

ADHD UPDATE

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Cultural Disparities in the Diagnosis and Treatment of Childhood ADHD



INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common disorders diagnosed in children. Research indicates that ADHD exists in multiple countries including various cultures and ethnic groups, and is not simply a product of Western industrialized societies.¹ Evidence suggests that children of ethnic minority status with ADHD are not identified or treated for this disorder to the same extent as nonminority children.² Cultural disparities present obstacles to the recognition and treatment of ADHD; obstacles include lack of knowledge, language barriers, fear of social stigma, and the financial burden of treatment.^{3,4}

Parents of children with ADHD often lack information or are misinformed about the signs of this disorder.⁴ The perception of ADHD symptoms among parents of minority children appears to differ from those of parents of nonminority children.⁴ Even when parents of minority children recognize the signs of ADHD, they may be reluctant or unable to discuss them with a health care professional.⁴ Inadequate financial resources among some minority families may further inhibit their ability to seek treatment.^{3,4} Greater effort toward recognizing, diagnosing, and treating ADHD in minority children is needed, which can be accomplished in part through increased cultural competence by clinicians. Cultural competence in the context of ADHD involves an understanding of cultural norms and values specific to ethnic and minority groups, including how different cultures perceive and approach mental health disorders.^{3,4} Developing culturally sensitive practices can help reduce barriers to effective treatment utilization.

This newsletter will explore cultural disparities and barriers to treatment for African-American patients and Hispanic patients with ADHD, and provide clinicians with tools to increase cultural competence in the clinical practice setting.

PREVALENCE OF ADHD IN THE GENERAL POPULATION AND MINORITIES

ADHD, a common childhood disorder that is frequently brought to the attention of physicians and psychologists by both parents and teachers, occurs in an estimated 7% of children aged 3 to 17 years.⁵ The prevalence of ADHD in African-American children is thought to be similar to that among the general population; however, fewer African Americans are diagnosed with and treated for ADHD.² According to the US Department of Health and Human Services, ADHD is the most prevalent mental health diagnosis, compared with mood disorder, adjustment disorder, and post-traumatic stress disorder (PTSD).⁶ Although estimates of ADHD prevalence are similar for Caucasian and African-American children, evidence suggests that Caucasian children receive an evaluation, obtain an ADHD diagnosis, or undergo treatment at a rate that is more than twice the rate of African-American children.⁷ Hillemeier and colleagues contend that measures used to identify the need for treatment must be equivalent between Caucasian and African-American populations in order to accurately compare the prevalence of ADHD in these 2 populations.⁸

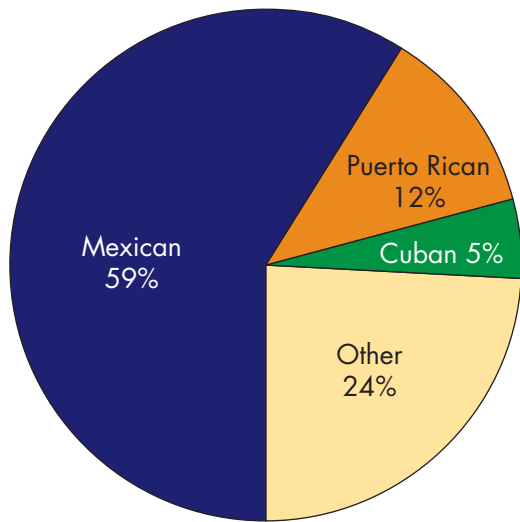


Figure 1. Distribution of Hispanic groups residing in the United States.⁶ [Permission to be requested]

In the United States, Hispanics constitute 15% of the total population and are the fastest-growing minority group.⁹ Hispanics represent a diverse group of cultures and national origins that include, but are not limited to, Mexico, Puerto Rico, Central and South America, and Cuba (**Figure 1**).¹⁰ Approximately 1 in 3 children in the United States is Hispanic,¹¹ which makes it highly likely that physicians will encounter Hispanic children in their practice. It has been reported that Hispanic children are at high risk for behavioral and developmental disorders, although many questions related to their mental health needs and use of services are unanswered.¹² Since few population-based studies have been performed, epidemiologic data on the prevalence of ADHD in the Hispanic population are lacking.¹⁰ Results of the National Health Interview Survey showed that the prevalence of ADHD in Hispanic males is 3.06%.¹³

ETHNIC/RACIAL DISPARITIES IN DIAGNOSIS AND TREATMENT OF ADHD

Findings from school-based samples indicate that rates of ADHD diagnosis are lower among ethnic minorities. According to data from the 1997–2000 Medical Expenditure Panel Survey (MEPS), white American children are more likely to be diagnosed with ADHD than African-American and Hispanic children (**Table 1**).¹⁴ A sample of more than 6000 children showed that only 4.0% of Hispanic children were likely to have been diagnosed with ADHD, compared with 9.1% of African-American children and 10.8% of Caucasian children.¹⁵ Specific behavior patterns in the Hispanic culture, however, may place Hispanic children at risk for overdiagnosis of ADHD.¹⁶ These patterns include organization of activities in a circular fashion, in which many things are done in one unit of time (polychronic culture). In this type of culture, schedules and punctuality are unimportant and Hispanic children may be at a greater risk of being seen as impulsive or inattentive.

Table 1. Children Aged 3-18 Years With ADHD.¹¹

Ethnicity	Sample Size (n) ^a	Diagnosed With ADHD (%) ^b
White American	748	5.1 ^c
African American	136	2.1
Hispanic American	177	1.8

^aUnweighted sample size included in the 1997–2000 Medical Expenditure Panel Survey (MEPS).

^bWeighted percentage of children with ADHD.

^cGroup difference was statistically significant (P<0.05).

Treatment trends of ADHD in ethnic minority children are similar to diagnostic trends. Although there was a significant increase in the overall rate of outpatient treatment of childhood ADHD between 1987 and 1997, Caucasian children were more than twice as likely as African-American and Hispanic children to receive treatment.¹⁷

THE RACIAL AND CULTURAL CONTEXT OF ADHD

Although ADHD exists worldwide, cultural factors may influence the manifestations of this disorder across cultures. Indeed, varying degrees of acculturation—the extent to which a person is familiar and proficient within a different culture—play an important role in mothers’ perceptions of ADHD-related behaviors¹⁸ and affect the extent to which parents recognize and seek treatment for a particular disorder such as ADHD. In a study that examined differences in parental evaluations of ADHD-related child behaviors, mothers from different Latino cultures and at different levels of acculturation had varying assessments of certain symptoms of ADHD.¹⁸ For example, Mexican mothers were less likely than Mexican-American and Puerto Rican mothers to report that their child was impulsive, whereas Puerto Rican mothers were more likely than Mexican and Mexican-American mothers to report that their child was restless.

A qualitative study consisting of telephone interviews was conducted to explore how African-American parents in low-income, urban communities dealt with their child’s disruptive or inattentive behaviors that ultimately led to their child’s diagnosis of ADHD.¹⁹ Results highlighted that parents went through an extensive process to identify their child’s problems and patterns emerged in how parents came to terms with their child’s ADHD. Clinician awareness of how ethnic and minority families decide to seek care for a child with ADHD symptoms can help provide insight into engaging such families sooner in the treatment process.

In Caucasian children, ADHD-associated behavioral and learning difficulties are often viewed within a medical and research model. In minority children, these difficulties are more likely to be stereotyped and viewed as related to poverty, violence, and lower educational opportunities.²⁰ One study explored how Hispanic parents managed their child’s ADHD within the sociocultural context of their everyday lives. Parents reported that in the Hispanic culture, Mexican culture, or “my second culture,” parents were expected to “handle the children” and there was a tendency to “blame the parents for a lack of discipline” rather than viewing ADHD as a mental health problem.²¹

CULTURAL DISPARITIES AND ADHD

Numerous disparities exist that impede the mental health care of ethnic minorities. Seeking and receiving treatment for a mental health disorder like ADHD can be a complex process that is influenced by a combination of access barriers and individual, cultural, and societal factors. For ethnic minorities, these factors include attitudes and perceptions about mental health care, language barriers, parental knowledge about ADHD, general access to treatment, and cost of treatment.

Communication Barriers

Throughout the United States, communication barriers between doctors and patients who are not fluent in English are major obstacles to providing quality medical care. Studies suggest that limited proficiency in English is associated with a substantial reduction in both access to care and quality of services rendered.^{22,23} Nearly a quarter of Hispanics in the United States are “linguistically isolated,” that is, those aged 14 years or over do not speak only English, and most of those who speak a language

other than English do not speak English “very well.”²³ English-language proficiency, which may differ markedly among Hispanic subgroups, is a factor known to influence health outcomes.¹⁰ Language barriers may interfere with a parent’s or caregiver’s ability to report their child’s ADHD symptoms to the patient’s primary care physician.

A study committee of the Institute of Medicine (IOM), which assessed the extent of racial and ethnic disparities in health care, reported that linguistic barriers (eg, the lack of interpretation services for patients with limited English proficiency) are sources of health care disparities for minority patients.²⁴ Because of fundamental language barriers, some minority parents may not have an understanding of the meanings of terms such as “hyperactivity” and “inattentive.” Strategies to help improve health care for children with ADHD in Hispanic populations must therefore include the availability of Spanish-speaking professionals in primary care sites that serve Hispanic populations and/or a medical interpreter.

Social Stigmatization

The stigma of a mental health disorder is problematic for many adults, and even more so for children. Attitudes and beliefs about mental health issues vary from culture to culture, and have a direct effect on whether parents will seek mental health services for their child. It is not uncommon for parents to recoil with “My child is not crazy!” when confronted with the suggestion that their child should undergo a psychiatric evaluation for behaviors characteristic of ADHD. In many cultures, going to a psychiatrist or taking medications is often stigmatized and may be viewed as shameful. The National Stigma Study-Children, a 4-part study that evaluated, among other factors, public awareness and beliefs concerning ADHD, found that men, minorities, and persons with less education were less likely to recognize ADHD.²⁵ Further results of this study showed that 64% of respondents said that they had heard of ADHD, but only 46% had specific knowledge of symptoms, causes, or medications used to treat it.

Parental Knowledge of ADHD

Persons from diverse cultures vary in their beliefs about what is considered an illness or disorder, what causes the disorder, and what should be done to treat the disorder or promote healing. Information about ADHD symptoms, how to recognize ADHD, and an appreciation for both the short- and long-term effects of this disorder is lacking for many. Results of a study that examined racial/ethnic patterns of parental beliefs about the causes of child problems showed that African-American and Hispanic parents were less likely than non-Hispanic white parents to endorse etiologies consistent with biopsychosocial beliefs about mental illness.²⁶ Consequently, parents who have beliefs about their child’s mental health issues that are less consistent with biopsychosocial causes are potentially less likely to accept mental health services. In a 2-phase study that examined ADHD prevalence among children in special education programs, children whose parents had reported significant problems on the ADHD screening measures were 3 times as likely to be treated with medication for ADHD.²⁷ Furthermore, rates of medication treatment for ADHD differed markedly according to race/ethnicity (22% for whites, 9% for others; $P < 0.001$).

A large nationwide survey (*Cultural Attitudes and Perceptions About Attention Deficit Hyperactivity Disorder*), conducted online and by telephone between May and July 2002, compared the experiences, attitudes, and levels of knowledge of more than 3300 parents or caregivers with at least 1 child aged 6 to 17 years.²⁸ There were 3 comparison groups: African American, Hispanic, and Other (Caucasian, Native American, Asian or Pacific Islander, Mixed).

This survey covered:

- ▶ Knowledge of and familiarity with ADHD
- ▶ Personal experiences with ADHD
- ▶ Observations and opinions about ADHD
- ▶ Cultural perceptions and beliefs about ADHD
- ▶ Awareness of available treatment
- ▶ Knowledge of sources for information about ADHD

Among other findings, this survey revealed that African Americans (38%) and Hispanics (42%) were less likely than those in the Other group (47%) to report ever having received information about ADHD. The overall results of this survey suggest that parental fear of social stigma, fear of overdiagnosis, and general lack of knowledge are more likely to inhibit the diagnosis and treatment of ADHD in minority children compared with other children.

Perceptions of ADHD-related symptoms among parents of African-American children appear to differ from those of parents of Caucasian children, according to a study that examined differences among African-American and Caucasian children in ADHD symptom measurement using the parental report instrument the Diagnostic Interview Schedule for Children (DISC).⁸ To better understand perceptions of ADHD among African-American parents, researchers conducted 5 focus groups in inner-city Baltimore and the Washington, DC, metropolitan areas.²⁹ Among the responses in this analysis, participants:

- ▶ Felt that behavior issues accompanying ADHD were caused by inappropriate parenting and disciplinary practices
- ▶ Viewed the diagnosis of ADHD as a label applied with racial inequality to exert social control over African Americans
- ▶ Expressed distrust in physicians who were quick to make a diagnosis of ADHD and recommend medications
- ▶ Worried that medication would lead to drug addiction in adulthood
- ▶ Perceived that children were labeled with ADHD because of poor educational environments that were unresponsive to the needs of African-American children

Even if minority parents recognize symptoms of ADHD in their children, they may not be likely to seek professional help for their child. A study specifically examining help-seeking among parents of African-American, Latino, and Caucasian children indicated that African-American and Latino parents were less likely than Caucasian parents to seek help from professionals for mental health problems and were more likely to contact family members or community resources.³⁰

Access to Treatment

Lack of access to treatment, another major obstacle faced by minority patients, is closely associated with socioeconomic status and race. Low socioeconomic status affects the options that an individual has in seeking and receiving health care. Furthermore, the physiological and psychological stresses associated with poverty (eg, low-quality housing, low-paying jobs, poor nutrition, lack of health insurance) directly impact access to treatment. These factors may also exacerbate the symptoms of ADHD in children. According to 2007 statistics, US blacks and Hispanics have high poverty rates (**Figure 2**).³¹ Minority groups such as African Americans and Hispanics are disproportionately represented among the poor and among those without any health insurance in the United States. In 2007, the uninsured rates were 7.3% for non-Hispanic white children, 11.7% for Asian children, 12.2% for black children, and 20.0% for Hispanic children (**Figure 3**).³²

Lack of representation in clinical trials is another factor that affects access to treatment among minority patients. Despite the fact that increasing numbers of female and minority children are diagnosed with ADHD, research has traditionally focused on white male patients. Recruiting minority children for clinical trials remains challenging for a variety of reasons, including parents' inability to maintain their child in a study due to financial and time constraints and, often, difficulty adhering to the requirements of a clinical trial.

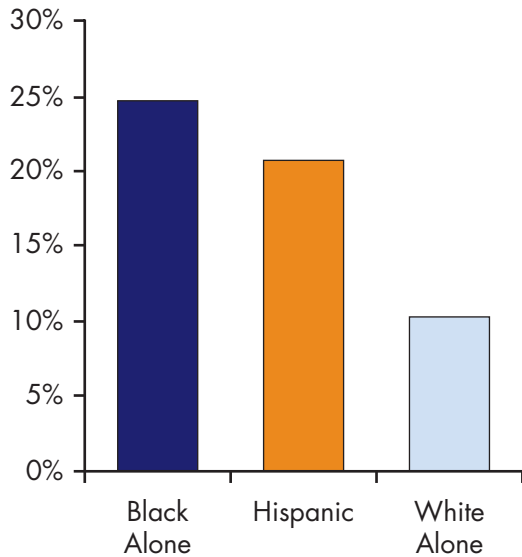


Figure 2. Poverty rates of whites and minorities in the United States—2007.²⁸

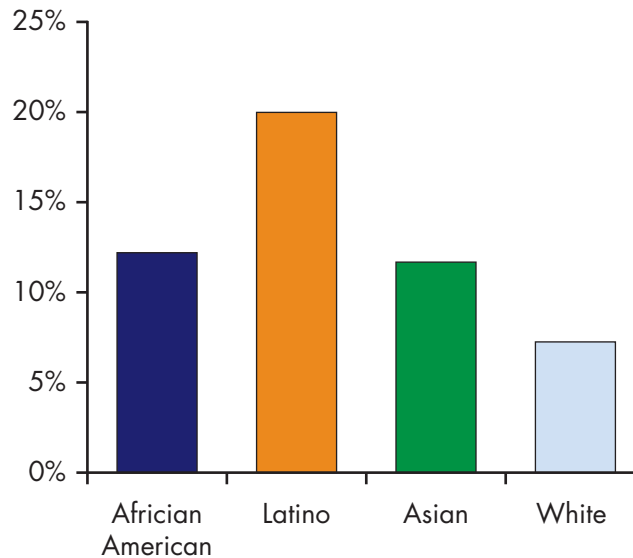


Figure 3. Children uninsured by racial/ethnic group in the United States.²⁹

THE ROLE OF CULTURE IN CHILD INTAKE ASSESSMENTS

Establishing a therapeutic alliance with patients and their families is fundamental to successful treatment outcomes. The benefits of a solid relationship between a physician and his/her patient are maximized when the physician understands and responds to the cultural and linguistic needs of their patients. For example, the task of forming a therapeutic alliance should take into account the family's readiness to cope with the possibility of their child having a disorder such as ADHD.

In order for the assessment process to be culturally sensitive, each clinical encounter should take into account the cultural context of the family and the physician. Including cultural factors throughout the intake assessment process with children communicates to the parents that presenting clinical concerns are often related to cultural experience.³³ The structure and content of assessment interactions must be understanding of the patient's and family's unique cultural experience and must be facilitated by respect for various cultures.³³ The physician must show sincere interest in the patient's race and ethnicity, seeking to explore how the patient's social and cultural system influences the symptom pattern.

It is important for the physician to allow the family to define why they are seeking treatment for their child, which is a component of establishing a therapeutic alliance between the clinician and patient. Once a dialogue is established with the family, the physician can define goals of treatment and how treatment will be carried out, aligning all of this with the family's culture.

Components of a culturally sensitive intake assessment include³⁴:

- ▶ Language – Assess patients in their primary language if possible
- ▶ Vocabulary – It is important to ensure that an individual understands the concept of what is being assessed, since ethnic/minority persons may use idiomatic terms that do not correspond with the language used in a testing instrument
- ▶ Familiarity with testing – Parents and patients may not understand testing or its uses; adequate explanation of testing and its application to the treatment plan is an important part of this process
- ▶ How the test was developed – Tests that have been developed, validated, and standardized on individuals of specific ethnic groups are of limited value in other groups; test scores may mean different things to different groups
- ▶ Level of acculturation – Variants of acculturation (eg, certain values, lifestyles, social networks) should be noted in a descriptive way without being judgmental

CULTURAL COMPETENCE AND MANAGEMENT OF ADHD

Racial/ethnic disparities in US health care have been well documented, and the field of cultural competence has emerged as one strategy to address these disparities.³⁵ Cultural competence is the ability of individuals and systems to respond respectfully and effectively to people of all cultures, races, ethnic backgrounds, sexual orientations, and faiths or religions in a way that recognizes, affirms, and values the worth of

individuals, families, tribes, and communities and protects the dignity of each.³⁶ Cultural competence became an important issue because of public health efforts to make health care services more responsive to underserved populations in rural and urban areas.³⁷ As racial, ethnic, cultural, and linguistic diversity in the United States has grown, so has the need for culturally competent clinicians who can integrate their patients' cultural needs into appropriate diagnostic and treatment decisions. Within the context of ADHD, child psychiatrists must be able to respond clinically to the expanding cultural diversity of children in need of mental health services. Moreover, developing and maintaining culturally sensitive practices is both ethical and helpful in reducing barriers to effective treatment utilization. However, achieving cultural competence can be challenging, and physicians may need assistance in eliminating health care disparities and implementing specific interventions in their practices.³⁸ Cultural competence must be viewed as an ongoing process that entails education, supervision, and experience.

Levels of knowledge, professional skills, and personal attributes are essential to providing culturally competent care to minority patients with ADHD.³⁴ Knowledge on the part of the clinician includes understanding the patients' culture, help-seeking behaviors, speech patterns, communication styles, and available resources. Professional skills include the ability to communicate accurate information, to openly discuss racial and ethnic differences/issues with families and patients, and to assess the meaning of ethnicity for individual patients. Personal attributes include empathy, acceptance of ethnic differences, and willingness to work with patients of different ethnic backgrounds. Diagnostic and treatment considerations that help facilitate culturally competent care are listed in

Table 2.^{18,34}

Table 2. Strategies for Implementing Cultural Sensitivity in the Management of Patients With ADHD.^{13,31}

- ▶ Establish a therapeutic alliance with the patient and his/her family
 - Determine the hierarchical structure of the patient's family and the degree of acculturation of different family members
 - Explain confidentiality and how it will/will not be affected by residency and immigrant status
- ▶ Take an objective stance, taking care not to form conclusions before making a diagnosis
 - Consider that behaviors from certain ethnic groups may place them at risk of overdiagnosis
 - Rely on information from multiple sources to decrease the possibility of bias
- ▶ Acknowledge differences in backgrounds that may exist between the physician and the patient's family
 - Encourage dialogue with the family about treatment concerns from a cultural perspective
- ▶ Ask questions that clearly illustrate examples of inattentiveness
 - Does the child daydream often?
 - Is the child easily distracted?
 - Does the child often lose items needed to complete tasks?
- ▶ Provide relevant examples of inappropriate behaviors across various settings (eg, home, school, play)

Table 2. (continued)

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- ▶ Provide linguistically appropriate and literacy-appropriate information in the patient's native language
 - Qualified medical interpreter should be available who is aware of language appropriateness and culture-specific health beliefs
 - ▶ Assess whether any culture-specific beliefs or attitudes are preventing diagnosis or treatment
 - Do the parents believe that sugar is causing hyperactivity in their child?
 - Are the parents afraid of using pharmacologic treatment for their child?
 - Inform the patient and parents about the consequences of untreated disease
 - ▶ Help family prioritize patient's problems and determine their expectations from treatment
 - Discuss the safety and tolerability of various treatments
 - Encourage open discussion about parental fears regarding medication
 - ▶ Consider using preprinted pamphlets to help explain aspects of ADHD
 - ▶ Consider drawing a flowchart that explains the process of treatment to the child and family
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Although racial and ethnic disparities in care are known to exist in pediatrics, results of one study suggest that pediatricians are less likely than other physicians and individuals to harbor attitudes that favor white Americans.³⁹ Furthermore, these researchers found no link between pediatricians' implicit racial attitudes and stereotypes and the quality of pediatric care.

In the clinical setting, approaches that may be used to facilitate greater cultural competence include making phone calls and home visits to the family of a patient with ADHD as a way of providing support and education and to learn more about the family's culture, becoming knowledgeable about indigenous healing resources within the patient's culture (eg, clergy, elders, folk healers), and basing interventions in highly visible areas of ethnic communities that can help identify individuals who are not currently receiving treatment or who are unaware that help is available (eg, via pamphlets or brief screenings).³⁴

CONCLUSION

ADHD is a common psychiatric disorder among children and adolescents that has received considerable public attention over the past few decades. Despite the number of patients who receive clinical services for this disorder, numerous ethnic and racial disparities exist, particularly in the African-American and Hispanic populations, rendering these populations underserved, underdiagnosed, and undertreated. Attitudes and perceptions about mental health care, language barriers, parental knowledge about ADHD, and access to and cost of treatment are among the cultural disparities that result in a

considerable level of unmet need. Clinicians who encounter ethnic and minority patients in their practices must not only recognize the cultural nuances of these groups, but fully integrate cultural sensitivity into assessing and treating patients with ADHD. Acknowledging and discussing cultural differences enhances trust and communication between physicians and families, and ultimately reduces barriers to effective treatment.

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