

# Research on the Culture and Awareness of Autism

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**Abstract.** Autism is a form of disorder having high prevalent rate in more than 80 nations globally, and there have been few studies that examine this disorder from a cultural perspective. In this literature review, an overview of autism's awareness and culture, citing relevant instances from both advanced and less advanced nations is provided. From the result, it was discovered that ASD are expressed in diverse ways based on various cultures. The level of understanding and perception of caregivers about ASD are influenced by demographic factors such as social economic status, gender, and educational level. Notwithstanding, these factors appear to impact residents of advanced nations since they not only already have a system that is stable and complete but also have legislation for ASD. Contrastingly, individuals residing in developing nations that are witnessing resource imbalance, likewise encounter relative lack of ASD perception, screening and diagnosis. To provide relatively affordable and accessible service to children suffering from ASD across the globe, it is necessary to intensify effort in the future.

**Keywords:** Autism; Culture and Awareness; Resource Imbalance.

## 1. Introduction

This literature review explores the global relationship between culture and awareness of autism, comparing recognition differences across various cultural backgrounds. It is divided into two parts: the importance of a global perspective in studying autism, and ASD awareness in different countries. Autism, or Autism Spectrum Disorder (ASD), is a complex developmental disorder characterized by communication and behavioral challenges. Symptoms vary widely, including difficulties in communication, understanding others' thoughts and feelings, and uneven skill development. Early diagnosis is crucial, as ASD affects approximately 1 in 36 children, with boys being four times more likely to be diagnosed than girls. Despite its prevalence, awareness and resources for ASD vary globally.

Cultural differences play a significant role in ASD recognition and understanding. Research predominantly focuses on developed countries, leading to a lack of knowledge about ASD in diverse cultural contexts. Moreover, disparities exist in access to resources and diagnostic tools, particularly in low- and middle-income countries. Cultural adaptation is essential in research and diagnosis. It involves linguistic and contextual adjustments to ensure cultural relevance. However, adaptation requires resources and training, posing challenges for low-SES countries. Cultural differences manifest in the expression, recognition, interpretation, and reporting of ASD symptoms. These differences influence when parents raise concerns about their child's development, how symptoms are interpreted, and explanations for ASD causes. Stigma surrounding ASD also affects help-seeking behavior, with barriers including affordability, availability, geographical accessibility, and cultural factors.

## **2. Culture and Awareness About Asd**

### **2.1. Awareness and Knowledge of Autism and Autism Intervention in Developed Countries (The Northern Ireland)**

The prevalence rate of autism has increased significantly in past few decades, as Williams, Higgins and Brayne (2006) reported the prevalence rate between 1979 and 2006 was 1 in 500 approximately, then Elsabbagh et al. (2012) reported the prevalence rate between 2000 and 2012 was 1 in 161, and then this rate increased to 1 in 50 (CDC, 2013), therefore, educating the public about ASD and raising awareness has been focus of many developed countries like the U.S. and the UK. Millions of dollars, pounds were investigated into campaigns and charities. Internationally, legislations even were introduced to raise public awareness and help disabilities, for example, the Combating Autism Act of 2006 in the U.S., the Autism Act of 2006 in UK and the Autism Act (NI) in 2011 in Northern Ireland (Dillenburger et al., 2013). Taking Northern Ireland as an example, though Act and autism related law were introduced, millions of pounds were also invested in autism awareness campaign, there was only one study talking about ASD awareness prior to those actions. It was study conducted in 2008, Stewart investigated 500 Northern Irish from the public and asked them about basic ASD background information, the results showed that 90% of them didn't know how common ASD was; 48% of them had inappropriate misconceptions of ASD; one similar study did in UK in 2007 (NAS, 2007), 92% of the total 2000 participants reported they have heard of Autism, but only 39% of them knew autistic people may have special abilities like Asperger Syndrome, and the awareness about ASD core symptoms was quite low. Dillenburger et al. (2013) therefore conducted a study in North Ireland with expanded knowledge to learn about public awareness of ASD.

This study compromised 1204 participants aged over 18 years old, they went through two sections, first one was a face-to-face interview, and the second one was a self-completion, the results showed about 82% of participants reported they heard about autism or Asperger Syndrome, while only 16% said they were unaware and 2% of them reported not sure. For the demographic information, non-minorities (main population in Northern Ireland is white Caucasian) who have heard about autism were 12 times greater than ethnic minorities (non-Caucasians); higher level of education background and using Internet in spare time also predicted higher level of ASD awareness; the odds of females who heard of autism were 2 times comparing to males. Among people who heard of autism, only 20% of them heard about the Autism Act in Northern Ireland. This study also asked participants about strengths and challenges that autistic group would have, the strengths of autistic people that participated answered included being intelligent, having a special talent, good memory, creative and good at art, music and math. For the "challenge" part, participants had mentioned correctly of core symptoms of ASD including communication, behavioral and interaction difficulties, they identified that autistic people would have deficit in understanding others' feelings, in adapting to daily routine change, and they felt hard to be independent and integrate with societies. Estimation of autism prevalence was another part of questionnaires, most people in the study who reported they had heard about ASD either underestimated the prevalence rate as 1 in 1000 (37%), or 1 in 10000 (10%), or they said they were not unaware (15%). Results showed this also related to demographic factors like gender level and age: the possibilities of females guessing approximate prevalence rate were 1.7 times greater than males, and people who were between 18-24 years old were more likely to know more knowledge about ASD comparing to age group between 55-64. However, for those who already reported a low awareness of autism legislation, female participants and 18-24-year-old participants still reported low level of autism knowledge about prevalence rate.

To conclude, 82% of total participants reported they had heard about ASD, this was a relative high rate of awareness. What's more important, they found autism awareness varied across demographic factors: to be more specific, low awareness of autism knowledge was related to being male, lower educational level, not using internet and being ethnic minorities. Among non-Northern Irish participants, half of them reported they didn't hear about ASD, the possible guess maybe translation

problem for those people that English was not their first language, or other cultural and societal influences that waiting for further researches.

## **2.2. Significant Racial /Ethnic Disparities Exist in the Recognition of Autism. (White Children VS Other Group Children)**

Existential evidences have showed that ASDs are usually misdiagnosed or diagnosed after several years since onset of symptoms (1-3), the delayed diagnosis may attribute to lack professional screening systems, parents' slow response and low awareness of symptoms. The reason for misdiagnosis may explained by similarities of ASD and other neurodevelopmental disorders, for example, repetitive behaviors can both exist in ASD and obsessive compulsive disorder (20-21), hyperactivity and other behavior problems in ASD can also be explained by attention deficit hyperactivity disorder (18-19). Moreover, as 50% - 60% of ASD individuals present intellectual disabilities, their primary diagnosis is easily to misdiagnosed as "intellectual disabled" instead of autism (22). Researches also showed misdiagnosis had racial differences, as Mandell et al. (25) found that Black ASD children were more likely to be diagnosed as conduct disorder or adjustment disorder comparing to white people (26). The limitation of these researches was only ASD children had diagnosis records participate, those autistic children who meet criteria but didn't get certain identification from clinics were excluded from researches. Getting accurate estimates of ethnic and racial disparities in ASD recognition is quite important, as if autistic children are continuing misdiagnosed, screening programs could ameliorate to adapt racial differences, and improve diagnosis precision. Based on previous researches, Mandell et al. (2009) therefore to conduct a similar study with improved methods, and the hypothesis was Black and Hispanic autistic children who meet diagnostic criteria are less likely to be identified, comparing to white group ASD children.

This study surveyed 2568 participants living the U.S., they were all 8-year old children met diagnostic criteria, professional clinicians were provided to review again—whether or not participants already had qualified confirmed results, they came from 8 racial groups included American Indian / Alaska Native; Asian, Black or African American and so on. After data analysis about their race and documented ASD record, researchers found that only 58% of them have documented result, Black children group was most likely to be diagnosed as intellectual disabled instead of ASD, Hispanic group, and other non-white racial group were also less likely to get a documented diagnosis result. For those children whose IQ were unknown, maternal education became an indicator, and results showed higher level of maternal education predicts higher probability to get a documented ASD result. To conclude, the hypothesis about racial disparities and ASD identification was supported, for Hispanic and Asian group of ASD children, they were most likely be missed due to co-occurring intellectual disabilities, who accounting for two fifth of whole participants. This result therefore is significant to remind the improvement of strategies that may help to identify overlooked ASD children.

## **2.3. Public Knowledge and Stigma of ASD Leading to Awareness Disparities in Different Countries. (U.S. VS China)**

There are great differences between autism in China and Western countries, in terms of prevalence, number of patients, education opportunities, and life outcomes of people who have ASD (Yu, Stronach, & Harrison, 2020). One of the main reasons of these disparities is public awareness, lacking awareness also leads to autism stigma include symptoms, comorbid impairments, and after-intervention prediction. Therefore, Yu, Stronach, & Harrison's research targeted at the comparison between public knowledge and stigma of ASD in China and the United States (2020). The prevalence rate of autism in the U.S. is 1:59 by 2014 (Baio et al., 2018), while the prevalence in China is quite lower in history, changing from 1 in 255(Wang et al., 2018) to 1 in 1205 (Jin et al., 2018). It is obvious that China's prevalence rate is seriously underestimated, as this is a country hosting one fifth of the whole world's population. Though China already reported less amount of ASD patients, according to Xiong & Sun's research on nine Chinese provinces the regular school enrollment rate for autistic

children is only 7.23% (2014); while 91% of American autistic children could go to regular school and one third of them may go to college (Shattuck et al., 2012). As talked above, lacking awareness is one important reason, according to Wang et al.'s study on northeast China, only 57.8% of parents could distinguish at least three ASD symptoms (2012), Liu et al (2016) also did a similar study to test background knowledge but mainly towards preschool teachers, 83 of these teachers (N=471) could not answer half of the questions correctly. Besides parents and preschool teachers that seem like amateurs, there is a great shortage of professional intervention providers in China, by the end of 2019, there is only 25 Board-Certificate Behavior Analysts (BCBA s) in Mainland China (Behavior Analyst Certification Board, 2019), comparing to 16000 BCBA s in the U.S. (Deochand & Fuqua, 2016). Shortage of teachers has been lasted for a long time, moreover, the corresponding supportive policies of institution and resource allocation still lack proper handling (Wu Cai Lu Autism Research Institute, 2017).

Misconceptions and stigma of autism are major barriers of low awareness and deficiency of professional diagnosis and intervention service. Denial of the illness or unwillingness to take ASD children to get diagnosis is caused of misconceptions or lack of knowledge, as surveys showed that only 9% of Chinese parents would choose to seek help at first time when they noticed their children have atypical symptoms (Sun et al., 2015), while 80% of parents choose to wait and observe if their children could be back on track (Huang et al., 2013). Lacking proper understanding of autism also leads to discrimination, knowledge deficiency and stigma seem to mutually reinforced. To sum up, increasing public awareness and popularize knowledge is urgent in China to improve life quality of autistic people.

Yu, Stronach, & Harrison therefore (2020) aimed to compare the U.S. and China, the U.S. has become the global leader in autism research and developed relatively complete protective policies for autistic people, however China left behind in this aspect, though it has the greatest population and economic growth. The comparison between these two countries would not only focus on prevalence rate, education opportunities, intervention resources, but also provide evidence of cultural differences in ASD knowledge that can be generalized. Researchers adopted a questionnaire called Autism Stigma and Knowledge Questionnaire (ASK-Q) that can be used in cross cultural contexts, four subscales are included: diagnosis / symptoms, etiology, treatment, and stigma that provide more information about ASD knowledge construct (Harrison, Bradshaw et al., 2017). About 1254 Chinese participants did the research through online survey link, and 1127 U.S. sample were collected through either Amazon Mechanical Turk or in- person interview, what's need to emphasize was the Chinese translated version followed a strict translation-back-translation process to fit the culture best (Guillemin et al., 1993). After careful data analysis, the general results showed 90% of the U.S. surveyed population had proper knowledge about autism in diagnosis / symptoms, etiology and treatment domains, nevertheless for Chinese participants, only 60% of them reached the standards, which means 40% of Chinese participants had stigma towards ASD to different extent. For specific ASD knowledge deficits comparison between Chinese and American, both Chinese (55% of them) and U.S.(14%) citizens had misconceptions that ASD is psychosocial disorder like depression, most Chinese participants also thought that ASD children were intellectually disabled (57%) and their daily life must depend on parents or others (64%), while the fact is 70% of ASD children have normal IQ (Baio et al., 2018). Comparatively, the U.S. sample had significant less stigma toward ASD due to knowledge deficits on each aspect, it seemed like autism in China has been personally narrowed to include people with severely disabilities and low IQ, which causing Chinese people have serious misconceptions, low quality of rehabilitation service that did not provide ASD children positive results may also a factor. Moreover, Chinese (44%) and American participants (39%) all reported wrong response about medication could be helpful for ASD core symptoms, while the fact is until now there is no Food and Drug Administration (FDA) approved for ASD treatment (Yu, Stronach, & Harrison, 2020), so this misunderstanding exists in both China and the U.S.. This research also highlighted sociodemographic factors related to stigma with ASD, these factors included gender, public education, information source and SES, and results showed the surveyed factors were closely

related to Chinese participants' ASD knowledge and stigma. In comparison, the U.S. data in every sociodemographic subgroup showed equivalent knowledge, which illustrated a great cultural influence on ASD knowledge and stigma. For gender aspect, the male participants in China had more stigma on autism comparing to females, however, no gender difference of ASD stigma was found in U.S. sample which already had more male participants than China. Cultural differences were proved again as China was a male-dominated country previously, males still have gender advantage even in the new era, they focused on more achievements instead of sympathy on disabilities. For public education aspect, in China, main reasons of low knowledge and stigma towards ASD included not knowing autistic people or not being a parent, but for the U.S. sample, being connected to autistic people or parenting experience did not contribute extra help to ASD knowledge, which reflecting the public awareness in China was weak unless they had personal experience with autistic people. For information source aspect, according to the research results, three major sources related to ASD stigma in China were TV shows / movies, Internet, TV news, while the U.S. citizen benefit equally from various information sources. Even though the report about ASD increased in past decades, the content of them need great improvement and enrichment. According to all Chinese news topics in 2019, reports of "public awareness" achieved the top amount (57%), which far more than other keywords about intervention agency and ASD related policies, moreover, the existing Chinese reports about ASD were short and superficial, most of the public awareness related news were written on Children's Day or Autism Awareness Day (Yu, Stronach, & Harrison, 2020). Therefore, for Chinese, acquiring professional and helpful knowledge from media is quite difficult. Lastly, SES was an important factor influencing Chinese participants' ASD knowledge level, as high SES people also had adequate knowledge and less stigma, while the SES effect was minimal in U.S. samples. To conclude, after comparing the U.S. and China from cross-cultural context, significant differences were found in many aspects, and generally speaking, the U.S. citizen had higher knowledge level on ASD and less stigma, and Chinese citizens had lower public awareness level and were more easily to have misconceptions about ASD.

#### **2.4. Gaps Exist in Awareness and Knowledge of Autism among Pharmacists (In Palestinian).**

As a developing country, there are gaps existing in awareness and knowledge between pharmacists across Palestinian, the intervention service is not as prevalent and available as developed in Palestinian, instead, pharmacists are the group of people that public relied on most. Though autism has no cure, pharmacotherapy is increasing popular to alleviate ASD related symptoms like aggressiveness, anxiety and hyperactivity (Kaplan & McCracken, 2012). Nowadays, pharmacists not only simply dispense medicine, but also responsible for maximizing the effectiveness and benefit of medication to alleviate symptoms. Different from other disorders, autism is not that familiar for pharmacists, as they usually lack opportunities to interact with autistic people. As a result, increasing pharmacists' awareness is necessary to help guide autistic families to professional resource. However, in previous studies, pharmacists seemed like lacking awareness and knowledge of ASD. In Khanna and Jariwala's reports, Mississippi pharmacists showed gaps in knowledge and awareness on ASD (2012), another similar study in Mississippi that surveyed pharmacy students also reported they were less familiar to ASD theories (Khanna et al., 2014), moreover, one study did in Turkey to investigate Istanbul pharmacists about attitude, awareness and knowledge about ASD, and they were likely to believe outdated theories (Luleci et al., 2016). In order to know about pharmacists' awareness in Palestine, Shawahna et al. (2017) conducted a research that included 420 licensed pharmacists out of 3000 in total, most of the participants did in-person interview and finished 4-sections questionnaires. Sections of questionnaires included demographic information like age, job title, degrees; and then the measurement of pharmacists' knowledge about ASD etiology, diagnosis, treatment and so on. For the **familiarity of Pharmacists with Symptoms, Treatment, and Community Resources of ASDs** section, 50% of the participated pharmacists reported low familiarity of ASD symptoms, and 54% of them of didn't know about medical use in ASD and its side effects. What's more, 57% of the sample were less confident to use information source and help guide autistic children families, over 69% of pharmacists reported low familiarities to local resources about ASD; for the **Knowledge of**

**Pharmacists of Etiology, Prevalence, and Treatment of ASDs** section, pharmacists had high awareness in some aspects like “children with ASDs have impairments in social interaction, communication or languages, and behavior development”, the role of gene in ASD, and Vaccines didn't cause ASD, however, others questions like ASD are not caused by improper parenting and ASD are not curable got poor response, few of participants were less familiar of them; for the **Training and Confidence of Pharmacists in Medication Management of ASDs** section, 62% of them reported that they were not confident about guiding parents for medication about their ASD children, as they were unable to either provide professional treatment method or explain side effects of medication, they were also felt unconfident to dispense medicine to ASD patients. Though most of them were not familiar with ASD knowledge, they agreed they would benefit if training courses about autism are provided, and 89% of them hoped to include ASD lectures in future pharmacy curricula.

In comparison, when asking about whether ASD is curable, 67% of Istanbul pharmacists either said yes or not sure (Luleci et al., 2016), while the Palestine data in this study was 73% of them said ASD is curable, and only 3.6% of Mississippi pharmacist believed this (Khanna et al, 2014). Moreover, as 55% of Palestine pharmacists in this study reported they were not familiar about ASD knowledge, and only 25% Mississippi samples reported this, which illustrated differences between countries. To conclude, results in this research highlighted the necessities to increase educational interventions, pharmacists as well as public should increase their awareness and knowledge to maximize the help to ASD individuals.

### 3. Conclusion

In summary, autism spectrum disorder (ASD) is a global condition with a high prevalence rate of 1 in 59. While not as immediately life-threatening as cancer or AIDS, individuals with autism and their families require urgent support. Many autistic individuals face challenges in communication and understanding social cues, often requiring professional interventions to facilitate expression and learning. Some may also experience intellectual disabilities, hindering their ability to live independently. Educating the public about ASD is crucial not only for supporting affected individuals but also for dispelling misconceptions and stigma surrounding the condition.

Despite the presence of national organizations for autism in over 80 countries, there remains a global disparity in understanding and services for individuals with ASD. Most research on ASD is based in developed countries, leaving a gap in knowledge and resources for low- and middle-income countries. Additionally, cultural adaptation is essential, particularly in non-English-speaking regions, to ensure diagnostic tools are relevant and effective across diverse populations. While cultural adaptations can enhance research efficiency and accuracy, they require time and resources, posing challenges for less economically developed countries.

The presentation of ASD symptoms may vary across cultures, impacting expression, recognition, interpretation, and reporting. Demographic factors such as gender, socioeconomic status, and education level also influence outcomes. Developed countries generally have comprehensive support systems and anti-discrimination legislation for individuals with ASD, whereas less developed countries often lack such infrastructure and awareness. This results in lower rates of diagnosis and increased misunderstanding of autism, affecting individuals' access to education, employment, and overall development.

In a global context, developed countries should prioritize allocating resources to support ASD initiatives in less developed regions and provide research opportunities for these areas. Less developed countries, meanwhile, must focus on raising public awareness as a crucial first step in the diagnosis process. Additionally, developing culturally adapted screening tools can make diagnosis more accessible and affordable for local populations, benefiting affected individuals and their families.

#### 4. Limitation and Future Directions

In the whole literature review, several limitations are evident. Firstly, there is a notable lack of generalization. As previously indicated, the bulk of autism-related research is conducted in Western, high-income countries. While this review includes examples from some developing nations such as China and Palestine, these examples are insufficient in providing a truly global perspective. Many low socioeconomic status (SES) countries and their respective cultures remain underrepresented.

Another limitation lies in the superficial treatment of certain aspects. For instance, variations in ASD identification among racial groups—where Black and Hispanic autistic children are more prone to misdiagnosis compared to their White counterparts—are not adequately explored. In addition to external factors such as limited screening resources and a scarcity of professional clinicians, a deeper examination of genetic underpinnings is warranted. This necessitates a more rigorous application of scientific principles.

Furthermore, the concept of culture is multifaceted and challenging to dissect. Discussing autism disorder within a global, cross-cultural framework requires an abundance of examples, given the impossibility of comprehensively addressing the influence of every culture and its language on ASD. Hence, a more focused and refined approach to the concept of culture may be necessary.

In terms of future directions and improvements, numerous questions and deficiencies emerge from this literature review. Despite relatively high public awareness of ASD in countries such as the U.S. and UK, there remains a significant population of overlooked ASD children who are unable to access assistance. Addressing this global challenge entails the integration of resources on a global scale. Furthermore, future research should aim to fill the gap in ASD studies across various racial and cultural backgrounds, as well as non-English-speaking regions. Such endeavors not only advance scientific understanding but also contribute to local awareness and knowledge dissemination, thereby benefiting autistic families worldwide.

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