Sociocultural Issues in African American and Hispanic Minorities Seeking Care for Attention-Deficit/Hyperactivity Disorder

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ABSTRACT

Objective: To review the sociocultural factors that may affect the diagnosis and management of attention-deficit/hyperactivity disorder (ADHD) in African American and Hispanic minorities seen in the primary care setting in the United States.

Data Sources: Searches on MEDLINE and PubMed were conducted in April and September 2012 on ADHD and its related problems and disabilities. A general search was conducted using the terms (*attention deficit hyperactivity disorder* OR *attention deficit/hyperactivity disorder* OR *ADHD* OR *AD/HD*) AND (*ethnicity* OR *cultural* OR *culture*). Issues of particular relevance to racial and ethnic minorities utilizing health care services were researched using the string (*black* OR *African* OR *Hispanic* OR *Latino* OR *minority* OR *racial*) combined with terms relating to access, insurance, comorbidity, high-risk behavior, treatment compliance, and nonpharmacologic modalities. Searches were limited to English-language citations, and no date parameters were used. References identified as pertinent to this review were selected for citation.

Study Selection/Data Extraction: Information revealing contrasts between minorities and the US non-Hispanic white population was organized in distinct categories, such as access to medical care and insurance, cultural attitudes, and the effects of stigmatization. The authors also provide perspectives for the primary care physician from their own clinical experience.

Data Synthesis: Rates of diagnosis of in the United States are higher for non-Hispanic whites than for minorities, yet true prevalence is probably similar across racial-ethnic groups. When the stigma of mental illness is added to the challenges faced by racial/ethnic minorities or immigrant status, patients may be especially sensitive. Underuse of clinical services may reflect economic limitations on access to care, cultural attitudes toward mental illness, and the effects of real or perceived prejudice and stigmatization.

Conclusions: Primary care clinicians in the United States should seek to become more aware of cultural factors that could interfere with the recognition and management of ADHD.

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Attention-deficit/hyperactivity disorder (ADHD) is a relatively common neurobehavioral disorder characterized by hyperactivity, impulsivity, and inattention and is often accompanied by comorbid behavioral and affective disorders. The condition is rooted in genetic and biological abnormalities as well as environmental factors[1] and is generally chronic, often persisting from childhood into adulthood. Over the life span, ADHD incurs a serious burden, causing functional impairments in academic, vocational, home, and social settings if left untreated.

In the United States, the prevalence of parent-reported ADHD among children aged 4 to 17 years was estimated at 9.5% based on 2007 data, with prevalence increasing over previous years and boys being diagnosed at least twice as often as girls.[2] Although the true prevalence of ADHD is believed to be comparable across racial and ethnic groups, some reports give lower rates of diagnosis and treatment in the US African American[3–5] and Hispanic[6] populations than in the white population. One systematic review found that African American children showed more ADHD symptoms than did white children but were diagnosed less often, possibly related to parental beliefs about ADHD and poorer access to treatment.[7] This finding is consistent with data showing that ADHD diagnosis by parental report is more common among white than among Hispanic or African American populations.[8] Compared with white children, Hispanic and African-American children were significantly less likely to receive an ADHD diagnosis from kindergarten to eighth grade; the time point–specific odds of a diagnosis of ADHD peaked at third grade and declined subsequently.[9] Furthermore, Hispanic and African American children diagnosed with ADHD were less likely to be using medication than were white children diagnosed with ADHD.[9]

Attitudes and beliefs of patients and family members can complicate the diagnosis and treatment of ADHD. When caregiver and patient come from different cultures, the challenge can be even greater. Conversely, the therapeutic relationship can be facilitated by the caregiver understanding and adapting to the patient's cultural norms.

This article offers practical guidance to primary care providers on the barriers to care faced by US African American and Hispanic minorities with ADHD from 2 perspectives: (1) a review of the published literature on barriers to care for minority patients and (2) the authors' personal experiences in overcoming such barriers to improve diagnosis and treatment.

However, it must be emphasized that all patients must be approached as individuals, not as representatives of any racial or ethnic group. To make generalizations and assumptions on the basis of race or ethnicity is the very definition of stereotyping. The intent, therefore, is not to create racial-ethnic patient profiles but to bring to the attention of primary care providers that there is a likely possibility that many Hispanics and African Americans are not adequately diagnosed and treated. It is also important to note that the information provided in

Clinical Points

- Primary care clinicians should seek to become more aware of cultural factors that could interfere with the recognition and management of attention-deficit/hyperactivity disorder (ADHD), with an emphasis on understanding how societal norms for behavior can vary on the basis of culture.
- Cultural-related barriers can affect all stages of patient care starting with awareness and recognition, which are influenced by extended family, friends, and neighbors, and proceeding through stages of evaluation, diagnosis, treatment, and compliance.
- Barriers that can affect clinical outcomes in ADHD for ethnic minorities include poor access to medical care and lack of insurance, negative attitudes toward mental health conditions, and poor physician-patient communication due to lack of rapport and/or language difficulties.

this review is intended to raise issues that are of a general concern when diagnosing individuals of different racial and ethnic backgrounds; it is not intended to imply that any single factor applies to a single group.

POTENTIAL CULTURAL BARRIERS FOR MINORITIES WITH ADHD

Racial and ethnic minorities in the United States face barriers to medical care,[10] especially for mental illness.[11] However, initiatives to improve access to care and quality of care, mainly through greater insurance access and coverage, have not eliminated racial-ethnic disparities.[12–14] Racial-ethnic disparities in the rates of diagnosis and treatment of ADHD are probably multifactorial, and it may be difficult to isolate nonbiological factors related directly to race and ethnicity (eg, prejudice against the patient's race or patient's own cultural reticence about seeing a physician, especially for a mental health problem) from factors related to the economic hardships often experienced by racial-ethnic minorities (eg, lack of adequate medical insurance, lack of access to medical care, inability to pay for medication/doctor visit) and environmental factors (eg, prevalent crime and substance abuse in poor neighborhoods).

Nonetheless, it is possible to identify specific types of problems that can adversely affect clinical outcomes for minorities. As reviewed here, these problems include poverty and lack of insurance, which can limit access to care[5,15]; language barriers in both acculturated and nonacculturated immigrants[16]; limited knowledge about ADHD[17,18]; cultural attitudes about childhood behaviors[19]; cultural attitudes about mental health disorders[20] and about pharmacotherapy[4,5,21]; and perceived discrimination and stigmatization related to both race-ethnicity and mental health.[22] Language barriers may play a role in communicating symptoms.[16] For example, a physician may ask the parents or child whether paying attention is problematic; this may be perceived or misunderstood as a question regarding alertness or intellect and may contribute to a misdiagnosis.

Problems may also exist within the clinical community, such as inadequate knowledge about ADHD, especially in the primary care setting: for example, the common belief that ADHD disappears after puberty[17]; unawareness that ADHD symptoms gradually change over time, with inattention becoming more prominent than hyperactivity in adults[18]; and hesitation to prescribe stimulant medications in ADHD because of their potential for abuse.[23] Also, there is a gap between best-practice management guidelines and actual practice patterns.[24] More specifically, there is potential for clinicians to be culturally obtuse or to harbor unconscious stereotyped attitudes toward minorities,[25] and minority patients may perceive that providers of mental health services provide them with inadequate information, treatment, and follow-up.[22]

LITERATURE REVIEW

Searches in MEDLINE and PubMed were conducted in April and September 2012 on ADHD and its related problems and disabilities in African American and Hispanic minorities. A general search with no date parameters was conducted for English-language entries using the terms (*attention deficit hyperactivity disorder* OR *attention deficit/hyperactivity disorder* OR *ADHD* OR *AD/HD*) AND (*ethnicity* OR *cultural* OR *culture*). Issues of particular relevance to racial and ethnic minorities utilizing health care services were researched using the string (*black* OR *African* OR *Hispanic* OR *Latino* OR *minority* OR *racial*) combined with terms relating to access, insurance, comorbidity, high-risk behavior, treatment compliance, and nonpharmacologic modalities.

After reviewing the search results and selecting the reports most relevant for inclusion in this review, the authors added their own experiences with these clinical issues. The following sections summarize the major findings of this review of the literature, organized by the types of barriers that may be encountered by racial-ethnic minorities seeking clinical help for ADHD.

FACTORS CONTRIBUTING TO DISPARITIES IN HEALTH CARE

Access to Medical Services

African Americans with ADHD may have limited access to the health care system, largely because of lack of insurance and high out-of-pocket costs for drugs and mental health services.[5,15] Perceived discrimination has been associated with lower use of medical services, which may reflect lack of access and reduced willingness to seek care.[26,27] In addition, gatekeeper strategies to reduce emergency room visits may have disproportionate effects on access to care for the African American population,[28] although the integration of mental health into primary care has been reported to improve access for elderly African Americans.[29]

As with African Americans, access to care in the United States has been reported to be poorer for Hispanic than for non-Hispanic white patients.[30,31] In particular, poorer access to and use of mental health services may be seen

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in lower rates of specialty care and a lower likelihood of receiving care consistent with current guidelines.[32] Among Hispanic patients, problems with access to care may be related not only to poverty and lack of insurance but also to unfamiliarity with the system, leading to inefficiency in obtaining health care services.[33] Citizenship status and sociodemographic factors account for much of the disparity of care between Hispanic and non-Hispanic white patients and among Hispanic subpopulations.[34] For example, access to and use of professional services have been reported to be poorer among Mexican Americans than non-Mexicans, chiefly due to differences in age, income, and insurance,[35] and better among the US-born children of US-born Hispanic parents than among the US-born children of immigrants.[36]

Finally, difficulty with English can be a substantial barrier to obtaining and complying with medical care among recent Hispanic and African American immigrants for whom English is a second language. This problem is serious enough to have warranted a federal mandate to improve access for people with language barriers.[16]

Insurance

Aside from the overall lower rates of insurance coverage among African Americans compared with white patients,[5,15] there are differences among population subgroups, such as lower rates of insurance (but better ratings of health) among foreign-born blacks than US-born African Americans.[37] Although some research suggests that Medicaid managed care has reduced racial disparities in insurance and access,[38] other research shows that managed care has had no particular effect on access to or satisfaction with medical care among African Americans.[39]

Within the Hispanic community, as in the United States as a whole, insurance coverage is more common among older and less-healthy individuals.[40] However, overall rates of insurance for adults have been reported to be lower for Hispanic than for white or African-American populations, with lower rates of public insurance for Mexican Americans than for Puerto Ricans.[41] In addition, recent arrival in the United States among Mexican immigrants and language difficulties within the Puerto Rican population have been reported to be major impediments to obtaining insurance.

Ethnic and racial disparities in access to health care among uninsured Americans are greater than disparities among the insured.[42] The gaps between uninsured minorities and uninsured whites were almost twice as large as the gaps between insured minorities and insured whites (ie, access to regular health care provider, access to specialists, reliance on emergency rooms).[42] African Americans were less likely to receive preventative services, such as Pap smear screening, breast examinations, mammography, smoking cessation counseling, or rectal exams.[43] Greater financial resources available to uninsured whites may contribute to greater access to health care compared with uninsured nonwhites.[42] However, it is important to note that such disparities in access and in use of professional services and clinical and functional outcomes are not totally explained by differences in health insurance and income.[43–46] In Canada, race-related disparities in the use of mental health services are observed independent of other demographic variables, despite universal access to health care, regardless of culture and socioeconomic status.[47] These data suggest that factors such as cultural attitudes may impact health care utilization independent of socioeconomic and race-related obstacles to health care access.

Cultural Attitudes

Attention-deficit/hyperactivity disorder involves genetic and biological factors as well as environmental factors.[48] Perceptions of hyperactivity and cultural variations in attitude toward appropriate childhood behavior vary significantly across cultures; this is evidenced by lower clinical identification rates of ADHD in African American and Latino populations in the United States compared with the white population.[19] Mental illness may be a source of shame if it is perceived as a sign of personal weakness or shortcoming. Such beliefs, reflecting lack of knowledge about the cause of ADHD and negative cultural attitudes toward mental illness, may be more prevalent within educationally disadvantaged minority populations and may discourage people from seeking professional help. Thus, the reason that African American parents of children (especially girls) with ADHD are more likely than white parents to decline professional services, school-based interventions,[20] and pharmacotherapy[4,5,21] may be based on differences in understanding of and attitudes toward ADHD. It should also be kept in mind that because disparaging attitudes toward mental illness can be passed from parents to their children, adults with ADHD who grew up in such environments might be reluctant to seek care. There also may be pressures from family and friends to refrain from seeking treatment for fear of jeopardizing future employment or ability to serve in the military, or fear that parenting abilities may be called into question.[15]

Discrimination and Stigmatization

The perception of racism or stigmatization can discourage parents of children with ADHD from seeking treatment, as indicated by a Harris Interactive Poll in which 36% of African American parents (versus 19% of Hispanic parents) reported that race could compromise the care provided for their children with ADHD, and more than half of parents in both groups attributed lack of treatment to fear that their children would be labeled by the ADHD diagnosis.[49] Patients may be especially sensitive about publicly disclosing their ADHD diagnosis. Thus, the use of short-acting medications (which might have to be taken in public places) and a need to attend counseling can exacerbate the sense of stigmatization.[50]

PERSPECTIVES FOR PRIMARY CARE PHYSICIANS

Culturally related barriers can affect the process of health care in any medical condition, but maybe most significantly

Table 1. Considerations in Recognizing, Diagnosing, and Treating Attention-Deficit/Hyperactivity Disorder (ADHD) in Racial and Ethnic Minority Populations

Recognition	Be aware of specific cultural factors that may influence recognition of ADHD symptoms Parents with "collectivist cultural values" may be more accepting and understanding of their children's behavior and less likely to accept a diagnosis of ADHD Different cultures may use different terminology to describe the symptoms observed in children Descriptive terms used to describe children with disruptive behaviors can include intelligent, spoiled/rude, and stubborn/willful Employ cultural screening tools as early as possible; these tools should contain relevant questions related to the most marked cultural issues that can affect/interfere or delay the assessment and treatment process
Diagnosis/assessment	For patients for whom English is not their first language, consider using ADHD assessment tools that have been translated into their native language Understand that existing assessment tools may not fully capture all of the manifestations of ADHD in every racial/ethnic group Determine whether the patient's behavior is discordant with his/her cultural norms Establishing a favorable rapport can assist a physician in overcoming cultural barriers, as it can facilitate the diagnostic process
Treatment	Understand that cultural resistance to stimulant medication or limited access to health care can negatively affect following through with recommended medical evaluation and with continuation of treatment Establishing a rapport with patients can facilitate a patient's acceptance of treatment and make him or her more likely to adhere to treatment If a history of folk medicine is alluded to, understand the rationale for using that remedy and be able to inform the patient about the inherent risks More pronounced functional impairments can make many parents more open and adherent to treatment Effectively treating parents who have ADHD can facilitate treatment of their children because it can help the parents overcome sociocultural misperceptions regarding the need for and benefits of treatment

when there is a mental health condition, which can add serious risk that the condition will be unacknowledged, undiagnosed, and untreated. The results can be devastating in terms of impaired functionality, especially in the presence of comorbid behavioral disorders, substance abuse, and other psychiatric conditions.

Even without any cultural barriers, the diagnosis of ADHD can be complex in the presence of comorbid behavioral disorders. Recognizing ADHD and related behavioral disorders in individuals of a culture different from that of the clinician can be especially challenging. For example, among African American youth in single-mother households, ADHD symptoms and conduct problems (aggression, rule-breaking) are influenced by neighborhood factors, but the links are not clear or consistent.[51] Likewise, in Hispanic adolescents, ADHD with comorbid conduct disorder showed only an indirect relationship to substance abuse and associated poor school performance.[52] Cultural bias in teachers and/or in the school system may also affect ADHD diagnosis and treatment because teachers are often involved in recommending students for diagnosis and recommending adjustments in treatment. In support of this possibility, it was reported that teachers rated African American children (both boys and girls) higher on externalizing behaviors than they rated white children when using the Conners Teacher Rating Scale, which raised the possibility of teacher bias.[53] Importantly, none of these cultural differences are likely to be restricted to African American and Hispanic populations, and physicians should consider how these factors may similarly or differentially impact other ethnic or cultural minorities, including those of Asian and Middle Eastern descent.

To address potential cultural barriers effectively when seeing patients of different racial-ethnic backgrounds, primary care clinicians should consider the following questions:

- Is the patient US born, acculturated to US society, or recently arrived in the United States? Does the patient understand the US health care system? Is there a language barrier?
- What is the patient's educational level? Is the patient's understanding of ADHD adequate to facilitate compliance with treatment?
- Does the patient rely on family, friends, clergy, or other nonmedical authority figures for advice, including advice on health and illness? Is the patient aware that such sources may not always provide appropriate medical advice?
- Are there different attitudes within the patient's culture toward pharmacotherapy versus nonpharmacologic treatment?

Table 1 highlights some of the possible special considerations that should be taken into account by primary care physicians when assessing and treating ADHD in individuals of different ethnic and racial backgrounds. Resources that should be considered by primary care physicians working with ethnic and cultural minorities include local social workers and translation services. Educational resources available for health care professionals to consult include the following:

- The Health Research and Educational Trust Disparities Toolkit (http://www.hretdisparities.org/)
- The National Initiative for Children's Health Quality (http://www.nichq.org/areas_of_focus/cultural_competency_topic.html)
- The National Alliance on Mental Health (http://www.nami.org/Template.cfm?Section=ADHD&Template=/ContentManagement/ContentDisplay.cfm&ContentID=106391)

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Obtaining answers to these types of questions decreases the risk that physician and patient will misunderstand each other and thereby increases the likelihood of accurate diagnosis and successful treatment outcome. For example, some symptoms of ADHD, such as excessive talking and disruptive or intrusive speech, are based on a relative deviation from the norm, but the norms for conversation may differ among cultures. Conversely, one should not assume that seemingly abnormal behavior is merely a cultural difference. The physician may ascertain whether the patient's behavior is discordant with his or her cultural norm by querying family members and getting their impressions about the patient's behavior or asking individual patients to describe norms of behavior in their cultural settings and in the wider community. In addition, to minimize the potential language barriers that can impede proper diagnosis and treatment, it is important for physicians to be aware that some ADHD assessment scales have been translated into and made available in other languages. For example, validated translations of ADHD assessment scales have been developed in Spanish (ADHD Rating Scale version IV, Vanderbilt ADHD Teacher Rating Scale and Vanderbilt ADHD Parent Rating Scale, Attention Deficit Disorder Evaluation Scale-Second Edition),[54] Chinese (Swanson, Nolan, and Pelham, Version IV Scale),[55] and Arabic (ADHD Rating Scale).[56]

Sensitivity to cultural differences may inform but must never replace the physician's own clinical judgment. For example, parents may have preferences between pharmacotherapy and psychotherapy for their child with ADHD; but the clinician, although sensitive to the parents' attitudes, must still plan treatment according to what is deemed most likely to yield the best results in the child. In all such situations, the assessment should be objective, never judgmental. For instance, if a patient giving a history mentions use of a folk remedy, rather than criticize or validate the practice, the clinician could inquire what the rationale was for that remedy and how satisfied the patient was with the outcome. However, the clinician has an obligation to inform the patient about the risks of some home remedies that may be dangerous, such as ephedra; sympathomimetic amines may increase heart rate and blood pressure, which are dangerous and have been associated with death.[57] Awareness in this situation allows the clinician to communicate effectively with the parents to explain the reasons for the treatment choice, the anticipated outcomes, and the importance of compliance. To the best of our knowledge, there is no evidence to suggest differential efficacy or tolerability of approved ADHD medications across racial-ethnic populations when taken as indicated. However, there is a paucity of clinical evidence related to treatment effects in these populations, perhaps because there may be too few minority participants in drug development studies from which to draw firm conclusions.

As noted in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition, culturally appropriate practices may be needed in assessing ADHD.[19] Additional research is needed in several key areas to improve the physician's ability to serve various ethnic and cultural minorities. First, research is needed that will expand our understanding of ethnic and cultural factors that consistently influence a wide array of populations so that a more global framework for addressing these issues can be developed. Additional research on the similarities and differences among subgroups within a given ethnic or cultural population may also provide further insight into the generalizability of the barriers that affect the recognition and treatment of ADHD. Lastly, with the passage of the Patient Protection and Affordable Care Act in March 2010, access to health care in previously underinsured or uninsured individuals is anticipated to improve. However, it is not yet understood how implementation of the Patient Protection and Affordable Care Act will actually affect access to and the cost of health care in minority populations.

Notwithstanding these daunting challenges, the primary care physician should be empowered by 1 fact: all patients, irrespective of cultural differences, want to be heard and want to be helped. It is essential to understand that listening to the individual patient is more important than familiarity with data on his or her race and ethnicity because that individual's life experience and characteristics may differ profoundly from epidemiologic trends. To assume that an individual has educational or socioeconomic disadvantages because of his or her race or ethnicity is prejudicial, not sensitive. The clinician needs to be aware that the impact of culture on the process of diagnosis and treatment may be complicated by many factors, including cultural attitudes toward mental health, expectations concerning treatment, access to appropriate treatment, and physician-patient communication.

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