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Article

Autism Information Progression and the Impact of Misinformation on Autism Knowledge, Awareness and Stigmatization

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Abstract

Recent studies have shown a growing prevalence of autism spectrum disorders, accompanied by heightened concerns about the impact of misinformation on autism stigmatization, shaping public perceptions of autism. With the increase in autism cases worldwide, it is critical to have sufficient understanding, knowledge, and awareness about autism, especially among the autism information seekers. This study focused on the progression of autism information over time and investigated the relationships among various factors such as autism knowledge, awareness, stigma, misinformation, cultural beliefs, and social norms. Employing a two-phase research design approach comprising systematic literature review and survey, the study indicated an overall increase in autism knowledge and awareness, although it revealed disparities in certain ethnicities and areas such as genetic testing. Despite advancements, stigma was found to persist. Survey findings validated these observations, emphasizing the necessity for heightened autism awareness and the continued presence of stigma. Furthermore, the survey demonstrated that knowledge influences awareness, whereas cultural beliefs and social norms directly affect autism misinformation. Importantly, the study highlighted how cultural beliefs, and misinformation can hinder accurate understanding and knowledge of autism, potentially exacerbating stigma. By employing evidence-based approaches, this study offers comprehensive insights into autism, enriching the broader literature on the subject.

Keywords: autism; knowledge; awareness; stigma; misinformation

1. Introduction

Knowledge, perceptions, and attitudes toward medical conditions evolve over time as research advances and information becomes more widely disseminated. Understanding these changes is important because they shape public awareness, influence decision-making, and affect the experiences of patients, families, and caregivers. Although research on autism knowledge, awareness, and stigma has grown substantially over the past two decades, most studies examine these constructs independently or within specific populations (Heidgerken et al., 2005; Dillenburger et al., 2017; Turnock et al., 2022). Consequently, limited research has explored how these factors interact or how they have evolved collectively over time especially in the context of autistic individuals, family members or caregivers. In particular, the role of sociocultural influences and the increasing spread of online misinformation in shaping autism knowledge and awareness remains underexamined. Addressing this gap is important for understanding how autism-related information is interpreted by autistic individuals and their families or caregivers and for identifying factors that may contribute to misconceptions or stigma.

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by differences in social communication, interaction, and patterns of restricted or repetitive behaviors (World Health Organization, 2023; American Psychiatric Association, 2013). Over time, the

understanding of autism has evolved significantly, from being considered a form of schizophrenia to recognition as a spectrum disorder with complex genetic and environmental determinants (Salari et al., 2022). With increasing global prevalence, it is essential for individuals seeking autism-related information to have accurate knowledge and awareness, and to recognize associated stigma (Zeidan et al., 2022; Salari et al., 2022).

Autism knowledge refers to the factual understanding of autism characteristics, causes, and treatments whereas autism awareness refers to the recognition and general familiarity with autism and its societal implications. Over the past few decades, autism knowledge and awareness have been the focus of numerous studies (Dillenburger et al., 2017; Altay, 2019). Research indicates that knowledge about autism varies across populations, with parents, educators, and health professionals often demonstrating gaps in understanding (Heys et al., 2017; Hussein et al., 2019). Research also indicates that autistic individuals themselves tend to have higher knowledge and lower stigma compared to non-autistic populations (Gillespie-Lynch et al., 2017).

Stigma is defined as a social process of exclusion, rejection, or devaluation, often arising from misconceptions or negative attitudes (Weiss et al., 2006). Autism stigma refers to the negative attitudes or stereotypes toward autistic individuals and autism has historically been associated with stigma due to misconceptions about causes and behaviors, and such stigma can negatively affect the autistic individuals, their family members and their caregivers (Papadopoulos et al., 2019; Turnock et al., 2022). Cultural beliefs and social norms also have affected autism and research is carried out in this area as well. Research shows that cultural beliefs and community attitudes strongly influence how autism is perceived and treated. Stigma, misconceptions about causes (e.g., genetics, environmental factors, or supernatural beliefs), and cultural norms can affect families' treatment decisions and contribute to higher levels of autism stigma in certain communities (Kang-Yi et al., 2018; Hebert & Koulouglioti, 2010; Alqahtani, 2012; Papadopoulos, 2016; Kim et al., 2022).

The growth of social media and the internet have made it easier to disseminate misinformation. As more people turn to these resources for health information, incorrect information about health-related concerns continues to be spreading (Krishna & Thompson, 2021). There is a lot of misinformation about autism as well (Keenan & Dillenburger, 2018). Autism misinformation refers to the inaccurate or misleading information about autism, often spread through media or social networks. Misinformation about autism, such as myths linking vaccines to autism or assumptions that all autistic individuals have mental health problems, continues to spread through social and traditional media, contributing to misunderstanding and stigma (Krishna & Thompson, 2021; White, 2014).

Considering factors such as knowledge, awareness, stigma, cultural beliefs, social norms, and misinformation, it is important to examine how these elements shape perceptions of autism, particularly among autistic individuals, parents, and caregivers. Despite advances in autism research and public awareness initiatives, gaps remain in understanding how autism knowledge, awareness, and stigma have progressed over time, particularly in relation to the impact of misinformation and cultural beliefs. This study addresses these research gaps by examining the progression of autism information, knowledge, awareness, and stigma over time, as well as the influence of misinformation, cultural beliefs, and social norms especially among autistic individuals, parents, and caregivers.

The Knowledge-Attitude-Behavior (KAB) model, widely used in health education (Xu et al., 2010), explains the relationship between knowledge, attitude, and behavior. In this model, knowledge refers to what a person knows, attitude to what they think, and behavior to how they act. The model suggests that knowledge influences attitude, which in turn affects behavior. While extensively applied in various research fields (Zwilling et al., 2022; Iyer, 2018; Colson et al., 2014; Albaqawi et al., 2020), it has been rarely applied to autism studies to investigate how knowledge affects awareness and stigmatization behavior. Using the Knowledge-Attitude-Behavior (KAB) model as a conceptual framework, this study examines the relationships among autism knowledge, awareness, and stigmatization. The KAB model was adapted to align with the variables examined in this study. Specifically, knowledge represents autism knowledge, attitude corresponds to autism awareness, and

behavior reflects autism stigmatization. In addition, the framework was extended to examine the influence of cultural beliefs, social norms, and misinformation on autism knowledge and awareness.

Below are the study's research questions:

RQ1: How has information about autism evolved over time, and what is the state of autism knowledge, awareness, and stigmatization in recent years?

RQ2: What is the impact of autism knowledge on autism awareness and stigmatization behavior?

RQ3: What is the impact of misinformation on autism knowledge and autism awareness?

RQ4: What is the impact of cultural beliefs and social norms on autism knowledge, awareness, and misinformation?

By exploring these questions, this study provides a comprehensive overview of autism knowledge, awareness, and stigma progression, offering insights for healthcare professionals, researchers, autistic individuals, and their families.

2. Methodology

In this study, the KAB model is used to develop a conceptual framework to understand the impact of autism knowledge on awareness and stigmatization behavior. The conceptual model also explores the relationship between cultural beliefs, social norms, and misinformation about autism, highlighting the interconnectedness of these constructs. Figure 1 depicts the conceptual framework for the current study.

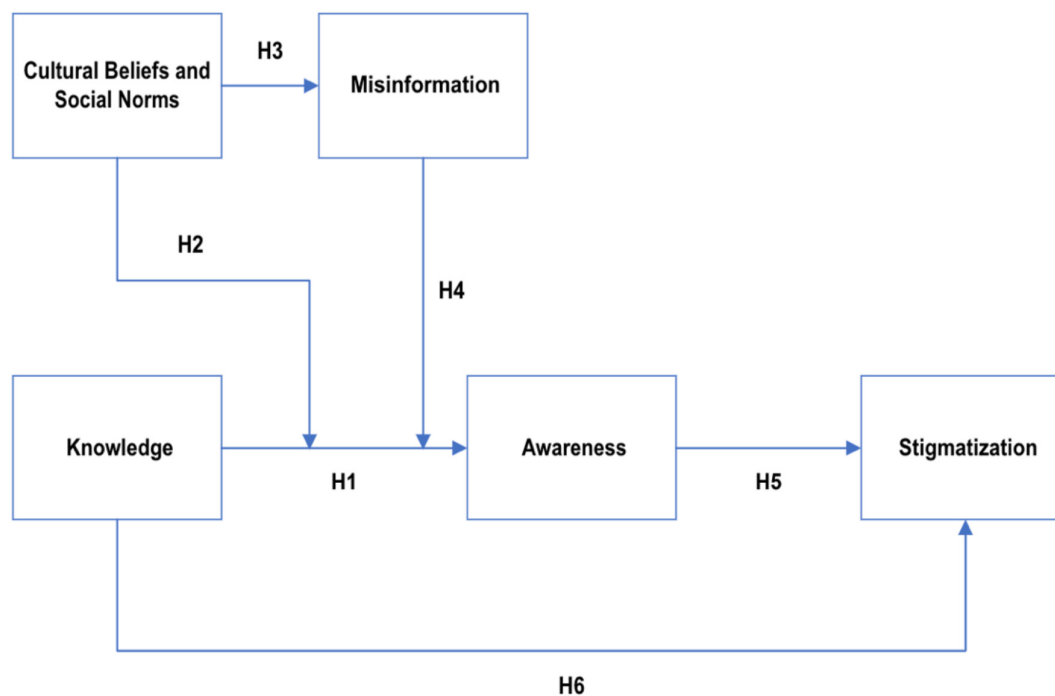


Figure 1. Conceptual model.

This study formulated and tested six hypotheses based on the proposed conceptual model, which are presented below.

Knowledge, defined as understanding gained through education or experience, plays an important role in shaping attitudes toward autism. Research shows that knowledge about autism symptoms, diagnosis, and treatment helps dispel misconceptions and improve attitudes, thereby

increasing autism awareness (Kuzminski et al., 2019; Lu et al., 2020). So, it is hypothesized the following:

H1: *Autism knowledge is positively correlated with autism awareness.*

Social norms and cultural beliefs are shared ideas and unwritten rules passed down through generations that influence how people think and behave. Although these beliefs may not always be supported by scientific evidence, they are often accepted without question and can significantly shape individuals' knowledge and attitudes (Yoo et al., 2019; Jegede & Okebukola, 1991; Sheikh & Furnham, 2000). Research shows that such beliefs and norms can contribute to the development of stigma, particularly regarding medical and mental health conditions (Quinn & Knifton, 2014; Ran et al., 2021). They may also facilitate the spread of misinformation, as culturally rooted ideas can make false information appear more credible (Gupta et al., 2023). These insights led to the development of the following hypotheses.

H2: *Cultural beliefs and social norms have direct correlations to autism knowledge and awareness.*

H3: *There is a direct relationship between cultural beliefs, social norms, and autism misinformation.*

Misinformation refers to inaccurate information that is often created or shared in ways that mislead people. In the healthcare context, misinformation can lead to serious consequences such as delayed diagnosis, inappropriate treatment, or broader public health risks (Au et al., 2021). Increasing awareness of misinformation is therefore important for identifying myths, promoting reliable information sources, and reducing the spread of false information. In the context of autism, awareness of misinformation can help individuals recognize inaccurate claims, encourage the dissemination of accurate information, and ultimately improve autism knowledge and awareness. Thus, it is hypothesized that:

H4: *Misinformation has direct correlation to autism knowledge and autism awareness.*

Autism is highly stigmatized in many societies, leading to negative consequences such as social isolation, discrimination, and mental health challenges for autistic individuals and their families (Tang & Bie, 2016; Papadopoulos, 2016). Increasing autism awareness helps people access reliable information, reject misconceptions, and better understand the condition, which can reduce stigmatizing attitudes and behaviors. Hence, it is hypothesized that:

H5: *Autism awareness negatively correlates with autism stigmatization.*

H6: *Autism awareness serves as a mediator between knowledge and stigmatization.*

To examine these hypotheses and explore the progression of autism knowledge, awareness, and stigma, this study adopted a two-phase research design consisting of a systematic review and a survey. The first phase involved a systematic literature review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines ("PRISMA," n.d.) to provide an overview of how autism knowledge, awareness, and stigma have evolved over time and to examine the relationships among these variables. The second phase involved a survey to validate the review findings, assess the impact of autism knowledge on awareness and stigma using the KAB model, examine the influence of cultural beliefs, social norms, and misinformation and test the study's hypothesis.

3. Data Collection and Analysis

3.1. Phase 1: Systematic Review

In phase 1, a systematic literature review was conducted to address RQ1 regarding the progression of autism knowledge, awareness, and stigma. The review followed the PRISMA 2020 guidelines, checklist and flowchart (“PRISMA,” n.d.) to ensure transparency and replicability. Journal articles related to autism knowledge, awareness, and stigma were collected and analyzed to understand the progress of autism information over the years. Journal articles published between 2000 and 2025 were included in the review. This timeframe was selected because it reflects a period of substantial development in the scientific understanding of autism (Happé & Frith, 2020) and allows for the inclusion of a sufficiently broad body of literature.

For the systematic literature review, the inclusion and exclusion criteria were defined first, based on which the search was conducted, and relevant records or sources were retrieved.

The inclusion criteria are:

- Study should be related to autism knowledge, awareness, or stigma.
- Study should be in English.
- The study participants should be either autistic individuals or family members. The review focused on autistic individuals and their families because these groups are directly affected by autism-related knowledge, awareness, and stigma.
- The study participants should be located in the U.S.

The exclusion criteria are:

- Studies published before 2000 and after 2025 were excluded.
- The study should not be a review or an opinion article.

Three databases—PubMed, Web of Science, and Scopus—were queried using keywords related to autism, knowledge, awareness, stigma, and participants (autistic individuals, family, caregivers). Below table lists the research question and the search terms

Table 1. Research Question and Search Terms.

Research Question	Search Terms
How has information about autism evolved over time, and what is the state of autism knowledge, autism awareness, and autism stigmatization in recent years?	((“autism” or “Asperger syndrome” or “asd” or “autism spectrum disorder” or “autistic disorder” or “pervasive developmental disorder”) AND (“knowledge” or “awareness” or “stigma”) AND (“autistic patients” or “autistic individuals” or “autistic” or “family” or “caregivers”))

Initially, 2,115 articles were identified, and 1,162 duplicates were removed. After applying inclusion and exclusion criteria, 215 articles were screened. Among these, 111 interventional studies were excluded because the study’s review focused specifically on perceptions and understanding of autism information rather than evaluating intervention outcomes. This resulted in identifying 23 relevant studies focusing on autism knowledge, awareness, or stigma. Figure 2 presents the PRISMA flow diagram, illustrating the step-by-step process of study identification, screening, eligibility assessment, and inclusion in the review.

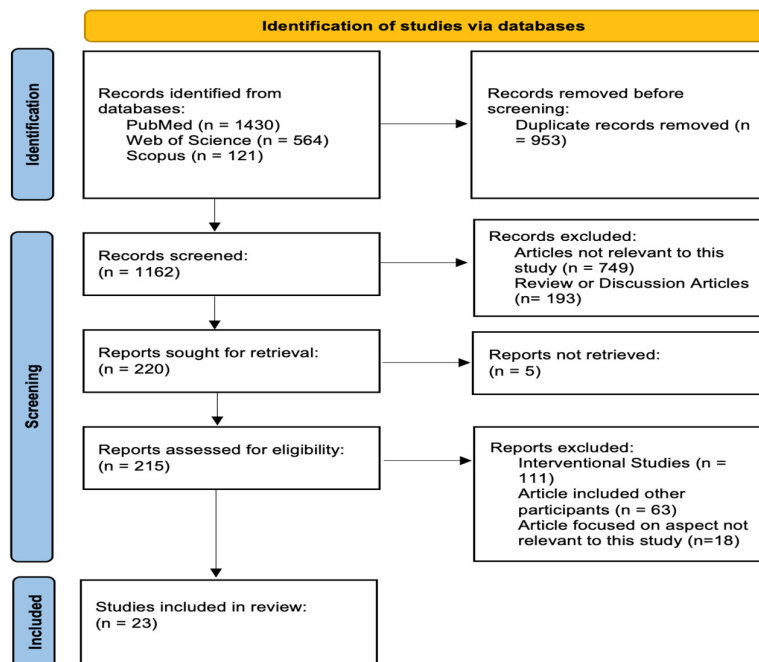


Figure 2. PRISMA flow diagram.

Data pertaining to the 23 journal articles was extracted using a standardized form capturing study characteristics, participant details, outcomes, and key findings. A thematic analysis was conducted on the finalized articles to ensure they met the predefined inclusion and exclusion criteria and aligned with the scope of the study. This process helped confirm the relevance and suitability of the selected literature for addressing the research question.

To ensure reliability, a team of two experts reviewed the article selection to minimize bias, ensure inclusion quality, and assess the strength of the evidence, with any disagreements resolved through discussion. Internal validity was also used to reduce selection bias in systematic literature review. Additionally, after coding the full texts, the codes were reviewed by a third person to confirm their consistency and reliability.

After finalizing the 23 included journal articles, a structured qualitative content analysis, including conceptual analysis, was conducted to examine the progression of autism knowledge, awareness, and stigma over time. NVivo and Microsoft Excel were used to code and categorize the literature, with Excel summarizing each article and its contributions to understanding the progression of autism-related information. The strength and certainty of the evidence were evaluated using the GRADE framework, and the findings were synthesized to identify the progression of autism knowledge, awareness, and stigma.

3.2. Phase 2: Survey

In Phase 2, a survey was used to collect data on autism knowledge, awareness, stigma, cultural beliefs, social norms, and misinformation, as outlined in the conceptual model. The survey aimed to examine the relationships among these variables as well as validate findings from the systematic literature review.

Some survey questions were adapted from the Autism Stigma and Knowledge Questionnaire (ASK-Q) (Harrison et al., 2017), a validated tool assessing autism knowledge across four subscales: symptoms/diagnosis, etiology, treatment, and stigma, which has been used across diverse populations including parents, healthcare professionals, and college students (Handayani & Paramita, 2020; Reckard, 2021). Only items relevant to this study were adopted and measured on a

five-point Likert scale. Although the original ASK-Q items used a nominal scale, they were adapted in this study to a five-point Likert scale to allow for greater variability in responses and more nuanced measurement of autism knowledge. Additional survey questions/items were developed based on literature review, the conceptual model, and expert input to assess autism awareness, cultural beliefs, social norms, and misinformation. These items were reviewed for content validity by an expert, and reliability for the full survey. The 31-question survey, administered via Qualtrics, included both open- and closed-ended items and took approximately 30 minutes to complete.

Before administering the main survey, a pilot study was conducted to assess validity and reliability. Survey items, including adapted ASK-Q items and newly developed items assessing awareness, cultural beliefs, social norms, and misinformation, underwent content analysis and expert review to ensure they measured the intended constructs without bias. Reliability was evaluated using Cronbach's alpha (Tavakol & Dennick, 2011), confirming internal consistency for the full survey.

The main survey employed purposive sampling, a non-probability method in which participants are selected based on predefined criteria (Jordan, 2021; Renjith et al., 2021). Autistic individuals, family members, and caregivers were chosen as participants, informed by the systematic literature review, which primarily included studies involving these groups. This alignment allowed the study to examine autism knowledge, awareness, and stigma from their perspectives, as well as relationships among autism-related variables. Participants were recruited via Amazon Mechanical Turk (MTurk) and the University of North Texas (UNT) Kristin Farmer Autism Center, targeting U.S. residents. A total of 178 responses were collected, of which 159 were deemed suitable for analysis, representing a diverse sample in terms of background, gender, race, and ethnicity.

Survey responses were analyzed using IBM SPSS Statistics for descriptive statistics, correlation, and regression analyses to examine relationships among autism variables, and NVivo was used for qualitative analysis, including word cloud visualization of open-ended responses (Handayani & Paramita, 2020; Reckard, 2021).

4. Results

This study adopted a two-phase approach to address the research questions. In the first phase, a systematic literature review was conducted following PRISMA 2020 guidelines to examine the progression of autism knowledge, awareness, and stigma among autistic individuals and their families and caregivers ("PRISMA," n.d.). The review searched three databases—PubMed, Web of Science, and Scopus which resulted in identifying 23 relevant studies on autism knowledge, awareness, or stigma.

Five of the twenty-three studies examined autism knowledge among autistic individuals or family members. Participant numbers ranged from 16 to 99, with interviews being the most used research instrument. The findings indicated varying levels of autism knowledge across different domains. For example, families demonstrated adequate knowledge of research-based early intervention services (Sansosti et al., 2012), whereas parents reported limited awareness of genetic testing for autism spectrum disorders (Hanish et al., 2018). Additionally, three studies compared autism knowledge across ethnic groups and found disparities in knowledge levels. While White mothers generally demonstrated greater knowledge of ASD, Latina mothers showed lower awareness, particularly regarding developmental milestones. Although knowledge increased following a child's ASD diagnosis, Latina mothers reported difficulties accepting the diagnosis and applying their knowledge to understand their child's needs. These findings highlight the influence of cultural factors on autism knowledge. Table 2 depicts all the studies analyzed pertaining to autism knowledge.

Table 2. Studies Related to Autism Knowledge.

Author (Year)	Number of Participants	Instrument	Title	Source	Content/Theme	Findings
Sansosti et al. (2012)	16	Interview and assessment scale	Family Experiences Through the Autism Diagnostic Process	Focus On Autism and Other Developmental Disabilities	Evaluate families' knowledge of the research-based interventions.	According to their findings, families seemed to have adequate knowledge about research-based interventions pertaining to ASD.
Ratto et al. (2016)	56	Questionnaire	Cultural Effects on the Diagnosis of Autism Spectrum Disorder Among Latinos	Focus On Autism and Other Developmental Disabilities	Investigate how knowledge of development and ASD, may vary among ethnic groups.	The results indicate that, in comparison to White mothers, Latina mothers knew far less about ASD and developmental milestones.
Hanish et al. (2018)	20	Interviews	Autism spectrum disorder and genetic testing: Parental perceptions and decision-making	Journal For Specialists in Pediatric Nursing	Parents' perceptions and decision making about genetic testing for autism.	Before visiting a genetics clinic, parents knew very little about genetic testing for autism.
Burke et al. (2018)	99	Survey	Examining differences in empowerment, special education knowledge, and family-school	International Journal of Developmental Disabilities	Examine the differences in special education knowledge among Latino and White families.	Compared to White parents, Latino parents reported far lower levels of

partnerships
among Latino
and White
families of
children with
autism
spectrum
disorder

empowermen
t and special
education
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Gordill o et al. (2020)	20	Interviews	Mothers' adjustment to autism: Exploring the roles of autism knowledge and culture	Journal of Pediatric Psychology	of parent's autism knowledge among mothers of different ethnicities.	Explore parent's autism knowledge among mothers of different ethnicities.	Following their children's autism diagnoses, all mothers gained a comparable understandin g of ASD. While Latina women found it difficult to accept their child's diagnosis and were not able to use their broad knowledge of autism to better comprehend their child's autism needs, non-Latina mothers (including immigrant and U.S. born) felt empowered by their newly acquired autism knowledge.
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Nine of the twenty-three studies focused on autism awareness among autistic individuals and family members. Participant numbers ranged from 22 to 155, and interviews and surveys were the primary research methods. These studies were categorized into three areas: genetic testing, awareness across ethnicities, and treatment awareness. Four studies examining genetic testing reported insufficient awareness due to factors such as limited knowledge and financial constraints (Vande Wydeven et al., 2012; Chen et al., 2013; Harrington et al., 2018; Zebolsky et al., 2020). Three studies addressing ethnic differences found no significant disparities in the age of ASD diagnosis between Hispanic and non-Hispanic White children, suggesting improvements in awareness and access to support (Magana et al., 2013; Ijalba, 2016; Ferguson & Vigil, 2019). Moreover, these studies show that there has been an increase of autism awareness over the years among certain ethnicities yet there is a need for autism awareness among other ethnicities. Two studies related to treatment indicated that while parents were generally aware of autism treatments, certain ethnic communities had limited knowledge (Deyro et al., 2016; Rosales et al., 2021). Overall, these findings highlight the need to increase awareness of genetic testing, improve treatment knowledge, and address awareness gaps across ethnic communities. Table 3 summarizes the articles on autism awareness.

Table 3. Studies Related to Autism Awareness.

Author (Year)	Number of Participants	Instrument	Title	Source	Content/The me	Findings
Vande Wydeven et al. (2012)	155	Survey	Underutilization of genetics services for autism: The importance of parental awareness and provider recommendation	Journal of Genetic Counseling	Genetics Services for ASD	Parents who did not receive genetic services had less awareness about it.
Chen et al. (2013)	42	Interviews	Autism genetic testing: A qualitative study of awareness, attitudes, and experiences among parents of children with autism spectrum disorders	Genetics in Medicine	Examine the awareness about genetic testing among parents of autistic children's.	Asian parents and parents from poorer socioeconomic backgrounds likely to be less aware of autism genetic testing and to have less access to it.

Magana et al. (2013)	104	Questionnaire	Access to Diagnosis and Treatment Services Among Latino Children with Autism Spectrum Disorders	Intellectual and Developmental Disabilities	Examine the diagnosis and treatment services among Latino and non-Latino White children.	The results point to the need for service providers to increase autism awareness and education while also improving service accessibility for Latino families.
Deyro et al. (2016)	83	Survey	Parental Awareness of Empirically Established Treatments for Autism Spectrum Disorders	Focus On Autism and Other Developmental Disabilities	Access to parental awareness about evidence-based treatments for autism.	For just nine of the twenty-six identified treatments, many parents agreed with the National Standards Report (NSR). Among the interventions mentioned by more than 35% of the parents, some were not included in the NSR consensus. The results indicate that parents are aware of autism treatments.
Ijalba (2016)	22	Interviews	Hispanic immigrant mothers of young children	American Journal of Speech-	Examine a group of Hispanic immigrant	Social isolation was exacerbated by a lack of

			with autism spectrum disorders: How do they understand and cope with autism?	Language Pathology	women's experiences in raising an autistic child (ASD).	awareness about autism, which was once thought to be transient and linked to melancholy or fear.
Harrington et al. (2018)	143	Survey	Parental Perception and Participation in Genetic Testing Among Children with Autism Spectrum Disorders	Clinical Pediatrics	Examine parental involvement in the decision to undergo genetic testing as well as the factors linked to genetic testing in children with ASD.	The most frequent excuses stated by participants for not getting genetic testing were lack of awareness, financial concerns, and not being offered genetic testing.
Ferguson & Vigil (2019)	47	Survey	A comparison of the experience of low-SES Hispanic and non-Hispanic white parents	Autism Research	Examine the experiences of American White non-Hispanic families and Hispanic families who had children diagnosed with ASD and who came from low socioeconomic status (SES) backgrounds.	The results show there is no difference in the diagnosis age among the Hispanic and non-Hispanic White children, which could be due to increased awareness and having access to active parent organization.

Zebolsky et al. (2020)	138	Survey	Awareness of genetic testing for children with autism spectrum disorder among caregivers in an autism support group	Journal of Community Genetics	Examine the genetic testing awareness among caregivers of ASD in an autism support group.	Even among participants in formal autistic support groups, research indicates that low awareness is a significant contributing factor to the underutilization of genetic testing for ASD.
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Rosales et al. (2021)	28	Interviews	A First Look at Applied Behavior Analysis Service Delivery to Latino American Families Raising a Child With Autism Spectrum Disorder	Behavior Analysis in Practice	Study's goal was to gather data on a sample of Latino American families residing in Massachusetts regarding their experiences receiving and sustaining ABA treatments.	Few parents reported lack of awareness about their child's eligibility to receive ABA services due to various reasons.
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There were nine studies identified related to autism stigma and these articles examined autism stigma among autistic individuals and their families. Interviews were the most used research method, and despite differences in sample sizes and study periods (2014–2022), all studies reported the persistence of autism stigma. One study emphasized the need to reduce societal stigma associated with ASD and disability labels (Jones et al., 2015). Other studies reported that Latino communities often face limited access to ASD-related information and experience stigma related to mental health and disabilities. Misunderstandings about ASD were also found to contribute to social isolation. Table 4 summarizes the studies on autism stigma.

Table 4. Studies Related to Autism Stigma.

Author (Year)	Number of Participants	Instrument	Title	Source	Themes	Findings
Zuckerman et al. (2014)	33	Focus groups and Qualitative interviews	Latino Parents' Perspectives of Barriers to Autism Diagnosis	Academic Pediatrics	Examine the parent's perceptions of autism and barriers experience during autism diagnosis.	Latino community members have expressed limited access to information about autism and significant stigma surrounding mental health and disabilities.
Blanche et al. (2015)	15	Interview	Caregiving Experiences of Latino Families with Children with Autism Spectrum Disorder	American Journal of Occupational Therapy	Analyze the caregiving experiences of Latino families raising autistic children.	Parents responses helped in identifying four themes: addressing the diagnosis, confronting stigma and isolation within family and community, comprehending the significance of mothers in altering family routines, and effectively utilizing available services.

Jones et al. (2015)	10	Interview	Are you by chance on the spectrum? Adolescents with autism spectrum disorder making sense of their diagnoses.	Disability & Society	Analyze how autistic adolescents and make meaning of their diagnosis.	The study's findings point to the necessity of lessening the societal stigma attached to ASD and disability labels.
Cohen & Miguel (2018)	25	Interview	Amor and Social Stigma: ASD Beliefs Among Immigrant Mexican Parents	Journal Of Autism and Developme ntal Disorders	Investigate the cultural perspectives of Mexican-heritage families on ASD and its causes.	Different ideas about social stigma, child traits, developmentally supportive circumstances, and parents' emotional stress were discovered via inductive analyses.
Dababnah et al. (2018)	22	Interview	"We Had to Keep Pushing": Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care	Intellectual And Developme ntal Disabilities	Examine the perspectives of Black Children's Primary Care Autism Screening and Referral Practices.	Delays in following up on referrals have been attributed by caregivers to Black community stigma, shame, and denial around ASD.
Marsack & Perry (2018)	51	Interviews	Aging in Place in Every Community: Social Exclusion Experiences of Parents of Adult children With Autism Spectrum Disorder	Research On Aging	Examine the aging processes of caregivers along with the potential for social marginalization that parents of adult children with autism spectrum	Misunderstandi ng about ASD and stigma was one of the ways that lead to social isolation.

disorder may
face.

Zuckerman et al. (2018)	380	Survey	Parent Perceptions of Autism Spectrum Disorder Stigma: Measure Validation and Associations in a Multi-Site Sample	Journal Of Autism and Developmental Disorders	Examine parent perceptions about ASD stigma.	Regression analysis revealed that stigma score was connected to unfulfilled ASD care needs. Higher stigma scores were linked to child public insurance, parent nativity, the number of ASD children in the home, parent-reported ASD severity, and family structure.
Habayeb et al. (2020)	20	Questionnaire and follow-up phone interviews	Cultural Experiences of Arab American Caregivers Raising Children with Autism Spectrum Disorder	Journal Of Autism and Developmental Disorders	Analyze the cultural experiences of Arab American caregivers with autistic children.	The range of perceived stigma ranged between low to moderate.
Stein Duker et al. (2022)	31	Interview	Caregiver perspectives on barriers and facilitators to primary care for autistic adults: A qualitative study	Frontiers In Medicine	Analyze caregivers' viewpoints on obstacles and aids to accessing primary care for adults with autism.	Interview responses showed the existence of stigma and preconceptions about autism.

The review also identified several factors associated with autism stigma, including child public insurance status, parental nativity, the number of children with ASD in a household, parent-reported

severity of ASD, family structure, unmet care needs, and limited access to autism information (Zuckerman et al., 2018; Stein Duker et al., 2022), as illustrated in Figure 3.

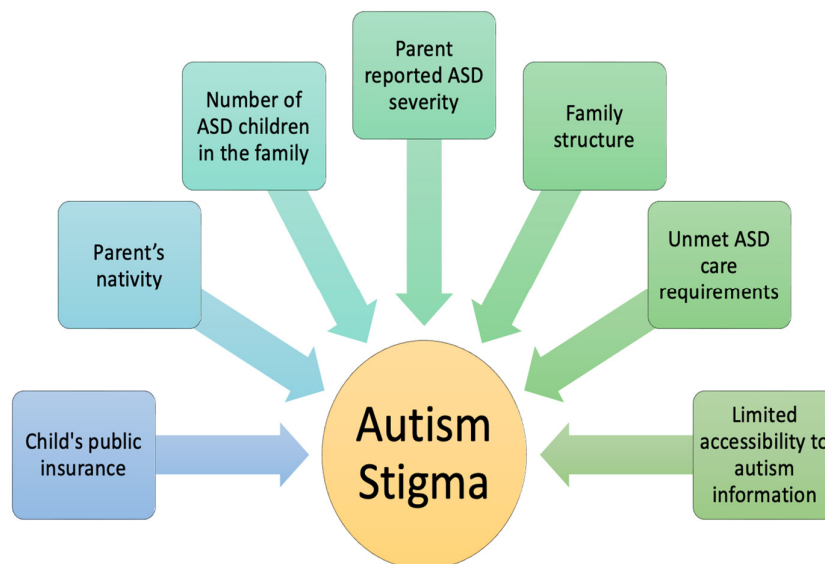


Figure 3. Factors that impact autism stigma.

Overall, the systematic literature review examined the evolution of autism-related information, focusing on knowledge, awareness, and stigma. Although progress has been made in increasing autism knowledge and awareness, gaps remain in areas such as genetic testing and within certain ethnic communities. The findings also highlight the persistent presence of autism stigma, emphasizing the need for targeted awareness campaigns and educational initiatives to improve understanding and reduce stigma.

In Phase 2, a survey was conducted among autistic individuals, family members, and caregivers to assess perceptions of autism knowledge, awareness, and stigma and to examine correlations among autism-related variables. A pilot study with six responses was first conducted to assess survey reliability using Cronbach's alpha. Each autism variable consisted of multiple items, and the mean values of these items were used to calculate reliability. As shown in Table 5, the variables demonstrated varying levels of internal consistency, with autism stigma showing acceptable reliability and autism misinformation demonstrating the highest reliability.

Table 5. Cronbach Alpha for Each Autism Variable.

Variables	Cronbach Alpha
Autism Knowledge	.773
Autism Awareness	.763
Autism Stigma	.706
Autism Cultural Beliefs and Social Norms	.942
Autism Misinformation	.957

Following the pilot study, the survey was distributed via Amazon Mechanical Turk and the UNT Kristin Farmer Autism Center. Participants first completed a consent agreement before proceeding with the 31 survey questions. The questionnaire was organized into seven sections: (1) Demographics (3 questions), (2) Background (7 questions examining participants' relationship with and understanding of autism), (3) Autism Knowledge (4 questions), (4) Autism Awareness (4 questions),

(5) Autism Stigma (4 questions), (6) Autism Cultural Beliefs and Social Norms (4 questions), and (7) Autism Misinformation (5 questions examining misconceptions and sources of misinformation).

A total of 177 responses were collected, of which 18 were excluded due to incomplete or irrelevant responses, resulting in 159 valid responses for analysis. Although the sample size is modest, it is comparable to exploratory studies examining perceptions of autism within specific populations. Standard deviations (SD) ranged between 0.45 and 0.72 from their respective means, providing additional insights into the variability of the data points. As shown on the table below.

Table 6. Descriptive Statistics (N=159).

Variable	N	Minimum	Maximum	Mean	Std. Deviation
Knowledge	159	1.6	4.8	3.811	.5177
Awareness	159	2.8	5.0	3.981	.4588
Stigma	159	1.0	4.8	3.737	.6228
Cultural Beliefs and Social Norms	159	1.0	5.0	3.629	.7204
Misinformation	159	1.6	5.0	3.517	.6944

The combined data from both platforms were analyzed using NVivo and IBM SPSS. Table 7 presents the demographic characteristics of the participants, indicating that most respondents were male, primarily between the ages of 18 and 30, and predominantly identified as White.

Table 7. Sociodemographic Characteristics of Participants (N=159).

Socio-demographics	Characteristics	n	%
Gender	Male	105	66.04
	Female	54	33.96
Age	18-30 years	74	46.54
	31-40 years	60	37.74
	41-50 years	16	10.06
	51-60 years	6	3.77
	61-70 years	3	1.89
Ethnicity	White	134	84.28
	Black or African American	1	0.63
	American Indian or Alaska Native	3	1.89
	Asian	20	12.58
	Native Hawaiian or Pacific Islander	0	0.00
	Other	1	0.63

Survey responses related to background (Table 8) showed that all participants had prior knowledge of autism, either as autistic individuals or family members. Personal experience was the primary source of information, followed by doctors and medical professionals. Secondary sources additionally included the internet and educational institutions, highlighting the role of online resources and academic settings in disseminating autism-related information.

Table 8. Background Questions Responses of Participants (N=159).

Questions	Responses	n	%
Do you know someone with autism	Yes	159	100
	No	0	0
If you know someone with autism, then what is your relationship with them?	Self	62	38.99
	Family Member	97	61.01
	Other	0	0
Please rate your understanding of autism.	Very familiar with autism	35	22.01
	Some understanding/Familiar with autism	95	59.75
	Minimal/Very little understanding	29	18.24
For how many years have you been familiar with the concept of autism?	1-10 years	124	77.99
	11-20 years	24	15.09
	20+ years	11	6.92
What is your primary/main source of information for your knowledge about autism?	Personal Experiences	72	45.28
	Doctor or other medical professional	61	38.36
	Learned about autism at school/university	13	8.18
	Internet	10	6.29
	News	3	1.89
	Social media.	0	0.00
	TV shows/movies	0	0.00
	Research Articles	0	0.00
Others	0	0.00	
What is your secondary source of information for your knowledge about autism?	Doctor or other medical professional	46	28.93
	Personal Experiences	41	25.79
	Internet	29	18.24
	Learned about autism at school/university	27	16.98
	TV shows/movies	9	5.66
	News	4	2.52
	Social media	1	0.63
	Research Articles	1	0.63
	Others	1	0.63

The survey also included questions to understand participants' perceptions and understanding of autism-related knowledge, awareness, and stigma. The collected responses were analyzed to evaluate the levels of autism knowledge, awareness, and stigma among participants. The results indicated that most respondents demonstrated a good understanding of autism. However, the

analysis also revealed discrepancies in autism awareness, suggesting that participants possessed varying levels of awareness. Additionally, the findings indicated the presence of some level of autism-related stigma among the surveyed participants.

4.1. Hypothesis Testing

The study used IBM SPSS to conduct a correlation analysis to examine the relationships among various autism variables, such as knowledge, awareness, stigma, cultural beliefs, social norms, and misinformation using the survey data. Pearson correlation analysis was used to determine the strength of the linear relationship between the variables. Multiple-choice items were analyzed to assess specific aspects of autism, and the resulting mean value was used to calculate the Pearson correlation and test the study hypothesis.

H1: *Autism knowledge is positively correlated to autism awareness.*

The first hypothesis posits a positive correlation between autism knowledge and awareness, based on the idea that gaining knowledge about autism increases awareness. A Pearson correlation analysis of the variables showed a correlation coefficient of 0.455, with a significance level of less than 0.001, supporting the hypothesis. This indicates that higher autism knowledge is associated with increased awareness.

H2: *Cultural beliefs and social norms have direct correlations to autism knowledge and awareness.*

The second hypothesis suggests that cultural beliefs and social norms influence autism knowledge and awareness. The study found a significant positive correlation between cultural beliefs and social norms and autism knowledge, with a Pearson correlation coefficient of 0.381 and a significance level of less than 0.001. However, the correlation between cultural beliefs and social norms and autism awareness was weak (correlation coefficient of 0.094, significance of 0.118), making it inconclusive. Therefore, hypothesis 2 was partially supported, indicating a significant correlation between cultural beliefs and social norms and autism knowledge.

H3: *There is a direct relationship between cultural beliefs, social norms, and autism misinformation.*

The hypothesis suggests that cultural beliefs and social norms are linked to autism misinformation. This hypothesis was formulated based on the premise that individuals who hold stronger cultural beliefs are more likely to endorse stigma and misinformation regarding autism, resulting in misconceptions about the condition. A correlation analysis showed a positive correlation coefficient of .605, confirming hypothesis three and suggesting that stronger cultural beliefs are linked to higher endorsement of misinformation.

H4: *Misinformation has direct correlation to autism knowledge and autism awareness.*

The fourth hypothesis posits a direct link between autism misinformation, knowledge, and awareness, grounded on the idea that misinformation obscures understanding and awareness of autism. However, a correlation analysis shows a positive correlation between misinformation and knowledge (correlation coefficient of 0.386, significance of <.001), but there is no significant relationship between misinformation and autism awareness (correlation coefficient of 0.73, significance of 0.180). Therefore, hypothesis 4 was not fully validated.

H5: *Autism awareness negatively correlates with autism stigmatization.*

The fifth hypothesis, assuming increased autism awareness would reduce stigma, was not supported by the correlation analysis, as autism awareness did not significantly influence stigma (correlation coefficient of 0.166, significance of 0.018).

H6: *Autism awareness serves as a mediator between knowledge and stigmatization.*

The sixth hypothesis suggests that increased autism knowledge leads to greater awareness, which reduces autism stigma. This hypothesis was tested using Andrew F. Hayes' mediation process analysis, which examines the relationship between two variables with the introduction of a third hypothetical variable as a mediator. Autism knowledge was the independent variable, and autism stigma was the dependent variable with autism awareness being the mediator variable. The mediation analysis showed a positive coefficient between knowledge and stigma, but no significant relationship between stigma and awareness.

The hypothesis testing outcomes revealed two confirmed, two partially supported, and two rejected hypotheses. The results highlight the relationship between cultural beliefs and social norms with knowledge of autism, as well as the impact of misinformation on knowledge.

4.2. Research Questions

A systematic literature review was conducted to examine the progression of autism knowledge, awareness, and stigma (RQ1). The review highlighted improvements in knowledge, particularly in research-based interventions, but identified persistent gaps in areas such as genetic testing. Disparities across ethnic groups were noted (Colbert et al., 2017; Lopez et al., 2018), indicating the need for culturally sensitive educational programs, community outreach, and collaboration among parents, professionals, and media platforms. The review also revealed the enduring presence of autism stigma, emphasizing the importance of awareness campaigns and educational initiatives to support families and reduce societal stigma (Papoudi et al., 2021; Liao et al., 2019; Salleh et al., 2020).

To validate these findings, a survey of 159 autistic individuals and family members assessed perceptions of knowledge, awareness, and stigma. Results showed that participants generally possessed satisfactory knowledge of autism, although awareness and stigma varied. Overall, the combined findings indicate that while knowledge and awareness have progressed, disparities and persistent stigma remain key areas for intervention, providing a comprehensive picture of the current state and evolution of autism-related understanding.

Research questions 2, 3, and 4 examined the relationships among the study variables. Scatter plots were generated for each variable pair to identify the most appropriate model. In most cases, a linear fit line provided the best representation, indicating that linear regression models were suitable for analyzing these relationships.

To address RQ2, the impact of autism knowledge on awareness and stigma was examined using linear regression analysis in IBM SPSS. Autism knowledge was treated as the independent variable, while awareness and stigma were analyzed as separate dependent variables. The results indicated a significant positive relationship between autism knowledge and awareness ($\beta = .455$, $t = 6.402$, $p < .001$), with the model explaining 20.7% of the variance ($R^2 = .207$, $F = 40.981$). Similarly, autism knowledge showed a significant positive relationship with stigma ($\beta = .400$, $t = 5.461$, $p < .001$), explaining 16.0% of the variance ($R^2 = .160$, $F = 29.823$). These findings suggest that higher levels of autism knowledge are associated with increased awareness and perceptions related to stigma. Improving autism knowledge through education, targeted programs, and accurate media communication may therefore enhance awareness and contribute to addressing stigma.

To address RQ3, linear regression analysis was conducted to examine the impact of autism misinformation on autism knowledge and awareness. Autism misinformation was treated as the independent variable, while knowledge and awareness were analyzed as separate dependent variables. The results indicated a significant positive relationship between misinformation and autism knowledge ($\beta = .386$, $t = 5.250$, $p < .001$), with the model explaining 14.9% of the variance (R^2

= .149, $F = 27.567$). However, misinformation did not show a significant relationship with autism awareness ($\beta = .073$, $t = 0.916$, $p = .361$), and the model explained only 0.5% of the variance ($R^2 = .005$, $F = 0.839$). These findings suggest that while misinformation may influence individuals' knowledge about autism, it does not significantly affect their level of awareness.

To identify the primary sources of misinformation, the survey participants were asked to identify the top three sources of autism misinformation. Responses were analyzed using NVivo, and participants identified social media, websites, blogs, unverified sources, anti-vaccination platforms, and misinformed individuals—including celebrities and public figures—as major sources of misinformation. These findings highlight the need for strategies to reduce misinformation, such as labeling unreliable sources and equipping healthcare providers with resources to guide autistic individuals, family members, and caregivers toward credible information.

To address RQ4, linear regression analysis was conducted to examine the influence of cultural beliefs and social norms on autism knowledge, awareness, and misinformation. Cultural beliefs and social norms were treated as independent variables, while knowledge, awareness, and misinformation were analyzed as separate dependent variables. The analysis revealed a significant positive relationship between cultural beliefs and social norms and autism knowledge ($\beta = .381$, $t = 5.15$, $p < .001$), with the model explaining 14.5% of the variance ($R^2 = .145$, $F = 26.606$). A significant positive relationship was also found between cultural beliefs and social norms and autism misinformation ($\beta = .605$, $t = 9.52$, $p < .001$), with the model explaining 36.6% of the variance ($R^2 = .366$, $F = 90.688$). However, the relationship between cultural beliefs and social norms and autism awareness was not statistically significant ($\beta = .094$, $t = 1.18$, $p = .237$), with the model explaining only 0.9% of the variance ($R^2 = .009$, $F = 1.410$). These findings suggest that cultural and social factors may influence individuals' knowledge and susceptibility to misinformation about autism, but they do not appear to significantly affect awareness levels.

5. Discussion and Conclusions

The increasing prevalence of autism spectrum disorder (ASD) has intensified the need for improved understanding, early diagnosis, and supportive social environments for autistic individuals and their families. At the same time, evolving perceptions of autism, particularly those shaped by misinformation and cultural beliefs, have raised concerns about how autism is understood within society. This study examined the evolution of autism-related information in terms of autism knowledge, awareness and stigma and also explored the relationships among autism knowledge, awareness, stigma, cultural beliefs, and misinformation. Using a two-phase approach that combined a systematic literature review and a survey of autistic individuals and family members, the study aimed to better understand how these factors interact and influence perceptions of autism.

The systematic literature review revealed several important trends in the development of autism knowledge, awareness, and stigma over the past two decades. Although awareness and access to autism-related information have increased, gaps remain in several areas, particularly genetic testing knowledge and access to services. Previous studies have shown that many parents remain unaware of genetic testing options for autism or encounter barriers such as financial constraints and lack of provider recommendations. These findings highlight the need for greater education among healthcare providers and improved communication between professionals and families to ensure that caregivers receive accurate and comprehensive information about available diagnostic and support resources.

The literature review also identified disparities in autism knowledge and awareness across ethnic communities. Some studies reported that certain groups, particularly Latino families, often experience lower levels of awareness and encounter barriers related to language, cultural perceptions, and access to information. These findings emphasize the importance of culturally sensitive educational initiatives and community-based outreach programs that address the unique needs of diverse populations. Additionally, the review highlighted the continued presence of autism-related stigma in many communities, which can contribute to delayed diagnoses, reduced access to

services, and social isolation for families and autistic individuals. These findings suggest that while progress has been made in improving awareness, stigma and cultural misconceptions surrounding autism remain persistent challenges.

The survey conducted in Phase 2 provided additional insights into perceptions of autism among autistic individuals and their family members. Overall, participants demonstrated relatively high levels of autism knowledge and moderate levels of awareness. However, variations in awareness levels were observed, indicating that not all participants possessed the same level of familiarity with autism-related information. Despite generally positive levels of knowledge, the presence of autism-related stigma was still reported among respondents, suggesting that increased knowledge alone may not necessarily eliminate negative perceptions or stereotypes associated with autism.

Qualitative responses further supported these findings. When asked to identify the primary challenges faced by autistic individuals, participants frequently referenced communication difficulties, social interaction challenges, repetitive behaviors, and socialization barriers. These responses align with established diagnostic characteristics of autism spectrum disorder, suggesting that participants had a general understanding of the condition. Participants also identified several strategies for improving autism awareness in society, including public events, educational campaigns, and inclusive community activities. Many respondents emphasized the role of social media, workshops, and community engagement programs in fostering more supportive and informed environments for autistic individuals.

The findings related to the study's hypotheses provide additional insight into how autism knowledge, awareness, and misinformation interact. The results indicated a positive relationship between autism knowledge and autism awareness, suggesting that individuals who possess greater knowledge about autism are more likely to demonstrate higher levels of awareness. This finding supports the knowledge–attitude–behavior framework, which proposes that increased knowledge can contribute to greater awareness and understanding of social issues. Educational programs, public awareness campaigns, and improved access to accurate information may therefore play an important role in increasing awareness of autism and promoting more informed perceptions.

The study also examined the influence of cultural beliefs and social norms on autism-related perceptions. The findings suggest that cultural beliefs and social norms are significantly associated with autism knowledge and autism misinformation. Cultural values and community narratives can shape how individuals interpret information about autism, influencing both the acceptance of accurate knowledge and the spread of misconceptions. In some cultural contexts, autism may be interpreted through social or spiritual frameworks, which can contribute to misunderstandings about the condition. These results highlight the importance of considering cultural contexts when designing educational interventions and awareness campaigns.

One notable finding of the study was the strong relationship between cultural beliefs and autism misinformation. Individuals who reported stronger adherence to cultural beliefs and social norms were more likely to endorse misinformation related to autism. This suggests that misinformation may spread more easily within social networks where cultural narratives strongly influence perceptions of health and disability. The identification of social media platforms, blogs, websites, and unverified sources as key channels for misinformation further underscores the need for improved digital literacy and the promotion of credible information sources. Healthcare providers, educators, and advocacy organizations may play an important role in guiding individuals toward reliable information and countering misinformation.

Interestingly, the study found that autism awareness alone did not significantly reduce autism stigma. This finding suggests that awareness, while important, may not be sufficient to change deeply rooted social attitudes toward autism. Stigma may be influenced by broader social and cultural beliefs that persist even when individuals possess basic awareness of the condition. As a result, interventions aimed at reducing stigma may need to go beyond increasing awareness and instead focus on addressing underlying cultural narratives, stereotypes, and misconceptions about autism.

Overall, the findings of this study indicate that autism knowledge, awareness, cultural beliefs, and misinformation interact in complex ways. While increasing knowledge about autism can contribute to greater awareness, cultural beliefs and misinformation can shape how individuals interpret and apply that knowledge. These findings highlight the importance of comprehensive educational strategies that not only provide accurate information but also address cultural perspectives and social attitudes toward autism.

Several practical implications emerge from this research. Educational initiatives aimed at improving autism knowledge should incorporate culturally responsive approaches that recognize the diverse perspectives of different communities. Public awareness campaigns should focus on promoting accurate information about autism while actively countering misinformation circulating on social media and other online platforms. In addition, collaboration between healthcare professionals, educators, advocacy organizations, and community leaders may help ensure that autism-related information is communicated effectively and reaches a broad audience.

This study has several limitations that should be considered when interpreting the findings. First, the sample size was relatively modest, which may limit the statistical power of the analysis and the generalizability of the results. Second, participants were recruited partly through Amazon Mechanical Turk (MTurk), which may introduce potential sampling biases, including inattentive responses or inaccuracies despite screening procedures. Additionally, the study employed a cross-sectional design, which limits the ability to establish causal relationships between the variables examined. Finally, the reliance on self-reported survey responses may introduce response bias or social desirability bias, potentially affecting the accuracy of participants' reported knowledge, awareness, and attitudes toward autism.

Future research should expand on these findings by examining larger and more diverse populations, including participants from different cultural and geographic contexts. Longitudinal studies may also help identify how autism knowledge, awareness, and stigma evolve over time. Additionally, future studies could explore the effectiveness of targeted educational interventions designed to reduce misinformation and stigma while promoting accurate understanding of autism within diverse communities.

In conclusion, this study contributes to the growing body of research examining autism knowledge, awareness, and stigma by highlighting the complex relationships among knowledge, cultural beliefs, and misinformation. While increasing autism knowledge may enhance awareness, addressing stigma requires broader efforts that consider cultural contexts and the influence of misinformation. Educational initiatives, community engagement efforts, and improved access to reliable information may play an essential role in fostering greater understanding and more supportive environments for autistic individuals and their families.

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