece pouco explorado e investigá-los é fundamental para orientar intervenções que qualifiquem o cuidado infantil.

Descritores: Letramento em Saúde; Cuidadores; Transtorno de Espectro Autista; Cuidado da Criança; Revisão de Escopo

Resumen

Objetivo: mapear la literatura relacionada con las condiciones de alfabetización en salud (AS) de los cuidadores de niños con trastorno del espectro autista (TEA). **Método:** revisión de alcance, realizada entre enero y febrero de 2024 y actualizada en agosto de 2025, en seis fuentes de datos y literatura gris. Los datos se extrajeron mediante un formulario adaptado del JBI, y luego se realizó un análisis descriptivo de la información obtenida. El protocolo ha sido registrado en el *Open Science Framework*. **Resultados:** de las 741 publicaciones identificadas, cuatro cumplieron con los criterios de inclusión y formaron parte de la revisión. Los cuidadores de niños con TEA enfrentan dificultades para acceder y comprender la información de salud, lo que dificulta la toma de decisiones. **Conclusión:** la AS de estos cuidadores sigue siendo poco explorada e investigarlos es esencial para orientar las intervenciones que mejoran el cuidado infantil.

Descriptores: Alfabetización en Salud; Cuidadores; Trastorno del Espectro Autista; Cuidado del Niño; Revisión de Alcance

Introduction

Autism spectrum disorder (ASD) is a chronic, complex neurodevelopmental condition with early onset, affecting the health of children and their families.¹⁻²

Diagnosis usually occurs in early childhood, when parents assume responsibility for decisions related to the use of health information and services. In this process, they become critical partners in caring for their child with ASD, and the health literacy (HL) they possess is a key determinant that can facilitate—or hinder—timely diagnosis and access to appropriate treatments, with the potential to improve health outcomes.³

HL encompasses the knowledge and personal competencies accumulated through daily activities and social and intergenerational interactions. These skills and knowledge are shaped by organizational resources and structures that enable people to access, understand, appraise, and use health information and services to maintain and improve health and well-being for themselves and those around them.⁴ To reflect HL's impact, competencies are commonly categorized into functional, interactive, and critical levels of health literacy.⁵

A caregiver is commonly defined as a family member or any designated person who assumes responsibility for caring for a dependent individual.⁶ Caregivers of children with ASD take on multiple aspects of care, including physical, psychological, and social support, often to a degree that exceeds what would typically be provided by parents of children without ASD. The intensive workload required to meet the child's needs, combined with inadequate access to relevant services and inefficient support, may contribute to reduced quality of life.⁷

The literature includes studies aimed at understanding caregivers' HL and the role they play in outcomes related to the care of children with special health care needs⁸ and child health more broadly.⁹ However, few studies focus specifically on caregivers of children with ASD.⁸ Knowledge gaps regarding these caregivers' HL levels are even more evident when considering how parents make decisions about and use health services for their child with ASD.¹⁰⁻¹²

Additionally, the role of health services in caring for these children may be limited, which can hinder parents' care management, as they must handle the routine challenges of meeting their children's needs using only the skills and knowledge they possess. The direct and indirect impacts of these HL levels in practice, therefore, remain unclear.⁹⁻¹¹

Understanding the individual HL competencies of caregivers of children with ASD is essential, since they frequently interact with health care professionals and often need to comprehend complex health information. Moreover, mapping these competencies is fundamental to supporting strategies that promote better conditions for understanding and using health information, as well as guiding the appropriate reorganization of services, considering the challenges involved and institutional responsiveness.¹³

Given the above, this scoping review aims to map the literature on the health literacy of caregivers of children with autism spectrum disorder.

Method

This scoping review was conducted in accordance with the methodology proposed by the Joanna Briggs Institute (JBI).¹⁴ Data were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).¹⁵ The study protocol is registered with the Open Science Framework (OSF) (<https://doi.org/10.17605/OSF.IO/RQWCZ>).

The review question was framed using the PCC mnemonic, in which "P" represents the population (formal or informal caregivers of children with autism spectrum disorder), "C" the concept (health literacy), and "C" the context (broad, with no restrictions). Thus, the review question was: What are the health literacy levels among caregivers of children with autism spectrum disorder?

Inclusion criteria comprised studies involving caregivers of children with ASD (family members, formal and/or informal caregivers) that addressed health literacy (HL) levels; primary and secondary studies regardless of approach or design; and literature reviews. No restrictions were applied to language or publication year. Expert opinion pieces, case reports, letters, and editorials were excluded, as were items without full-text access after attempts to contact authors or libraries.

JBI recommends a three-step search strategy.¹⁴ The first step—a preliminary search in databases—aims to identify keywords present in publication titles and abstracts. Accordingly, we conducted an initial scan of the Virtual Health Library (VHL/BVS) and the Medical Literature Analysis and Retrieval System Online (MEDLINE) via the National Center for Biotechnology Information (NCBI/PubMed), using the search terms Health Literacy, Caregivers, and Autism.

The final search strategy was developed by the review team in consultation with a librarian, applied to PubMed, and adapted for the other databases (Table 1).

Table 1 - Final search strategy applied to PubMed, Brasília, Federal District, Brazil, 2025

Database	Strategy
Pubmed	(“caregiver s”[All Fields] OR “caregivers”[MeSH Terms] OR “caregivers”[All Fields] OR “caregiver”[All Fields] OR “caregiving”[All Fields] OR (“parent s”[All Fields] OR “parentally”[All Fields] OR “parentals”[All Fields] OR “parented”[All Fields] OR “parenting”[MeSH Terms] OR “parenting”[All Fields] OR “parents”[MeSH Terms] OR “parents”[All Fields] OR “parent”[All Fields] OR “parental”[All Fields]) OR (“familiarities”[All Fields] OR “familiarity”[All Fields] OR “familiably”[All Fields] OR “familials”[All Fields] OR “familie”[All Fields] OR “family”[MeSH Terms] OR “family”[All Fields] OR “familial”[All Fields] OR “families”[All Fields] OR “family s”[All Fields] OR “familys”[All Fields])) AND (“autism s”[All Fields] OR “autisms”[All Fields] OR “Autistic Disorder”[MeSH Terms] OR (“autistic”[All Fields] AND “disorder”[All Fields]) OR “Autistic Disorder”[All Fields] OR “autism”[All Fields] OR “autism spectrum”[All Fields] OR “Asperger Syndrome”[All Fields] OR “Autistic Disorder”[All Fields] OR “Autism Spectrum Disorder”[All Fields]) AND (“Health Literacy”[All Fields] OR (“literacies”[All Fields] OR “literacy”[MeSH Terms] OR “literacy”[All Fields] OR “literacy s”[All Fields]))

Searches were conducted between January and February 2024 in the following databases: MEDLINE via PubMed; the Nursing Database (BDENF) and the Spanish Bibliographic Index in Health Sciences (IBECS), via the VHL/BVS; Embase (Elsevier); the Cochrane Library; Scopus; and PsycINFO.

We also conducted backward citation tracking (reference list screening) of the publications included in the review to maximize retrieval. The search was updated in August 2025 to include gray literature via Global ETD Search. During this process, 56 records did not meet the inclusion criteria.

Search results were imported into Rayyan, where records were deduplicated, and the screening workflow was carried out.

Following title and abstract screening according to the eligibility criteria, potentially eligible records were retrieved for full-text review and assessed independently and in duplicate by two reviewers. Disagreements were resolved by consulting a third reviewer.

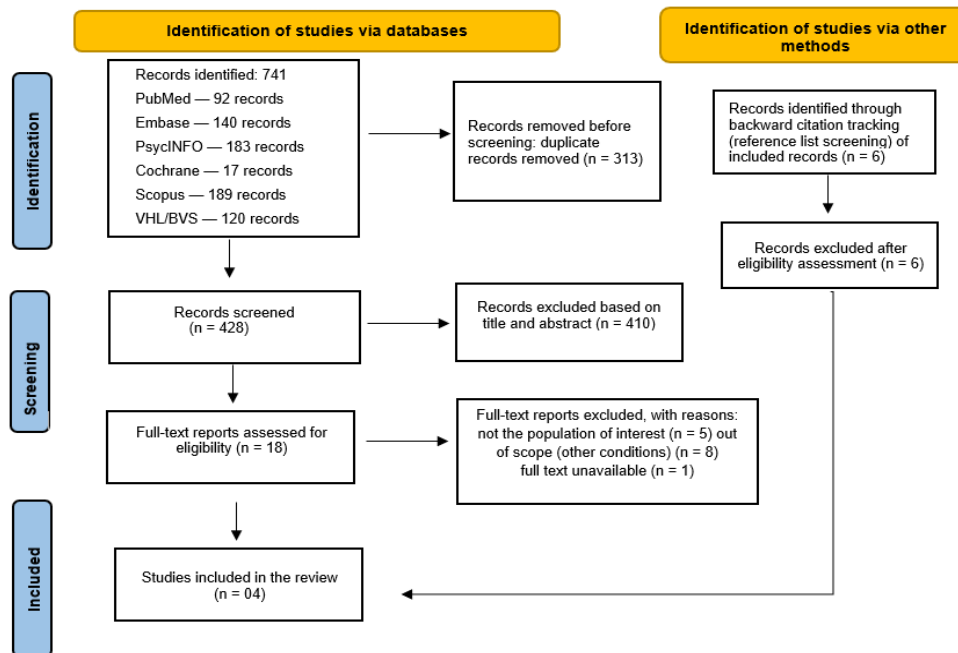
For data extraction from the included studies, we used an instrument developed by the reviewers based on the template in the JBI Manual.¹⁰ The extraction form comprised two sections: (1) study identification—title, authors, year, country, study type, and sample; and (2) mapping caregivers' HL conditions—HL subdomain assessed, HL dimensions, and specific HL conditions among caregivers of children with ASD.

Data analysis followed JBI guidance, which recommends that scoping reviews be descriptive in nature. Accordingly, characterization data were analyzed using descriptive statistics and presented in tables accompanied by a narrative summary. The narrative summary described how the findings relate to the review objective and question.

As this is a review study, approval by an Institutional Review Board (IRB) was not required, in accordance with Resolution 510/2016.

Results

A total of 741 records were identified. After deduplication and title/abstract screening against the eligibility criteria, 18 records were retrieved for full-text review, of which 14 did not meet the inclusion criteria. Thus, the final sample comprised four studies. The selection process is depicted in the PRISMA flow diagram (Figure 1).

Figure 1 - PRISMA flow diagram of study selection for the scoping review. Brasília, Federal District, Brazil, 2024

The four studies included in this review are presented in Table 2, along with their identification codes, publication year and country, study design, and participant characteristics.

Table 2 - Characteristics of the included studies, Brasília, Brazil, 2025

Year	Country	Study design	Participant characteristics
2020 ¹²	Canada	Descriptive qualitative study	8 mothers and 1 father, caregivers of children with ASD.
2024 ¹⁰	United States	Analytical cross-sectional study	356 mothers, 35 fathers, 24 parents, and 2 other caregivers of children with ASD.
2022 ¹¹	United States	Mixed-methods study	78 biological/adoptive parents and 2 grandparents who were caregivers of children with ASD; mean age 35.0 ± 6.5 years; 48 (60%) with a college degree.
2023 ¹⁶	Malaysia	Analytical cross-sectional study	51 mothers, 9 fathers, and 1 aunt, caregivers of children with ASD.

With respect to HL assessment strategies, approaches included an author-developed questionnaire,¹⁰ validated instruments in the quantitative studies,^{11,16} and a qualitative study¹² developed using a semi-structured interview guide grounded in an HL theoretical framework.¹⁷

Overall, three studies (75%) assessed general HL; distinct HL levels⁵ were also examined, including functional (2/4; 50%) and multidimensional (1/4; 25%). Additionally, one study (1/4; 25%) assessed the specific HL subdomain of mental health literacy (MHL) among caregivers. In studies adopting a multidimensional perspective, the dimensions evaluated were access, understanding, appraisal, and use of information for decision-making. The publication that assessed functional HL examined comprehension (reading and writing) and numeracy, as detailed in Table 3.

Table 3 - Mapping of health literacy conditions among caregivers of children with autism spectrum disorder. Brasília, Brazil, 2025

Subdomain of HL	HL dimensions assessed	HL conditions — description
Health literacy (multidimensional perspective) ¹²	<ul style="list-style-type: none"> • Access; • Understanding; • Appraisal; • Use of information for decision-making 	<ul style="list-style-type: none"> • Access to information was insufficient to meet needs around the time of diagnosis. • All parents reported difficulty understanding information they found independently or that was provided to them. • Use of information for decision-making was limited.
Functional health literacy ¹⁰	<ul style="list-style-type: none"> • Reading and writing (form completion) • Reading comprehension (difficulty understanding written health information) 	<ul style="list-style-type: none"> • Difficulty completing forms independently. • Difficulty understanding written health information.
Functional and multidimensional health literacy ¹¹	<p>Quantitative phase</p> <ul style="list-style-type: none"> • Reading comprehension • Numeracy <p>Qualitative phase</p> <ul style="list-style-type: none"> • Access; • Understanding; • Appraisal; • Use of information for decision-making 	<p>Quantitative phase — adequate HL in 80% of caregivers.</p> <p>Qualitative phase:</p> <ul style="list-style-type: none"> • Need for centralized, tailored information to families' unique needs and challenges. • Difficulties appraising high-quality, evidence-based information versus misinformation about their child's autism.
Mental health literacy ¹⁶	<p>MHLS attributes:</p> <ul style="list-style-type: none"> • Ability to recognize disorders; • Knowledge of risk factors and causes; • Knowledge of self-treatment; • Knowledge of available professional help; • Knowledge of where to seek information; • Attitudes that facilitate recognition or appropriate help-seeking behavior. 	<p>Caregivers' mental health literacy was higher than reported elsewhere; mean MHLS score 119.28 (approximately 74% of the maximum).</p>

Caregivers of children with ASD reported HL-related challenges in the following areas: access to information was insufficient to meet their needs around the time of diagnosis; difficulty understanding information found independently or provided to them; and difficulty using information for decision-making. However, in studies that measured HL using validated instruments, HL was classified as adequate¹¹ or above average compared with other populations.¹⁶

Discussion

Our analysis mapped the available evidence on HL conditions among caregivers of children with ASD. We identified gaps in HL related to access to information, as well as difficulties understanding and using information for decision-making.

The topic remains underexplored and has only recently become a focus of investigation, as suggested by the concentration of publications in the past four years. There is also a need to expand investigations in Global South settings, which feature diverse social, cultural, and health system contexts; in Brazil, for instance, we found no studies specifically addressing HL conditions among caregivers of children with ASD.

Across the four included studies, HL assessment strategies varied. Notably, one study used an adapted questionnaire without reporting validity evidence.¹⁰ The literature underscores the importance of using instruments that provide validity evidence—i.e., evidence that the tool assesses the intended construct.¹⁸ This is essential to minimize interpretive bias and reduce the risk of stigmatizing individuals at either end of the HL spectrum.¹⁹

Studies that employed instruments with validity evidence focused on functional HL, such as the Newest Vital Sign (NVS).¹¹ Functional HL comprises basic competencies in reading, writing, and numeracy required to function effectively in everyday situations and is consistent with the narrow definition of HL.²⁰ The adequate HL observed in that study may have been influenced by higher educational attainment and younger age, both predictors of better HL.²¹ A subsequent qualitative phase expanded the assessment to include access, understanding, appraisal, and use of information for decision-making.

Sørensen et al.'s conceptual model of HL¹⁷ was the most frequently used to develop qualitative interview guides and to broaden the understanding of HL beyond the functional level. The model centers on competencies (dimensions) related to accessing, understanding, appraising, and using health information: (1) access refers to the ability to seek, find, and obtain health information; (2) understanding refers to the ability to comprehend the health information accessed; (3) appraisal describes the ability to interpret, filter, judge, and evaluate the health information accessed; and (4) use refers to the ability to communicate and use the information to make a decision to maintain and improve health.¹⁷

Overall, in the qualitative studies,¹¹⁻¹² parents expressed a strong need for easily accessible information about available autism services throughout their child's care journey, as well as for plain-language information that is easy to understand. This finding underscores the need for health-literate health care organizations and the adoption of health literacy universal precautions to facilitate access, understanding, and use of information across care settings.²²⁻²³

Mental health literacy (MHL) is a subdomain of HL, defined as the knowledge and beliefs about mental disorders that aid their recognition, management, or prevention.²⁴ The concept has been operationalized around three main components: (1) knowledge about mental health, (2) attitudes and stigma, and (3) help-seeking behavior related to mental health care. In this review,¹⁶ MHL was assessed using the Mental Health Literacy Scale (MHLS),²⁵ which also encompasses three additional components: knowledge of self-treatment, knowledge of available professional help, and attitudes that facilitate recognition or appropriate help-seeking behavior.

In families with children diagnosed with ASD, this competency is essential, since parents serve as primary mediators between their children and health services. Caregivers of children with ASD exhibit significantly higher levels of stress, anxiety, and depression than parents of typically developing children.²⁶ Understanding caregivers' MHL is therefore critical, as it can affect their ability to access, understand, and apply therapeutic guidance to care for the child with ASD, which, in turn, may hinder child development.

This review has limitations; chiefly, the small number of included studies, which warrants caution when interpreting the findings. Additionally, heterogeneity in HL assessment strategies across studies may hinder the delineation of a clear profile of HL conditions in this population. Variability in caregiver characteristics across the included studies should also be considered when interpreting results, given that caregivers' socioeconomic factors (education level and age) are established predictors of HL.

Conclusion

This scoping review shows that assessing HL among caregivers of children with ASD remains underexplored, particularly in Global South contexts, where studies are scarce.

The included studies indicate gaps in general HL, especially in access to, understanding of, and use of health information. These difficulties are particularly pronounced around the time of diagnosis, when families face information overload that is not always accompanied by adequate support for appraisal and decision-making. In the subdomain of mental health literacy, although there is some awareness of mental disorders, stigmatizing beliefs persist and negatively affect attitudes within families and in the broader social context.

These findings underscore the need for future research to deepen understanding of the challenges faced by caregivers of children with ASD, to inform the development of educational interventions and public policies that promote HL.

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