

Overcoming Challenges in the Diagnosis and Treatment of Attention-Deficit/Hyperactivity Disorder in African Americans

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The incidence of ADHD appears to be similar in African Americans and white populations. However, fewer African-American than white children are diagnosed and treated for ADHD. Reasons for this disparity have not been fully elucidated; causes are most likely complex. Whereas certain barriers to treatment are driven by patients and their families, others are due to limitations in the healthcare system. Patient-driven obstacles to care include inadequate knowledge regarding the symptoms, treatment and consequences of untreated ADHD and fear of overdiagnosis and misdiagnosis. A survey conducted to explore cultural differences between African-American and white respondents found that African Americans were more likely than whites to be unfamiliar with ADHD. In addition, African Americans felt that they were diagnosed with ADHD more often than whites and that teachers blamed ADHD for learning or behavior problems more often in African Americans. Health system barriers include a lack of culturally competent healthcare providers, stereotyping/biases and failure of the clinician to evaluate the child in multiple settings before diagnosis. Strategies to overcome these challenges include increased dissemination of ADHD information through community events; improved training of clinicians in cultural competence; and open communication among parents, clinicians and school personnel.

Key words: African Americans ■ attention-deficit/hyperactivity disorder ■ disparities

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) is a neurobehavioral disorder characterized by hyperactivity, impulsivity and inattention. The etiology of ADHD is thought to involve genetic factors and dysfunction of the dopamine and norepinephrine neurotransmitter systems in the frontostriatal circuitry.¹ Comorbidities, such as conduct disorder, oppositional defiant disorder, depression, anxiety, learning disabilities, and alcohol or drug addiction, are often noted in patients with untreated ADHD. Thus, the primary goals of therapy for ADHD are to decrease disruptive behaviors, enhance academic performance, improve relationships with family and peers, improve self-esteem and promote independence.

Difficulties in the diagnosis of ADHD include the absence of a specific diagnostic test, the lack of specificity of symptoms, the inability to observe symptoms that may not be present in an office setting, the low rate of concordance in symptom-reporting among various informants (i.e., parents, teachers and patients) and the lack of a standard evaluative process.² Various medical professionals may use different diagnostic routes to diagnose ADHD. However, most agree that the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) is the basis for an appropriate diagnostic process.³ In recent years, major medical organizations, such as the American Academy of Pediatrics (AAP) and the American Academy of Child & Adolescent Psychiatry (AACAP), have researched this subject extensively and published guidelines to assist physicians in making this medical diagnosis.⁴

The prevalence of ADHD in African Americans is most likely similar to that among the general population (3–5%); however, fewer African Americans are diagnosed and treated for ADHD.^{5–9} The reasons for this phenomenon have not been fully elucidated. However, the challenges related to the insufficient treatment and diagnosis of ADHD in this population must not be oversimplified because myriad factors most likely contribute to the complexity of this issue. Of note, investigators who explored the effects of ethnicity on ADHD treatment in the Multimodal Treatment Study of Children with ADHD, a cooperative treatment study conducted by six independent research teams together with the Division of Clinical and Treatment Research of the National Institute of Mental Health, reported that response to methylphenidate was substantial among African Americans and

© 2005. From Bryce State Hospital, Birmingham, AL (Bailey, medical director) and University of Texas Medical Branch, Galveston, TX (Owens, fellow, Child & Adolescent Psychiatry). Send correspondence and reprint requests for *J Natl Med Assoc.* 2005;97:5S–10S to: Rahn Bailey, MD, 614 W. Main St., Suite D101, League City, TX 77573; phone: 281-554-7188; fax: 281-554-9084; e-mail: RahnBailey@yahoo.com

that response was clinically similar between African Americans and whites.¹⁰ Initial analyses showed that compared with white children, African-American children responded more favorably to behavioral therapy than routine community care. However, no significant differences were observed between the groups when public assistance was considered; this suggested that enhanced response to behavioral therapy related more to socioeconomic status than ethnicity.

As a step to increase awareness among healthcare providers and the African-American community regarding the special needs of this patient population, an effort must be made to explore barriers to the diagnosis and treatment of ADHD in African Americans. This paper identifies some potential obstacles to the care of ADHD in African Americans and offers suggestions for interventions that are targeted to patients and their families and to healthcare providers. The success of ADHD treatment requires that these hurdles be overcome; hence, the first crucial step involves increasing awareness among parents and other caregivers and members of the medical community.

Parent-Driven Obstacles to Care

Similar to parents from other ethnic backgrounds, many African-American parents are not well informed about the symptoms and treatment of ADHD. However, results of studies suggest that African-American parents may be even more uninformed about the causes and treatment of ADHD than are parents from other ethnic or racial backgrounds.¹¹⁻¹³ One study that sought to identify differences in ADHD knowledge between 224 African-American parents and 262 white parents reported that only 69% of African Americans had ever heard about ADHD, compared with 95% of white parents ($P < 0.001$), and that 36% of African Americans knew “a lot”, “some” or “a little” about ADHD, compared with 70% of white parents ($P < 0.001$). In addition, African-American parents reported that only 18% received information about ADHD from their physician, compared with 29% of white parents ($P < 0.01$).¹¹ Of note, this study found the effects of ethnicity on ADHD familiarity were independent of other covariates, such as socioeconomic status. The investigators speculated that several reasons might have accounted for their findings. These reasons included the possibility that ADHD was unrecognized in the social network of the parent causing the parent to be less likely to recognize the symptoms, the possible perception by African-American parents that ADHD symptoms are behaviors that the child will outgrow, the belief that ADHD is another example of how African-American children are discriminated against or that ADHD ranks low as a priority because of competing concerns or needs.

African-American families may not attribute the symptoms of ADHD to the disorder itself and are less aware than white families about the etiology of ADHD. For example, sugar intake has been reported as a common explanation for the symptoms of ADHD among members of the African-American community.^{11,14} Bussing et al. reported that nearly twice as many African-American parents (59%) as white parents (30%) of children with learning disabilities felt that ADHD was caused by excess sugar consumption and that

only 10% of African-American parents were certain that sugar did not cause ADHD, compared with 37% of white parents ($P < 0.001$). Furthermore, compared with 91% of white parents, only 75% of African-American caregivers thought that ADHD had genetic causes ($P < 0.01$). Medical labels, such as ADHD, ADD, attention deficit or hyperactivity, were used by only 25% of African Americans to describe their child's condition, compared with 62% of white parents ($P < 0.001$). The lack of knowledge about ADHD among the African-American community has been described as a “vicious cycle” that may be caused when members of this community seek medical advice from other individuals within their own ethnic background who are equally uninformed about ADHD.¹¹

Bussing and colleagues interviewed 182 parents of school-aged children who met the diagnostic criteria for ADHD to examine how culture affected their understanding of ADHD, including treatment-seeking behaviors.¹² Their data showed that African-American parents were less likely than white parents to associate the demands of school with the exacerbation of ADHD symptoms. In addition, African-American parents were less likely than white parents to request pharmacological treatment or school interventions and were less likely to mention emotion-based outcomes, such as conduct disturbance. A potential disconnect between African-American parents and the school system was suggested based on the fact that African-American parents expressed fewer worries about ADHD-related school problems and fewer preferences for school intervention. In addition, fewer African-American parents than white parents acknowledged the role of the school system in the identification of ADHD in their children. Investigators hypothesized that lower rates of parental awareness about school problems may result in lower rates of medical treatment.

African-American parents may feel more uneasy than white parents about treating their children with pharmacological interventions. Dos Reis and other researchers evaluated parental perceptions of stimulant medication for the treatment of ADHD.¹³ Their findings demonstrated that significantly ($P < 0.001$) more nonwhite parents (63%) than white parents (29%) thought that counseling was the best treatment for ADHD, whereas medication was preferred over counseling in 59% of white parents and in 36% of nonwhite parents ($P < 0.001$). Furthermore, more nonwhite parents than white parents felt that use of stimulants would lead to drug abuse (16% of nonwhites vs. 5% of whites, $P < 0.001$) and adverse effects (24% of nonwhites vs. 11% of whites, $P < 0.001$).¹³ The study defined nonwhites as those who were African-American (50%), Asian (5%), American Indian (5%), Hispanic (10%) or other/mixed (30%) races or ethnicities.

For some African Americans, socioeconomic barriers include the lack of medical insurance or the prohibitive costs of mental healthcare and prescription drugs. For example, some patients may have limited access to mental health services because insurance coverage for psychiatric or psychological evaluations is lacking. Because of limited health insurance coverage, access to behavior modification programs, school consultation, parent management training or

other specialized services is often limited. Furthermore, substantial cost barriers result in out-of-pocket costs, which may further limit access to certain services. A retrospective study of 9,399 children that compared the relationship among ADHD, race and relevant sociodemographic factors found that African-American families were more likely than white families to report difficulty in affording prescription medication and mental health counseling.¹⁵ It is important to note that no federally funded special education programs are designed for children with ADHD.¹⁶ However, some children with ADHD may benefit from federal funding directed to special education needs.

Additional barriers to the treatment and diagnosis of ADHD must be considered. For example, many parents fear the perceived social stigma of an ADHD diagnosis, and some fear overdiagnosis and misdiagnosis. Pressure from family and friends to refrain from seeking treatment, fear of jeopardizing future employment or ability to serve in the military, concern that parenting skills will be questioned, and fear of the unknown are other factors that have been described by patients and families and are thought to impact the diagnosis and treatment of ADHD.¹⁶ In the African-American population, fear of the unknown may be related in part to the consequences of the Tuskegee experiment, which caused many African Americans to lose trust in the field of medical research.¹⁷ These feelings may cause some African-American parents to question the treatment of ADHD, a disorder whose diagnosis and treatment remain unaccepted by some members of the medical community.¹⁸

A survey conducted by Harris Interactive for McNeil Consumer & Specialty Pharmaceuticals from May to July of 2002 explored cultural differences between 1,074 African-American and 1,238 white respondents to identify barriers to the treatment of ADHD in these populations. Online or telephone surveys were conducted in households with at least one member between 6 and 17 years of age. A random selection process using two sampling methods was used to sample respondents. The first sample was comprised of respondents who completed a survey within the past two years; this sample was generated through random-digit-dialing procedures, and the second sample was comprised of a random-digit telephone sample targeted to exchanges with a higher-than-average number of minority residents. This ensured inclusion of minority participants who might not have been included if the survey was limited to Internet users. The online sample was constructed by sending e-mail invitations to individuals who participated in past surveys. In order to maintain the reliability and integrity of the online sample, invitation letters contained a password that was uniquely assigned to a potential respondent. The data were weighted to represent the general population with respect to age, race, gender, education and income, and the weighting parameters were derived through previous research conducted. Professionally trained personnel conducted all telephone interviews. Online interviews were conducted from June 11 to July 9, 2002, and telephone interviews were conducted from May 21 to June 24, 2002. Subject matter included the perceived

seriousness of ADHD, available treatments for ADHD, people most likely to be affected by ADHD and personal knowledge of someone with ADHD.

Although results of this survey revealed a great number of similarities and common beliefs about ADHD among people with diverse backgrounds, data also demonstrated some important differences between ethnic groups with regard to attitudes and perceptions about ADHD. For example, the stigma of ADHD and lack of information about ADHD were found to be significant barriers to treatment among African Americans (Table 1). African-American respondents were more likely than white respondents to say that they were "not at all familiar" with ADHD. African-American respondents were more likely than white respondents to believe that ADHD is a "very serious" condition. Compared with white respondents, African-American respondents were much more likely to believe that minority children were more apt to be told that they have ADHD and were more often misdiagnosed than were white respondents.

Advantages of telephone surveys include a broad reach to potential respondents and the ability for interviewers to ask clarifying questions. However, the difference between those who are reachable and those who are not may bias the results of telephone surveys, and there is no way to reach individuals who do not have a telephone in their home. Advantages of Internet surveys include rapid response rates, low costs and increased respondent flexibility. However, Internet access is not available in all households. In the present survey, targeting a sufficient number of minority respondents in the telephone survey sample controlled for the limitations of Internet surveys.

Together with findings from others studies, these data suggest that the need is great for increased awareness and information among members of the African-American community about the subject of ADHD, including the symptoms that might be observed, the consequences of untreated ADHD and indications that a healthcare professional should be contacted.

Health System Barriers and Other Obstacles

A substantial number of obstacles to the successful diagnosis and treatment of ADHD overall are related to limitations in the diagnosis and treatment of ADHD in African-American patients. Some of these barriers may be easier to remove than others. For example, one hurdle relates to the influence of race or ethnicity alone on the diagnosis of ADHD in African Americans.¹⁹ During the clinician-patient encounter, negative social stereotypes are known to shape behaviors and influence decisions made by healthcare providers.²⁰ Race or ethnicity is known to adversely influence the medical care provided for other conditions, as reflected by a lower rate of referrals for cardiac procedures, lower rates of analgesic prescribing and less appropriate treatment of cancer or depression among minorities.²¹⁻²⁶ Patients with ADHD are likely to be affected by this as well. Historically, there have been patterns of disproportionate diagnoses among African-American, Hispanic and Asian children in categories of disability. Whereas some of the

reasons for this phenomenon relate to disproportionately higher exposure rates to risk factors and psychosocial stressors and an increased prevalence of economic disadvantage, another explanation is related to the commonly used assessment instruments, which could provide misleading or invalid results when used alone to assess patients from various cultural backgrounds.²⁷ Often, the quality of healthcare is compromised when healthcare providers are insensitive to cultural differences among their patients.²⁶ Important cultural differences exist among persons of diverse ethnic backgrounds with regard to attitudes and beliefs about illness, choice of care, access to care, degree of trust toward authority figures or institutions and tolerances for certain behaviors.²⁸

The use of culturally sensitive diagnostic tools may assist investigators in uncovering important aspects about ADHD that may be unique to the African-American population. For example, preliminary findings from one small study that used an ethnically sensitive evaluation in the diagnosis of ADHD in African-American children revealed only modest levels of comorbidity in these patients—a factor that suggests that ADHD may be more manageable and treatment-responsive in African-American patients than in white children.²⁹ However, these results must be interpreted with caution; additional data from large, well-controlled trials are needed.

Conscious and unconscious bias or prejudice can cause the cross-cultural diagnosis of ADHD to be challenging. A commonly held misperception is that African-American children are normally more active than their peers from other ethnic backgrounds. Gingerich and colleagues reviewed several com-

parison studies from the 1970s, which used teachers' ratings to compare the prevalence of hyperactivity among ethnic minority and white children.¹⁹ They reported that in one large study, which included 1,700 elementary school children from rural and urban Texan locations, African-American children were rated by teachers as more hyperactive than expected based on their representative population, except in schools that were located in white, middle-class neighborhoods, where the frequency of hyperactivity was consistent across all ethnic groups. Therefore, differences in activity level may be related to socioeconomic status rather than ethnicity.

Another obstacle that may prevent optimal care for ADHD in African-American children is a lack of African-American healthcare providers. More clinicians from minority groups are needed to alleviate intercultural issues of trust and communication that often arise.²⁸ One case report described an African-American mother who experienced feelings of intercultural mistrust after it was suggested by a white teacher that her son should be evaluated for ADHD.²⁸ This mother expressed that the real problem was "an inexperienced white teacher who wants to drug children into compliance." However, after receiving education on the topic of ADHD and directly observing her son during the school session, this parent acknowledged the importance of diagnosis and the usefulness of medical and behavioral treatments. Hence, recruiting the parent as an ally can help the clinician to pave the way to acceptance and trust.

Even for those who seek treatment, genetic polymorphism may cause drug metabolism to vary among persons of various

Table 1. Most prominent differences between African-American and white respondents in perceptions and attitudes about ADHD

	African-American	White
<i>Familiarity with ADHD</i>		
"Not at all familiar" with ADHD	10%	2%
ADHD is a "very serious" condition	36%	28%
Know someone diagnosed with ADHD	56%	78%
Have a child with ADHD who is receiving treatment	46%	60%
<i>Cultural Perceptions and Beliefs</i>		
African Americans are more likely than other ethnic groups to be diagnosed with ADHD	41%	13%
African-American children are told more often than children of other ethnic groups that they have ADHD	33%	8%
Teachers are more likely to suspect ADHD in African-American children with learning or behavioral problems than in other ethnic groups	45%	12%
Very concerned about what others may think	13%	5%
Concern about treatment based on race or ethnic background prevents parents from seeking proper treatment	36%	13%
Limited access to healthcare professionals knowledgeable about ADHD prevents children from receiving appropriate treatment	44%	39%
Aware of treatments that help to lessen the symptoms of ADHD	66%	84%
Have sought help from a medical professional for suspected ADHD	86%	94%
Would be very concerned if their child was diagnosed with ADHD	71%	53%
Know where to go for help if their child is diagnosed with ADHD	64%	79%

ethnic backgrounds. Other pharmacokinetic variables, including plasma protein-binding and distribution, may also contribute to variations in psychotropic responses among persons of varying ethnicity and even within persons from the same ethnic group.³⁰ Therapeutic concentrations of various psychotropic agents have been shown to differ among ethnically diverse patients. Additional studies are needed in this area.

Other health system barriers include a greater tendency of clinicians to solely rely on parent input rather than teacher input when diagnosing ADHD as well as poor communication between diagnosticians and those who implement and monitor treatment in schools.¹⁵ These factors may inhibit the objective diagnosis of ADHD in some children or may limit the ability of the clinician to manage pharmacological treatment.

Strategies for Intervention

To improve outcomes in African Americans with ADHD, a number of strategies are suggested that are targeted at increasing awareness about ADHD, decreasing stigmatization and teaching the benefits of ADHD treatment. For example, healthcare and educational services must be integrated. Patients and their families should have greater access to culturally sensitive materials or programs that educate families about the symptoms of ADHD and teach them how treatment can improve behaviors. Educating patients affords them the opportunity to become partners in their own care and increases the likelihood that patients will cooperate as much as possible. Often, if the patient does not understand the importance of treatment or follow-up care, medical care becomes compromised. Management of ADHD requires adherence to treatment regimens and medical appointments. A study conducted by Odom and colleagues evaluated the usefulness of educational intervention in a population of mothers who were predominantly African-American and reported that mothers who were taught about ADHD experienced an increase in parental satisfaction and confidence—qualities that are needed for coping with this chronic illness.³¹ Similarly, teachers who serve the African-American populations must be better trained on recognizing the symptoms of ADHD to facilitate necessary treatment so that school-related outcomes are optimized.

Clinicians may consider using ethnically sensitive, structured parent questionnaires or rating scales to aid in the diagnosis of ADHD in African-American children. However, it is very important for clinicians to obtain a thorough medical history and to utilize guidelines on the diagnosis and evaluation of ADHD rather than relying too heavily on questionnaires to diagnose ADHD.⁴ Furthermore, a thorough medical history and accompanying examination will rule out significant medical issues associated with hyperactivity, such as lead poisoning or mental retardation. A recent study describes a new formalized diagnostic protocol to improve adherence to published guidelines for the diagnosis of ADHD.³²

Clinicians and healthcare providers can make substantial strides in improving outcomes by initiating pilot programs that track the efficacy of a longitudinal care model. For example, it may be useful for primary care clinicians to partner with men-

tal healthcare professionals. Furthermore, collaborative efforts should be made among schools, primary care providers and service agencies to monitor the symptoms of ADHD and the response to treatment. Successful management of ADHD is contingent on cooperation and open communication among these caretakers. It is also of great importance that a sufficient number of minority healthcare providers are accessible in schools, clinics and hospitals to alleviate potential issues of cross-cultural bias and mistrust. Thus, healthcare organizations must recruit and retain a diverse staff whose demographic characteristics are representative of the service area.²⁶

Suggested venues for the dissemination of information by the clinician include health fairs and office-run informational sessions. In addition, we suggest that physicians provide training workshops at their local schools to teach about ADHD, particularly when there are concerns that children are referred for evaluation of ADHD more often than necessary. Clinicians may also refer patients to such advocacy organizations as Children and Adults with ADHD (CHADD), the Attention Deficit Disorder Association (ADDA) and the National Association for Mental Health Alternatives (NAMHA) for additional support and provide patients with information available from national medical organizations, such as the AAP and the AACAP.

Healthcare institutions must consider ways of offering improved access to medical services and raising the level of awareness in the community. This can be accomplished in many ways. For example, information can be disseminated during community events, such as health fairs, and in churches and day-care centers to teach about ADHD, raise awareness regarding the importance of treatment and lessen fears of stigmatization. Group programs afford the opportunity for involvement of multifamily groups, which can improve the level of moral support the patient receives while undergoing treatment.

It is important to note that care must be tailored to suit the needs of various ethnic groups, such as the African-American community. Culturally competent medical care ensures that all patients will receive care that is compatible with their cultural beliefs and practices.²⁶ Ethnic or cultural sensitivity involves a broad understanding of cultural concepts and issues and a great awareness of cultural differences in responses, perception of diseases/disorders and care needs of patients. The need to increase cultural competence in healthcare is described in detail in *Healthy People 2010*, which is a statement of national health objectives that was designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats.^{26,33} In brief, these guidelines seek to eliminate barriers to the provision of culturally competent care and to provide organizational supports for cultural competence. Many other resources, including journal articles, training courses, conferences and books, are also available to assist physicians and other healthcare providers in developing cultural competence.^{34,35}

Culture can be viewed as one of our greatest assets for healing and mental wellness as many elements of culture support positive emotions. Some of these elements include family events, cultural foods, art, music and stories.³⁶ As

components of treatment plans, positive cultural experiences can promote optimism and hope.³⁶ Key goals and principles of culturally competent systems of care include incorporation of cultural knowledge and sensitivity into policymaking and administration.³⁴ Other goals of cultural competence include developing the necessary attitude, skill and knowledge base to serve African-American patients.³⁷

In conclusion, healthcare providers must be diligent in their commitment to reduce or remove barriers to the proper diagnosis and treatment of ADHD in African Americans. To begin, efforts should be made to increase awareness in the African-American community regarding the symptoms of ADHD and its treatment, and to improve cultural awareness and sensitivity toward African-American patients among clinicians to reduce the challenges involved in cross-cultural diagnosis. Future research should evaluate the usefulness of interventions such as these in removing impediments to the effective management of ADHD in the African-American population.

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