



KNOWLEDGE AND INFORMATION ABOUT ADHD: EVIDENCE OF CULTURAL DIFFERENCES AMONG AFRICAN-AMERICAN AND WHITE PARENTS

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Abstract—Attention deficit hyperactivity disorder (ADHD) is considered the most common child psychiatric disorder in the United States of America. Despite the high prevalence (estimated at 3–5%), little is known about the level and source of knowledge about ADHD among those affected by the disease, and about cultural and ethnic variations in knowledge levels and information sources. This represents a serious deficit, because health behavior, including demand for health services, is thought to be strongly influenced by knowledge or beliefs held by individuals and their networks. Furthermore, recent research suggested minority children may be less likely to receive services for ADHD. To examine possible differences in ADHD knowledge and information source, a sample of 486 African-American and white parents of children at high risk for ADHD were surveyed by telephone and subsequently participated in face-to-face interviews addressing their explanatory models of ADHD. Results revealed significant ethnic differences in knowledge and sources of information about ADHD. Fewer African-American parents than white parents indicated that they had ever heard of ADHD (69% compared to 95%, $P < 0.001$), or that they knew some or a lot about it (36% compared to 70%, $P < 0.001$). African-American parents were more likely to attribute ADHD to excessive sugar in the diet than whites (59% compared to 30.0%, $P < 0.001$). Finally, even though the physician was listed as the most preferred information source for both groups, only 17.5% of African-American parents reported they had received information about ADHD from the physician compared to 29% of whites ($P < 0.01$). African American parents reported less use of and less preference for written informational materials (newspapers, journals, library) than white parents. We conclude that substantially more research should be undertaken to examine the relationship between ethnicity and ADHD knowledge, to inform culturally appropriate education campaigns and to improve access to services for this important treatable child mental health condition. © 1998 Elsevier Science Ltd. All rights reserved

Key words—attention deficit disorder, hyperactivity, knowledge and attitudes, ethnicity

INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) is considered by many to be the most common child psychiatric condition in the United States (Szatmari *et al.*, 1989; August *et al.*, 1995), affecting 3–5%, or as many as two million of U.S. children and adolescents and their families. The scientific knowledge base concerning ADHD has expanded considerably over the last decades, reflected in revisions of medical terminology for the condition, from minimal brain damage, and hyperkinesis, to its present designation of Attention Deficit Hyperactivity Disorder (American Psychiatric Association 1994). The etiology of ADHD is unknown, but research suggests that an interplay of biological and psychosocial factors leads to a final common pathway expressed as the syndrome of ADHD (Barkley, 1990). Strong evidence implicates genetic factors in the etiology (Goodman and Stevenson, 1989;

Hechtman, 1994), while popular beliefs about the role of nutrition, in particular sugar, in the onset of ADHD have not been supported in scientific studies (Wolraich *et al.*, 1995).

ADHD commonly interferes with the child's ability to function successfully in school or social settings (Greene *et al.*, 1996). Furthermore, studies indicate that problems due to ADHD are not just transient childhood phenomena, but can adversely affect the developmental path of affected youngsters, resulting in eventual impaired adult productivity and well-being (Mannuzza *et al.*, 1991, 1993). To minimize such adverse developments, effective health care interventions have been used for ADHD (American Academy of Child and Adolescent Psychiatry, 1991; Swanson *et al.*, 1993; Pelham, 1994), and the general health sector (primarily pediatricians and family practitioners) provides a higher proportion of ADHD-related services than the specialty mental health sector (Rappley *et al.*, 1995).

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Despite the widespread prevalence of ADHD and concomitant increased attention by the scientific community, little is known about the level and source of knowledge about ADHD among the general population and among those affected by the disease. ADHD knowledge has only been cursorily explored among samples of parents from specialty ADHD clinics, and among teachers (Jerome *et al.*, 1994; Kasten *et al.*, 1992; Rostain *et al.*, 1993; Kwasman *et al.*, 1995). Even less known about cultural variations in knowledge and attitudes about ADHD. Minorities have generally been under-represented in ADHD research populations in the past. Yet, recent studies suggested higher rates of unmet ADHD treatment needs among minority children than among white children (Bussing *et al.*, 1996; Bussing *et al.*, in press). Access to care is known to be strongly affected by economic enabling variables (income, health insurance status) (Andersen, 1995), however, cultural variations in knowledge and attitudes may also play an important role in explaining these findings.

Exploring the role of ethnic or cultural variations in health knowledge and behavior requires complex considerations. While recent reviews indicate that race and ethnicity serve as potent predictors of variations in health status (Williams and Collins, 1995), concepts of race still lack conceptual clarity, varying widely in the amount of importance attached to biological, social, or political aspects of race (LaVeist, 1994). Some studies treat racial categories as proxy for socio-economic risk factors, while others use them as substitute for 'culture' (Lillie-Blanton and LaVeist, 1996). While race and socio-economic status (SES) are typically strongly correlated, the terms are nevertheless not interchangeable. Despite the public health relevance of ADHD, virtually nothing is currently known about variations in parental ADHD knowledge by SES or ethnicity.

To address these deficits, this study has the following aims: (1) to describe levels of self-rated ADHD knowledge among a sample of parents of children at increased risk for the condition; (2) to determine relevant ADHD information sources used and preferred by this sample; (3) to examine the relationship between ethnicity and ADHD knowledge levels, information sources and preferences, and explanatory models of ADHD.

METHODS

Eligible participants included the caregivers of all African-American or white 2nd–4th grade children in a medium-size county school district qualifying for exceptional student education (ESE) services based on PL94-142 ($N = 709$). Children met criteria for specific learning disabilities and/or emotional handicapping conditions. We excluded 13 children of other ethnic backgrounds from this analysis,

because their sample size was too small to allow separate analyses. Respondents in the study were the primary caregivers of the child, mostly mothers (83%).

Phase I

Parents completed a 20–30 min telephone interview, which included the ADHD knowledge survey, screening measures for symptoms of ADHD, and general information about the presence of ADHD treatments.

Phase II

Children were classified as being at high risk for ADHD if they scored in the clinically elevated range on the two parent-report screening measures for ADHD administered in phase 1, or had a history of current or past treatment for ADHD. Parents of all 207 high risk children were invited to participate in a structured parent interview for diagnosis of ADHD. This interview also included closed and open-ended questions addressing parental opinions and explanatory models of ADHD.

MEASURES

Sociodemographic characteristics

We dichotomized ethnicity as non-Hispanic white or African-American. The Hollingshead 4 factor index, based on educational level and occupational category of the child's caregivers, was used to calculate socio-economic status (SES) levels 1 through 5 (Hollingshead, 1975). These SES levels were dichotomized; levels 1–2 were defined as 'high SES' and levels 3–5 designated as 'low SES'.

ADHD knowledge

In phase I caregivers participated in a computer assisted telephone interview (CATI). The interview obtained information about several areas including health of the child, medical care, mental health service utilization, and child behavior. Because no commonly accepted survey standards exist to assess parental ADHD knowledge, we developed a simple questionnaire designed to access the most basic knowledge issues related to ADHD. Twelve survey questions were modeled after the format of the AIDS knowledge inquiry contained in the 1988 national health interview survey (Chyba and Washington, 1993). Our questions address (a) whether the respondent has ever heard about "attention deficit disorder, hyperactivity, ADD, or ADHD"; (b) the recency of having heard about the disorder; (c) the extent of self-rated knowledge; (d) the respondent's most common and preferred information sources; and (e) whether or not the respondent knows a person with ADHD. Three statements address basic knowledge and opinions about ADHD, including (1) "attention deficit or

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