

A Systematic Review of Primary Care Physicians' Understanding of Autism and Evidence-Based Autism Interventions

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Abstract

Autism Spectrum Disorder (ASD) presents significant challenges in diagnosis and management, particularly in healthcare settings. This study explores the knowledge, attitudes, and practices regarding ASD among healthcare professionals, focusing on the barriers and opportunities for improving diagnosis and care. A review of literature and survey data reveals varied levels of understanding about ASD, with significant gaps in knowledge, especially regarding early identification and intervention. Factors influencing healthcare providers' awareness include training opportunities, professional background, and access to updated resources. The research identifies the need for targeted training programs to enhance the competency of healthcare professionals in managing ASD, particularly in primary care and pediatric settings. Furthermore, it discusses the implications of these findings for improving ASD detection, early intervention, and overall care, emphasizing the importance of continuous professional development and collaboration with specialists. The study concludes with recommendations for policy adjustments and strategies to address the identified knowledge gaps and ensure better outcomes for individuals with ASD.

Introduction

Autism is a neurodevelopmental disorder characterized by ongoing difficulties in social and communication abilities, as well as repetitive or restrictive behaviors and interests (American Psychiatric Association, 2013). The prevalence of autism has been reported to vary, with earlier estimates suggesting that 1 in 88 individuals were affected in 2012 (CDC, 2012). However, more recent figures show that approximately 1 in 59 children are diagnosed with autism (Baio et al., 2018). This rising prevalence is thought to be influenced by factors such as increased awareness and advancements in diagnostic methods (Lee et al., 2015).

Signs of autism can often be identified in children as early as 12 months (Bryson et al., 2008), with a formal diagnosis possible by age 2 (Anglely et al., 2007). Currently, there are no reliable biomarkers for diagnosing autism, so healthcare professionals rely on behavioral observations and clinical judgment (Grodberg et al., 2015; Taylor et al., 2016). Early diagnosis is crucial, as it enables timely intervention and supports the development of appropriate educational plans (Filipek

et al., 2000). Studies have shown that children who receive early and intensive behavioral interventions tend to have better outcomes compared to those in general special education settings (Reichow et al., 2012), and these improvements can have long-lasting effects (Dawson, 2013). The brain's plasticity during early development may play a key role in these enhanced outcomes (Dawson, 2008).

Despite the importance of early identification and intervention, there is evidence suggesting that many children with autism are diagnosed later than optimal (Self et al., 2010). Factors contributing to this delay include the need for consultations with multiple professionals and the wide variety of diagnostic tools available, which differ in their approach, sensitivity, and suitability for children of various ages and conditions (Karim et al., 2012; Falkmer et al., 2013). As a result, there is significant variation in how autism is diagnosed, with some studies reporting that a notable proportion of healthcare providers do not use standard diagnostic tools (Penner et al., 2018).

Autism diagnosis can be complicated by factors such as the child's developmental history and potential co-occurring medical conditions (Lenne & Waldby, 2011). Additionally, healthcare providers must be cautious when relying on parental reports of symptoms, as parents may seek a formal autism diagnosis to access educational resources and financial support (Johnson & Myers, 2007; Taylor et al., 2016).

Primary care physicians (PCPs) often serve as the first point of contact for parents concerned about their child's development, making their role in early autism detection crucial (Zuckerman et al., 2013). These physicians, which include family doctors, general practitioners, pediatricians, and internists, are typically the first to notice developmental "red flags" related to autism, particularly since caregivers may not recognize these signs themselves (Angley et al., 2007). For this reason, it is essential for PCPs to be well-versed in the early signs of autism and to provide clear guidance for further assessment and intervention (Karande, 2006).

While clinical practice guidelines from the American Academy of Pediatrics (AAP) exist to aid PCPs in screening, diagnosing, and managing autism (Johnson & Myers, 2007), studies have found that many PCPs still face challenges in this regard, particularly when it comes to diagnosing autism in minority populations (Zuckerman et al., 2013). To address these challenges, the AAP developed a surveillance and screening algorithm to help PCPs identify at-risk children earlier (Johnson & Myers, 2007). Additionally, the AAP guidelines emphasize the importance of recognizing early behavioral cues, being alert to the needs of younger siblings of children with autism, and understanding the social and communication deficits that are characteristic of the condition (Johnson & Myers, 2007).

Despite growing awareness of autism, many PCPs still lack sufficient knowledge of its diagnostic criteria (Hartley-McAndrew et al., 2014). Studies have shown that teachers often have a better understanding of autism than physicians, with some physicians providing inaccurate definitions of the condition (Kirby et al., 2005). PCPs also struggle to identify autism symptoms due to the wide variation in how the disorder presents in individual children (Johnson & Myers, 2007), and they must also consider the possibility of co-occurring disorders (CCWD, 2001). Additionally, PCPs often report feeling uncomfortable managing patients with autism or lack the self-confidence needed to provide effective care (Mazurek et al., 2017; Broder-Fingert et al., 2014).

Knowledge alone is insufficient; PCPs also need to be familiar with evidence-based interventions (EBIs) to guide families in accessing appropriate treatments that can improve outcomes in areas such as communication, emotional regulation, and daily living activities (Nicolaidis et al., 2014). Unfortunately, many PCPs are not adequately prepared to offer such guidance, and parents often

report dissatisfaction with the information provided by physicians regarding educational and treatment options for their children (Williams et al., 2012). Some physicians may also be overwhelmed by the array of treatments for autism, including pseudoscientific therapies that lack empirical support and can expose children to unnecessary risks (Green et al., 2006; Schreck & Miller, 2010). It is essential for PCPs to be aware of these unsupported treatments and steer families toward proven interventions (Barbaresi et al., 2006; Green et al., 2006).

Ultimately, early recognition and diagnosis of autism can significantly impact the timely provision of appropriate interventions (Volkmar et al., 2006). As the first point of contact for many families, PCPs need to be well-informed about autism and the EBIs available to ensure that children receive the best possible care.

Methodology

Eligibility Criteria

For inclusion in this review, studies had to meet the following criteria: (a) involve primary care providers (PCPs) such as family doctors, general practitioners, pediatricians, or internists working in community settings; (b) focus on either the knowledge of autism or evidence-based interventions (EBIs) for individuals with autism, or assess an intervention aimed at enhancing knowledge regarding autism and related treatments among PCPs; and (c) be published in a peer-reviewed journal in English. There were no restrictions on the publication year. Studies were excluded if they (a) did not involve PCPs as participants, (b) focused on knowledge of developmental disabilities other than autism, (c) dealt with PCPs' attitudes or experiences in treating individuals with autism, (d) examined the preparedness of PCPs for managing autism care, (e) explored parents' perceptions of PCPs' readiness to treat autism, (f) focused on PCPs' health assessments of individuals with autism, or (g) analyzed the use of diagnostic or screening tools for autism by PCPs. Studies that combined data from PCPs with other participant groups, such as parents or psychologists, were excluded, as they made it difficult to extract relevant data solely for PCPs.

Search Strategy

The review followed the guidelines outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework. A systematic search was conducted across five electronic databases : Medline, Scopus, PsycINFO, Academic Search Complete, and CINAHL Complete. Each database was searched individually, and a sample search strategy for Medline was provided. Search terms were tailored for each database, with detailed information available in the supplementary materials. The titles and abstracts of articles retrieved were screened by one of the authors based on the inclusion criteria. In cases where it was unclear whether to include or exclude an article based on the title or abstract alone, the full text was reviewed by both authors. Any discrepancies were resolved through consensus with a third author. The reference lists of included studies were also reviewed to identify additional relevant studies.

Data Extraction

Data was systematically extracted on several variables: (1) participant characteristics, such as profession, age, experience, and gender; (2) study location; (3) research design and tools used; and (4) study outcomes. Data related to the outcomes of each study were categorized based on whether they assessed knowledge of autism or knowledge of EBIs. The outcomes were further classified as reflecting adequate, inadequate, or mixed knowledge among the PCPs. Descriptions of knowledge levels (e.g., positive or negative) were used to assign these categories, with studies reporting positive descriptions indicating adequate knowledge and those with negative

descriptions indicating inadequate knowledge. Studies reporting variable levels of knowledge were categorized as having mixed knowledge.

Interrater Reliability

To ensure consistency in data extraction, two raters independently extracted data from each study. The degree of agreement between raters was calculated as the number of agreements divided by the total number of agreements and non-agreements. The average interrater agreement across all studies was 91%, with a range of 75–100%. Disagreements between raters were discussed and resolved until consensus was reached. For the quality assessment using the QATSDD, initial interrater agreement was 82%, with discrepancies resolved by discussion until full agreement was achieved.

Results

Initially, 9,237 articles were screened, ultimately resulting in the inclusion of 20 studies. Among these, 13 were classified under the category of autism knowledge, five under evidence-based interventions (EBIs), and six under intervention studies. Four studies qualified for inclusion in multiple categories, addressing both autism knowledge and EBI. Data from these studies are presented in the corresponding sections below.

Autism Knowledge

A total of 2,706 primary care providers (PCPs) participated in the 13 studies included in this category. Among them, 1,100 were pediatricians, 1,077 were general practitioners (GPs) or family physicians, and 529 were unspecified across the studies. The average age of participants was 38.3 years, with an average clinical experience of 13.2 years. In terms of gender, 689 participants (25.5%) were female, 648 (23.9%) were male, and for 1,369 participants (50.6%), gender data was unavailable.

Research Methodology

The majority of studies (69.2%) employed a cross-sectional survey design, while 30.8% used mixed methods. Surveys and questionnaires were the primary tools used to assess knowledge, including true/false questions, the Knowledge about Childhood Autism among Health Workers (KCAHW) scale, autism surveys, and bespoke questionnaires. In addition, two studies incorporated interviews to explore knowledge and attitudes of GPs regarding autism.

Outcomes

The results revealed a significant variation in the knowledge of autism among the participants. Three studies (23.1%) reported adequate knowledge, while 69.2% of studies indicated that participants had inadequate knowledge, and 7.7% reported mixed results. A notable lack of understanding was observed concerning key features of autism, with some participants mistakenly associating it with mental retardation, psychosis, or schizophrenia in adulthood. There were also gaps in knowledge about the typical onset age for autism and its comorbidities, such as seizures. Misconceptions regarding the cause of autism were also common, with some attributing it to parental rejection or coldness.

Higher levels of autism knowledge were generally observed in studies conducted in Western countries. For instance, more than 89% of participants in some studies answered correctly regarding autism's key features. Another study found that over 90% of respondents would consider autism when encountering a patient with limited eye contact or atypical communication styles.

Predictors of Autism Knowledge

Six studies did not report predictors of autism knowledge, while the remaining seven identified several factors associated with increased knowledge. These included years of clinical experience, age, personal connections to autism, continuing medical education, prior experience with autism, gender, and profession. Some studies found that clinical experience was inversely related to knowledge, with younger physicians and those who had completed their medical degree in the last five years being more knowledgeable. Additionally, receiving autism-specific training, having a personal connection to autism, and working in a tertiary healthcare facility were linked to better knowledge. Gender also played a role, with male participants generally displaying better knowledge in one study. Some studies suggested that pediatricians had a better understanding of autism compared to general practitioners. Furthermore, certain factors like self-perceived confidence, personal experience, and autism training were associated with higher self-efficacy scores among providers.

Methodological Quality

The average total score for the QATSDD across the studies in this category was 27.6, with scores ranging from 16 to 45. The studies performed well in providing a "clear description of the research setting" and offering "detailed recruitment data." However, they were less successful in demonstrating "user involvement in design" and providing "evidence that sample size was considered in terms of analysis."

Knowledge of Evidence-Based Interventions (EBIs)

A summary of five studies in this category is detailed in Table 3 (for a more in-depth version, refer to Table B in Electronic Supplementary Material 2). Four of these studies also met the inclusion criteria for assessing knowledge about autism.

Participant Characteristics

A total of 1,171 participants responded to questions about EBIs for autism. Among them, 782 (66.8%) were pediatricians, 289 (24.7%) were general practitioners or family physicians, and 100 participants (8.5%) had unspecified professions. The mean age of participants was 40 years, although two studies did not report this data. The average number of years of clinical experience was 12.2, but this was not provided in three studies. Gender data were reported in only two studies, showing 207 males (17.7%) and 254 females (21.7%). The remaining three studies did not include gender information, which accounted for 710 participants (60.6%).

Location of Study

Studies were conducted in various regions, with a mix of countries contributing to the research pool.

Experimental Design and Research Tools

Four studies employed a cross-sectional survey design, while one study used a concurrent mixed methods design combining questionnaires with a qualitative component to gather GPs' perspectives on their educational needs and medication use with autistic patients. All studies utilized questionnaires or surveys. Some incorporated specific items about evidence-based autism treatments, applied behavior analysis (ABA), and special educational strategies.

Outcomes

The knowledge of EBIs for autism was inconsistent across the studies. One study found adequate knowledge, one found inadequate knowledge, and three reported mixed levels of understanding. For example, a small percentage of physicians displayed adequate knowledge of EBIs, while misconceptions about treatment options, such as dietary interventions, were prevalent. Many

physicians believed that certain treatments, such as hyperbaric oxygen therapy, were not part of evidence-based practices for autism. Concerns were also raised about the overuse of psychotropic medications and the reliance on alternative therapies by patients.

Predictors

Two studies did not report predictors. Among the most common predictors of knowledge about EBIs were receiving continuing medical education on autism and having a personal connection to the condition, such as knowing someone with autism. Additionally, one study found an inverse relationship between the number of years of clinical experience and knowledge of EBIs. The number of consultations with autistic individuals and self-perceived competency were also associated with increased knowledge in some studies. There were no reported differences in knowledge based on gender.

Methodological Quality

The average total score for the QATSDD across the included studies was 26.8, with a range between 16 and 45. The studies scored the highest on criteria such as the “statement of aims/objectives in the main body of the report” and “clear description of the research setting.” However, they received the lowest scores on items like “consideration of sample size for analysis” and “statistical assessment of reliability and validity of measurement tools.”

Intervention Studies

A total of 301 participants were involved in the intervention studies, consisting primarily of pediatricians (73.1%, 220 participants) and general practitioners/family physicians (26.9%, 81 participants). Two studies provided age data, yielding a mean age of 32.2 years, while one study provided information on clinical experience, with an average of 20.7 years of experience. Gender distribution was reported for 211 participants: 69 males (22.9%) and 142 females (47.1%), with data missing for the remaining 90 participants (29.9%).

Study Design and Methodology

Among the studies, four used pre-post-test designs (66.7%). One study employed a cluster randomized controlled trial (RCT), and another was structured as a multi-phase pilot training program involving workshops and follow-up assessments. Three studies utilized educational interventions with pre-post assessments. These interventions included workshops, case discussions, and learning materials like video clips and case studies. The remaining three studies focused on autism screening programs, employing a variety of tools such as checklists and training programs to improve screening adherence.

Outcomes

For the studies evaluating educational interventions, all demonstrated significant improvements in healthcare providers' knowledge of autism. For example, one study showed that 81.8% of participants improved their knowledge, and another study reported a rise in knowledge scores from 58.6% to 75.3%. A third study revealed that participants' understanding increased from 34.7% to 88.0% post-training. Additionally, evaluations of the training were highly positive, with 100% of participants rating the course as excellent or good in one study, and 94% found it useful in another. One study also assessed the relationship between clinical experience and knowledge, noting no improvement linked to years of experience. In terms of the screening tool interventions, two of the three studies found a significant increase in knowledge following the introduction of the tool, particularly with the inclusion of workshops. However, the third study found that while a computer-based system did not improve knowledge, it did enhance the use and accuracy of the autism screening tool.

Methodological Quality

The overall QATSDD score for these studies averaged 24.8, with a range of 20 to 30. These studies excelled in clearly describing the research setting and stating their aims/objectives. However, they scored poorly on items such as “consideration of sample size for analysis” and “evidence of user involvement in design.”

Discussion

As primary care providers (PCPs) are often the initial healthcare contact for parents of infants suspected of having autism (Zuckerman et al., 2013), it is essential for these professionals to possess a comprehensive understanding of autism and evidence-based interventions (EBIs) to effectively support parents both before and after an autism diagnosis. This systematic review synthesizes existing research on PCPs' knowledge of autism and EBIs for individuals with autism, while also evaluating the nature and outcomes of interventions designed to enhance their knowledge. Key findings highlight the generally low level of autism knowledge among PCPs, particularly in lower-income regions, a significant gap in research regarding their awareness of EBIs for autism, and the availability of several interventions that have proven effective in increasing their knowledge.

The studies reviewed indicate that many PCPs struggle to recognize early signs of autism, with a particularly notable lack of knowledge in less-developed areas. Most studies concluded that PCPs' understanding was insufficient ($n = 9$; 69.2%), with only a small percentage displaying adequate knowledge (23.1%). Contributing factors to this knowledge gap include outdated beliefs, misconceptions about autism symptoms (Heidgerken et al., 2005; Imran et al., 2011; Khatri et al., 2011; Rahbar et al., 2011), insufficient resources (Unigwe et al., 2017), limited autism-specific training (Lian et al., 2003; Zerbo et al., 2015), and low participation in autism-related education programs (Haider & Shehzad, 2015). The lower level of awareness in developing regions might not be surprising, given the comparatively lower reported prevalence of autism in some of these countries (Samadi et al., 2012), as well as the tendency to under-report the condition due to societal stigma and reluctance to place children in special education settings (Samadi et al., 2012). Moreover, the lack of information on autism and limited resources in these areas (Zeglam & Maouna, 2012; Sengupta et al., 2015) contribute to these challenges. However, even in more developed regions, studies from places such as Singapore (Lian et al., 2003) and the USA (Heidgerken et al., 2005; Zerbo et al., 2015) also found gaps in PCPs' knowledge. This is concerning, as accurate autism diagnosis requires a multidisciplinary evaluation, with clinical diagnosis based on DSM-V criteria remaining the standard (APA, 2013). However, as these criteria provide a broad framework without detailed descriptions, they leave room for considerable clinical judgment (Barbaresi et al., 2006). While screening tools are available and effective (e.g., Johnson & Myers, 2007), they do not guarantee perfect diagnosis, and it is crucial for PCPs to recognize when screening for autism is warranted. In addition to diagnostic knowledge, it is important for PCPs to be familiar with autism's broader symptomology, including sensory sensitivities, to provide appropriate care in healthcare settings (Olejnik, 2004). Educated PCPs are better equipped to adjust their clinical environment to facilitate evaluation for individuals with autism (Venkat et al., 2012). Clearly, further research is needed to address these gaps in knowledge.

Another concerning finding from this review is the lack of research on PCPs' awareness of EBIs for autism. Since PCPs are viewed by parents as a vital source of information on treatment options (Williams et al., 2012), it is troubling that only one study found adequate knowledge of EBIs (20%; Golnik et al., 2009), while others reported inadequate (20%; Haider & Shehzad, 2015) or mixed knowledge (60%; Garg et al., 2014; Imran et al., 2011; Özçelik et al., 2015). On a positive note,

one study found that PCPs were able to recognize and recommend Applied Behavior Analysis (ABA), an established EBI for autism (Wong et al., 2015) (Golnik et al., 2009). However, PCPs in other studies exhibited uncertainty regarding the effectiveness of early intervention programs (Garg et al., 2014; Imran et al., 2011), and several misconceptions about treatments persisted, such as 35.6% of PCPs believing dietary interventions were appropriate, and 26.3% of pediatricians erroneously endorsing hyperbaric oxygen treatment (Özçelik et al., 2015). These misconceptions must be addressed. Research has shown that many parents turn to alternative therapies for autism (Green et al., 2006), sometimes based on recommendations from their doctors. With the internet providing an overwhelming amount of information about autism treatments, parents may present unverified therapies to PCPs, complicating treatment decisions (Barbaresi et al., 2006). This gap in knowledge about EBIs may help perpetuate the use of pseudoscientific treatments, underscoring the need for educational interventions and support for healthcare professionals. Further research is essential to develop and assess curricula that address these knowledge gaps.

On a more positive note, the review does suggest that effective interventions to improve PCPs' knowledge of autism exist. Although relatively few intervention studies were identified, most were conducted in the USA (66%). These interventions took various forms, including autism screening programs, workshop training (Eray & Murat, 2017), lectures, case discussions (Bordini et al., 2015), and Autism Case Training involving learning goals, case studies, handouts, and videos (Major et al., 2013). In all but one study (Bauer et al., 2015), these interventions successfully improved PCPs' knowledge of autism. While Bauer et al. (2015) did not observe improvements in knowledge, their intervention did enhance the usage and accuracy of autism screening tools. Notably, two studies reported that PCPs had positive reactions to the interventions (Bordini et al., 2015; Major et al., 2013). These findings suggest that even short training programs (ranging from one to three hours) can significantly enhance PCPs' knowledge (Bordini et al., 2015; Carbone et al., 2016; Eray & Murat, 2017). Furthermore, studies involving autism screening programs led to improved knowledge and increased self-efficacy in treating the condition (Carbone et al., 2016; Warren et al., 2009). However, there remains a need for more research in developing countries, where training opportunities are more limited (Sengupta et al., 2015) and cultural beliefs about autism may differ significantly (e.g., beliefs in witchcraft or supernatural causes; Gona et al., 2015). Additionally, there is a lack of consistency in the content of training programs, making it difficult to compare results and assess which programs are most effective. Future research could focus on comparing training programs to identify the most effective approach and investigate the cost and optimal duration of these programs, as these factors will influence their adoption.

Limitations

Despite the thorough search strategy and the use of the QATSDD to evaluate the methodological quality of the studies included, several limitations should be acknowledged. First, the review focused exclusively on the knowledge of primary care providers (PCPs), which could be seen as restrictive, as other professionals such as psychologists and speech therapists also play key roles in the treatment and management of autism across the lifespan. However, since PCPs are often the initial point of contact for parents concerned about their child's development, their knowledge and support remain critical. Future studies might expand the scope to include a broader range of professionals who diagnose or provide care for individuals with autism and their families. Second, the classification of knowledge as adequate, inadequate, or mixed based on the authors' reports may be subject to bias, as it depends on the data presented and may be influenced by selective reporting. Despite this, such a categorization was necessary for synthesizing the diverse measures

and findings across studies. Third, the decision to include only English-language studies could be viewed as a limitation, though English is generally considered the global language of scientific research, and no significant number of non-English studies were found during the search. Fourth, the omission of gray literature may also be noted as a limitation, but the lack of standard methods for identifying gray literature and concerns about its quality made its exclusion a reasonable choice in this review. Fifth, the geographical scope of the studies included should be considered when interpreting the findings, as the studies come from both developed and developing countries. While this inclusion was justifiable given the limited amount of relevant research, future reviews focusing on specific regions could offer more representative insights. Lastly, the QATSDD scores were presented to help readers assess the methodological quality of the studies rather than as a factor in determining study inclusion or exclusion. This approach, while debatable, was deemed appropriate given the small number of studies available.

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