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Children's Accounts of Attention-Deficit/Hyperactivity Disorder

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As a postmodern illness, attention-deficit/hyperactivity disorder (ADHD) is embedded in controversy, reflective of the cultural times in which we live. Within this debate, 2 perspectives, ADHD as myth and ADHD as behavioral disorder, are most frequently voiced. This article describes these 2 differing perspectives and reports qualitative data from 39 children and adolescents with a diagnosis of ADHD regarding their perceptions, meanings, and experiences of living with this disorder. None of the participants in this study denied that they had difficulties and many of the difficulties they described corresponded to *DSM-IV-R* criteria and the scientific literature. Given these discoveries, the continual debate about the authenticity of ADHD only further victimizes families who are in desperate need of services. **Key words:** *ADHD*, *children*, *postmodern illness*, *qualitative research*

POSTMODERN CRITIQUE situates attention-deficit/hyperactivity disorder (ADHD) as a contested diagnosis involving a vague set of behavioral criteria and lacking biological diagnostic certainty. Complicated by ambiguity and a confusing medical picture, ADHD, as a postmodern illness, begs the question of whether medicine has gone amuk and created a disorder to treat teachers' and parents' anxieties regarding childhood by routinely drugging children into good behavior.[1] On the other hand, a vast research literature documents the existence of ADHD as a legitimate and serious disorder. According to the *Diagnostic and Statistical Manual of Mental Disorders*,[2] ADHD accounts for the largest number of referrals to child mental health clinics of all psychiatric and behavioral problems of childhood. Yet, public debate rages as to the validity of ADHD as a bonafide psychiatric medical disorder, questioning whether a fraud has been perpetrated on us by the educational, medical, and pharmaceutical community. Consequently, ADHD has become one of the most controversial health conditions of the last 15 years.

Juxtaposed against this on-going debate are the voices of the children and adolescents who are most directly affected. Rarely are children's and adolescent's perspectives heard in regard to ADHD. This article is a report of findings from interviews with 39 children

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and adolescents with ADHD regarding their perceptions, meanings, and experiences of living with this disorder.

CONTEXT OF THE DEBATE

Recognizing that there are diverse definitions and descriptions of postmodernism on issues of health and disease, for purposes of this article we define *postmodern illness* as a changing experience of human affliction that is shaped by convergences of biology and culture.[1] Postmodern illnesses, such as ADHD, Gulf War syndrome, chronic fatigue syndrome, multiple personality disorder, and chronic pain, convey traditional biomedical meanings through their symptom expression, yet also carry a tacit subtext of the artificial distinctions between contemporary culture and subjectivity, thereby restricting understanding of symptoms and creating needless, detrimental distance between patients and their health care providers.[1]

The hallmark sign of what constitutes postmodern illnesses lie in the controversy surrounding them as to their legitimacy as real illnesses. Postmodern illnesses are generally those illnesses that puzzle mainstream biomedicine, are sensationalized and augmented by the popular media, and stupefy the rest of us. In general, there is concern as to whether or not the expression of these biological/medical symptoms is an exaggerated response to something "normal" and then sensationalized, whether it is a response to postmodern anxiety (living in a volatile technological world devoid of emotional connectedness), or whether it is a true manifestation of an underlying illness only now understood because of recent cultural and biomedical advances. The question arises as to whether society has created the illness from the omnipresent anxiety of living in uncertain times, masked by overcompensatory and destructive lifestyles that devalue existential connectedness to others and nature, or whether the illness is truly a bonafide biological disease, making us question, as a society, whether ADHD and other postmodern illnesses actually exist.[1]

The intensity of the debate surrounding an illness is often the surefire sign that it will fall into the category of a postmodern illness. In the case of ADHD, this debate is often passionately voiced with opposing, yet equally compelling arguments, and is witness to the polarizing aspects of the phenomenon that typify these illnesses. Within this debate, 2 distinct perspectives are commonly held by the public at large: ADHD as myth and ADHD as a medical/behavioral disorder. These will be briefly described.

ADHD as myth

Taking the position that ADHD is bogus, Breeding and Baughman[3] believe that an ADHD diagnosis represents malpractice and prescribing medication for it violates informed consent. They warn parents to be skeptical and resistant to such practices. "In numbers unmatched in any part of the world, U.S. school children are diagnosed and drugged in a quid pro quo association between education and for-profit psychiatry and psychology. Labeled 'brain-diseased,' the schools have an excuse for the rampant illiteracy and unpreparedness, cause enough for the mounting unhappiness and failure of the children, while psychiatry/psychology gains lifetime patients".[4(p1)] Further, Baughman claims that the pharmaceutical company Novartis colluded in perpetuating the myth of ADHD as a disease in order to sell Ritalin, for a profit, and that the national ADHD support group, CHADD (Children and Adults with ADD) was originally founded and supported by Novartis primarily as a method for encouraging more drugs onto children. These ideas are further reinforced by the knowledge that sales of Ritalin have increased 6-fold in the last decade[5] without a clear understanding of why this increase has occurred. Living in a capitalist society where disease is profitable, these concerns are noteworthy. However, it should be noted here that a suit filed against Novartis, the American Psychiatric Association, and the American Psychological Association, claiming to have colluded in overdiagnosing ADHD as a way to increase

sales of Ritalin, was dismissed in 2001 by US District Judge Rudi Brewster, stating that the case was vague and did not state a legal claim. Despite this ruling, a recent congressional hearing took place in order to investigate these issues further and numerous Web sites are dedicated to the belief that ADHD is a fraud, warning parents to be aware of this medical, capitalist scheme on their children.[6]

Others insist that traditional methods of child rearing are being replaced by new forms of medical and social treatment, teaching children and families to trust the state and its new "science" to define and determine the ways in which children are raised.[7–9] This argument is reminiscent of the work of Thomas Szasz in the 1960s of the danger of psychiatry and the construction of mental illness as a method of oppression and social control. Those who voice concerns that ADHD is myth are genuinely concerned about the welfare of children and believe that normal, exuberant childhood behaviors have been pathologized and mislabeled as diseased as an aspect of the profit-driven and oppressive nature of living in a capitalist society.

In addition, many believe that the use of stimulant drugs is harmful to the growing child. Indeed, the huge increase in the distribution and use of Ritalin in the last decade, in concert with the ambiguity of diagnosis, lack of biological markers, and concern regarding the long-term effects of stimulants, does, and should, make us all pause.

ADHD as behavioral disorder

On the other hand, there is a very large scientific literature documenting the existence of ADHD as a common behavioral disorder of childhood. *ADHD*, as defined in the *DSM-IV*, is a "persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than typically observed in individuals at a comparable level of development".[2(p28)] These dysfunctions are manifested in symptoms, such as aggression, poor rule regulated behavior, poor delay of gratification, behavioral disinhibition, learning difficulties, poor impulse control, and low motivation, that interfere directly with achievement of developmental tasks, academic performance, and social relationships.[10] While common estimates of prevalence claim that ADHD exists in 3% to 5% of children under age 18,[2] recent reports suggest that ADHD may affect as many as 8% to 17% of children and adolescents in the United States today, posing a much more significant public health concern than was previously thought.[11,12]

There is significant correlation of ADHD with diagnoses of conduct disorder (CD), oppositional-defiant disorder (ODD), depression, anxiety, learning disabilities, and alcohol/drug addiction. Children with ADHD are significantly more impaired in their adaptive functioning than are controls and this impaired functioning is accounted for largely by psychiatric comorbidity of conduct, major depressive, or anxiety disorders.[13–17] As many as 30% to 50% continue to have the full disorder into late adolescence.[18] Aggressive behaviors and conduct problems are consistently reported as some of the primary problems associated with ADHD. As many as 70% of children and adolescents with ADHD have comorbid ODD and/or CD and 25% of ADHD adults have antisocial personality disorder.[19] Those children and adolescents with high levels of aggression and with additional comorbid diagnoses of ODD and CD, are more likely to have poorer academic, social, and legal outcomes.[19] Estimates suggest that 70% of juvenile offenders and 40% of adult prisoners have ADHD[19] and that 23% to 45% of ADHD youth have juvenile convictions.[20]

The primary biological theories of ADHD involve genetics, abnormal neurochemistry (dopamime transmission), abnormal neuroanatomy (smaller brain structures), and various other hypotheses, including adverse effects of soy-based formula on brain development in infants, infections, head injury, and environmental toxins and pollutants. However, because certain psychosocial factors, such as parent-child interactions, degree of family stability, and environmental supports, are believed to contribute to the

exacerbation or remission of symptoms,[21–23] ADHD is often called an *environmentally dependent disorder*.[24] Therefore, strategies for stabilizing the social/familial environment have the potential to improve the day-to-day life experience of these children and families, as well as decreasing the most severe symptoms of behavior.

Research on the effects of ADHD on the family indicate that parents of children and adolescents with ADHD have more negativity in their social life, less positivity in parenting, and higher levels of child-related stress than parents of non-ADHD children.[19,25,26] ADHD in children predicts depression in mothers, even without the presence of ODD or CD.[27] Therefore, because of the high rate of psychiatric comorbidity in children with ADHD and their families, family members are at increased risk for psychosocial difficulties. These difficulties warrant intense efforts to increase our knowledge of ADHD and its effects on family life, as the degree of family stability is related to the severity of ADHD symptoms and outcomes in children.

In the scientific literature, there seems to be little doubt as to the existence of ADHD. However, with the ADHD diagnosis raised to such an intense level of public debate, we set out to listen to the voices of children and adolescents diagnosed with ADHD, from diverse ethnic and socioeconomic backgrounds, and asked them what they felt was true for them and how they viewed ADHD and its treatments. While the authors are not callous to the political and ethical concerns about ADHD from the larger society as depicted in definitions of ADHD as myth, we decided to lay the debate on its side for a while and listen to what the children suffering from this illness have to say about their experience. Our compassions as researchers and clinicians lie in the struggles of the children and families where ADHD has been a major obstacle. The confusion surrounding an ADHD diagnosis propelled us into seeking further documentation of the problems associated with this disorder and to seek further clarification of what it is like to live with this disorder, from the perspective of the children themselves.

METHOD

Qualitative data from in-depth interviews with 39 children and adolescents diagnosed with ADHD from their health care providers formed the basis for the findings. These data are a subset of qualitative data from a large mixed-method study of 157 families with children with ADHD. Because ethnic and racial minorities bear a greater disability burden from unmet mental health needs relative to whites, our research design sought to recruit equal or greater numbers of African American and Hispanic families as white families. Of the 157 families included in the larger study, 50 families were white, 50 were African American, and 57 were Hispanic. A subset of these families was asked to participate in qualitative interviews, based on their willingness to participate and their ability to provide rich data. Families were recruited through advertisements and visits to ethnically diverse clinics, schools, and cultural support agencies in the Portland, Ore, and the San Diego area. Each member of the family who agreed to participate was interviewed privately. Except in the case of abuse or medical urgency, all data were held strictly confidential, both within the family and outside the family.

Two researchers with expertise in mental health services to children and families, 1 African American and 1 Hispanic American, and 2 community "insiders," served on the research team to ensure that the research was conducted in a culturally sensitive manner and to help the team understand the realities, perceptions, meanings, and experiences of the group under study.[28] These team members had knowledge and experience in the local ethnic community and served as liaisons to the African American and Hispanic community in the Portland and San Diego areas and consulted with us on the research process.

Qualitative interviews

In-depth semistructured qualitative interviews were used to collect data in regard to how children with ADHD perceived the meanings and experiences of ADHD in the context of their everyday lives. Qualitative interviews were selected because of their effectiveness for obtaining direct data of how people experience their world. Observations during the family contacts were written as field notes in a series of brief narratives, or as family portraits. These observations and family portraits on the relational patterns and the family environment were used to provide additional insights into the theoretical understandings of the data. According to Ransom,[29] holistic family research needs to include both relational family patterns and individual responses as a move toward greater clarity and accuracy of family health phenomena.

Interviews lasted from 15 to 45 minutes, depending on the age of the child, ability of the child to attend and focus on the conversation, and level of interest the interview held for the child. All interviews were taperecorded and transcribed. Six of the 39 interviews were conducted in Spanish, transcribed in Spanish, and then translated into English. The translated English versions were then reviewed by the person who originally conducted the interview in Spanish, to verify the correctness of the transcription and translation. Interview questions related to the children's experiences, descriptions, and beliefs about ADHD were asked (see Appendix).

Although controversies exist regarding the use of interviews as a data collection instrument with children, guidelines have been developed and interview data have been reported as valid and reliable.[30–35] The interview questions and procedures for this study were developed from previous work with children and families with ADHD.[36–41]

Data analysis

Interview data were audiotaped and transcribed. Transcriptions of the interviews and field notes taken by the researcher were analyzed using constant comparative analysis.[42,43] The purpose of this method is to generate conceptual categories and their properties from the data. The data analysis process began with open coding, the process of fracturing data into conceptual properties or dimensions. Through the process of comparing, conceptualizing, and categorizing data, phenomena were labeled and described in terms of properties, characteristics, attributes, and dimensions. Conceptual saturation was reached once no new codes emerged from the data.

As similarities and differences in the codes became more clearly conceptualized, the coding scheme was further refined by clustering codes together to make categories. Conceptual saturation was reached when no new categories were generated from the open codes and the remaining gaps in the emerging conceptual scheme were filled. The categories were then examined for their relationships to each other. The integration and interrelationships of the categories formed the basis of the theoretical understanding of the data. Theoretical notes were kept throughout the coding process to track conceptual decisions. A computer software package, NUDIST, was used to manage data.

Credibility of the data was established by using the techniques of peer debriefing (presenting analyses and conceptual abstractions of the data to other expert qualitative researchers, so that inquirer biases are probed, meanings explored, and the basis for interpretations clarified). Consultants served as auditors and reviewed the analysis process to ensure that conceptual decisions stayed grounded and that category development and abstract conceptualizations came from the data rather than from researcher bias or nonreflective a priori theory.

SAMPLE DESCRIPTION

A purposive sample of 39 children and adolescents with a diagnosis of ADHD was the source of the data for the findings

($n = 39$). The sample consisted of 26 boys and 13 girls. Fifteen self-identified as African American (11 boys and 4 girls), 13 as Hispanic, of mostly Mexican descent (11 boys and 2 girls), 9 as Caucasian (4 boys and 5 girls), and 2 as biracial (Hawaiian/Caucasian girl and Samoan/Hispanic boy). The mean age was 11.2 years (range from 6 to 17 years). Seventeen families were single-parent families (16 single mothers and 1 single father) and 21 were 2-parent families. One family had 2 children with ADHD. Twelve families had an annual family income below $10 000, 6 families from $10 000 to $29 000, 16 families from $30 000 to $75 000, and 4 families over $75 000. All but 2 families, both Hispanic Mexican, indicated that they received some health insurance benefits. The mothers in 31 families had at least some post–high school education, with 10 receiving college degrees and 1 with a master's degree. These sample characteristics, per ethnicity, are listed in Table 1.

FINDINGS

These findings are described using the original wording of the children and adolescents as much as was possible, with in vivo coding used frequently. We attempted to report the children's voices accurately, using as little interpretation as possible, while categorizing and reducing the data. Six categories were generated through the process of constant comparison and are described below; problems (learning/thinking, behaving, feeling), meaning and identity (hyper, bad/trouble/weird, illness/normal), pills (positives, negative), Mom, causes, and ethnicity/race/racism.

Table 1. Demographic characteristics by ethnicity

	African American		Hispanic American		Caucasian		Biracial	
	N	%	*N*	%	*N*	%	*N*	%
Primary caregiver's education								
Grade 0–8	0	0.0	1	7.7	0	0.0	0	0.0
Grade 9–11	1	6.7	1	7.7	0	0.0	0	0.0
HS diploma/GED	3	20.0	0	0.0	1	12.5	0	0.0
Some college	9	60.0	5	38.5	4	50.0	2	100.0
College graduate	2	13.3	6	46.2	2	25.0	0	0.0
Master's degree	0	0.0	0.0	0.0	1	12.5	0	0.0
Health insurance coverage?								
Yes	15	100.0	11	84.6	8	100.0	2	100.0
No	0	0.0	2	15.4	0	0.0	0	0.0
Family situation								
Single parent	10	66.7	5	38.5	2	25.0	0	0.0
Two parent	5	33.3	8	61.5	6	75.0	2	100.0
Income								
Below $10 000	8	53.3	3	23.7	1	12.5	0	0.0
$10 000–18 000	0	0.0	1	7.7	1	12.5	0	0.0
$18 000–25 000	1	6.7	2	15.4	0	0.0	0	0.0
$25 000–29 000	1	6.7	0	0.0	0	0.0	0	0.0
$29 000–40 000	2	13.3	2	15.4	0	0.0	0	0.0
$40 000–75 000	2	13.3	4	30.8	5	62.5	1	50.0
Over $75 000	1	6.7	1	7.7	1	12.5	1	50.0
Totals	15	39.5	13	34.2	8	21.1	2	5.3

Problems

When asked about ADHD, the children and adolescents in this study identified numerous everyday problems related to what they saw as ADHD. While a few children did report that their outgoing personality or sense of humor were good qualities of having ADHD, most children reported problems that often got them "into trouble." These problems were described by these children as learning/thinking, behaving, and feeling problems.

Learning and thinking

Several participants talked about problems with learning and cognition related to ADHD, particularly in relation to their "slower" rate of learning, feeling constantly distracted and confused about what was said to them or what they were supposed to do, and being bored. They often felt as if they were different from their peers because of these traits. As a 17-year-old boy stated, "Yes—I do believe I have ADHD, because I can tell that I am a slower learner and that's what I think that is. I have a hard time reading and stuff. I think I'll have it for the rest of my life. I'll always be slower at learning and stuff. ADHD is just about kids who are a bit slower in things. It's harder for me to think. . . . I always feel distracted . . . . but I don't tell anybody about that."

Others talked about it in a more self-deprecating manner. One16-year-old boy said that he thought he was mentally challenged and that it felt like he was "retarded. . .I see my friends who are at the speed of everyone else and I'm not." Some children were ostracized and teased at school because of these problems. One 13-year-old girl stated, "Some people say I'm dumb because I'm slower. I just ignore it. I don't let it get to me, because, you know, I don't think those things are true."

Sometimes, the participants talked about being confused and not understanding the circumstances around them, almost as if their struggles involved poor metacognition and self-evaluative abilities. As stated by a 14-year-old girl, "Sometimes I think I'm doing really well at something and then it comes back really bad—but I thought I had done good. That's really hard." Thinking one is doing better than one actually is, did not appear to be as much about ego inflation as it was about misunderstanding the "big picture" and lacking the ability to use feedback and be self-evaluative in a growth-producing way. Adding to this dimension was the commonly described experience of boredom and inability to sustain attention when subjects were not intrinsically interesting. "I get bored very easily and I have a hard time sitting down in the classroom because I get bored easily. . .when things are not interesting."

The vast majority of these children were either in special classes or had an Individual Educational Plan (IEP). Responses varied as to the usefulness of these classes and services. While one 17-year-old boy stated that he disliked his special math class so much that it motivated him to work harder and get reassigned to a regular classroom, another 16-year-old boy said he liked his transitional classes because it helped him learn and improved his attendance. "If I didn't have a transitional class, I wouldn't go to school. It helps my attendance. Smaller classes and more attention helps. When adults (teachers) are serious it makes it easier. A good teacher doesn't take no crap from nobody."

Behaving

Most of the children and adolescents in this study talked easily about the problems they had following rules and getting along with others. These problems included throwing and breaking things, running away, cussing and yelling at teachers, and fighting. Fighting was repeatedly talked about as being one of the major problems experienced in relation to ADHD, indicating they had difficulty controlling their behavior. Clearly, these children and adolescents seemed to struggle with the symptoms of disinhibition and impulsivity, which interfered with their ability to function socially. One 12-year-old boy said, "I'm like whacko. I beat up kids." In addition to the

amount of aggression many of these children demonstrated, many also seemed to carry this aggression as a badge of honor. "He threw a punch at me so I pushed him down on the ground and started jumping all over him and punched him. It felt good. . .he deserved it. He was such a big bully."

In conjunction with these acts of aggression, many of the participants also saw themselves as victims of others' misperception. They stated they were often the first to be blamed when something happened and felt as if they were not always believed when denying accusations. As one 9-year-old boy said about his credibility problem, "They don't believe me. Like when someone gets me in trouble and it's not my fault, I get grounded and I can't get them believe me. Those people made me in trouble and then they lied about it. I try to get them to believe me but I am still grounded." When asked why he thought this occurred, he stated he did not know, although throughout the interview he repeatedly talked about how often he got into similar types of trouble. He did not seem to understand that there was a reason his credibility was sometimes called into question.

On the other hand, some children did seem to understand that their behavior was extreme, and talked about how difficult it was to control. As one 15-year-old boy said in response to the question of what he would like teachers, doctors, and counselors to know about ADHD, "That it's something I can't control, really. It's like a part of you, like it's hard . . . like even if you try to control it, its still like the better part of you is still in there, you know. So it's not all the kid's fault. You just can't control it sometimes."

Feeling

Many of these children also described ADHD in terms of how badly they felt much of the time. Feeling sad, mad, frustrated, and ashamed were common themes throughout the interviews, indicating that these children were aware of the emotional effects ADHD had on them. These emotional responses were most often a result of the learning and behavioral problems they were experiencing. As one 16-year-old girl said, "I get frustrated in school. I get frustrated at things. When I get home I get frustrated with people and stuff. I get really sad sometimes. I see my friends who are at the speed of everyone else, and I'm not. I get sad." an 11-year-old boy said, "It feels like I'm a good person. I wouldn't do anything bad on purpose. I just feels really bad." This boy also talked about how sad he felt for his family having to do so much to take care of him.

Others talked about their sadness in relation to loss; of others not wanting to be around them, not feeling welcomed from their extended families, or loss of family members due to drugs and alcohol abuse. A 9-year-old boy who had lived with various relatives because his mother was addicted to drugs and alcohol said, "It just bugs me that nobody wants me." This was from the same boy who also believed that he had ADHD because his mother used drugs while being pregnant with him. He had had a great deal of difficulty controlling his behavior and was moved from one family member to another family member. The severity of his symptoms was undoubtedly related to both the neurological damage caused in utero and also from the environmental stressors of living in an unstable family environment.

Anger was also a common theme, from both boys and girls, and was often linked to feelings of sadness, as if the anger was secondary to and in response to the experience of sorrow and frustration. An 8-year-old boy said, "I get mad and I throw an attitude—I have an attitude and I talk mad . . . . It just gets hard sometimes."

Some of the children reported feeling ashamed of having ADHD. One child noted that other children at school made "fun of her" when she had to leave class to get her medicine. Another reported: "I don't want anybody to know that I take pills. . .because then they would laugh at me." Still others reported that children at school "think I'm stupid." These circumstances often led to feelings of shame and stigma.

Meaning and identity of ADHD

By far the most troubling aspects of these data were the meanings and the overidentification these children placed on having ADHD, as if they had an ADHD identity. Although some of these responses seemed to overlap and border on the problems associated with having ADHD, as described above, what was distinct in these data was the significance of what ADHD meant to them. These children often talked about ADHD in terms of who they were, rather than the symptoms they experienced. ADHD seemed to define much of who they were.

Hyper

Children in our study typically reported that ADHD meant being hyper: "I have hyperness," and "ADHD is hyper and you need a lot of attention." ADHD meant "being out of control," that they were unable to "concentrate," were "easily distracted," had "trouble focusing," were "confused," and had difficulty "staying on track." They reported "talking too much" and having a "hard time sitting down." One respondent summarized these perceptions when answering the interviewer's questions about why she was taking Ritalin. "Cos if I don't take it, I'll be bad, like hyper. I get out of control. I sometimes talk a lot and I'm bad. And I get mad. . .I sometimes throw things.

Being hyper was associated with "being bad." As an 11-year-old girl described, "ADHD means you're hyper, and you act up and acting up means like doing something bad that you are not supposed to be doing and like doing something that just (is) not right."

Bad, trouble, and weird

The word "bad" was used frequently throughout these interviews, but particularly so for African American children. Some struggled with the idea that they were "bad" and began to incorporate this idea into their identities: "I believed I was the baddest kid. . .(but) I'm a good person." After starting on Ritalin, another said, "I was a little badder than I am now. I was really bad." A 7-year-old boy said, "(I take the medicine) so I won't be bad . . . . cos if I don't take it I'll be bad."

For others, particularly the Hispanic children, ADHD meant repeatedly "getting into trouble" both at school and at home. "ADHD gets me in trouble. . .just not being able to sit still and stuff. . .I'm really fidgety." Caucasian children similarly reported that ADHD got them into trouble, but several also noted that it made them feel "weird. . .'cos sometimes you can't answer some of the questions in math and some stuff like that and it kind of makes me upset."

Illness/normal

Although most of the children talked about the problems they had always had and the trouble they got into, ADHD did not become a "real thing" for them until it was legitimized and formalized through authority figures, usually when physicians, mothers, fathers, and teachers told them they had ADHD. Authorities helped to construct the reality of ADHD as an illness. When asked how he knew he had ADHD, one boy reported: "My mom. We went to a doctor." Another said, "My teacher discovered my ADHD." Others noted more than one person was involved in the diagnosis: ". . .'cause all through school. . .I was always, like, in trouble by a teacher. So, they took me to the doctor, and the doctor told me that I had it." These authorities legitimized the problem, giving it a name.

A 13-year-old girl stated, "This dude, like a psychiatrist person, told me that I had it and stuff, and then I was scared, and I told him that I didn't have it, and I refused to think that I had it. Probably like a year ago . . .I started medication. . . I finally let them give me medication."

Although most of the participants believed they had ADHD, not everyone thought of ADHD as an illness. Several conditions had to exist before children discussed ADHD in terms of a "disease" or illness. Authorities had to legitimize it and give it a name, it had to be severe enough to cause problems, and it had

to interfere, in some way, with how one functioned. Children assessed the severity of both their own ADHD and that of others. Generally, ADHD became a "problem" when it started to interfere with functioning. "Like some people who have it really bad, probably feel more that its an illness than the people that don't have it as bad." Another commented: ". . .if it's (ADHD) really bad, then it can get in the way of your schoolwork and that kind of stuff, and therefore, be an illness. But for some people, it's just the way they are."

Participants who considered ADHD an illness reported numerous difficulties living with it, but also reported the strategies they used to deal with it: "ADHD is an illness—yeah—you can either take care of it or not take care or it. You can let it get worse and let it take over your life, or you can accept it and get rid of it." Noteworthy is the chronic nature of ADHD that emerged in these stories: "I do good some days and on others, I do bad."

For some children, however, ADHD was not considered an illness, but rather, a normal "part of who they were." Those who considered it relatively normal separated ADHD from what they identified as their health, and they saw themselves as "just different." These children described ADHD as the "thinking in your mind" or "something wrong with your mind." Others reported, "It's just who I am," "It's just the way you are," and "It's just something . . .that God made you with." One child noted that ADHD was not a disease but a "disability." Still others told us that ADD/ADHD was "a pill" that they took. As illustrated below, taking "pills" was a major storyline throughout these data.

Pills

Taking pills was a common theme throughout these data. For some, ADHD meant the pills themselves. "ADHD is the pill I take." For most, however, they understood that "the pills" were a way to help them with the problems they were having. All of the children and adolescents in this study had taken medications for ADHD at some point in their lives; the ones most frequently mentioned were Ritalin and Adderal. The participants reported both positives and negatives in relation to taking pills for ADHD.

Positives

Many of the participants talked about how helpful the medications were to them. Some talked about how their medication helped them control their hyperactivity, increase their concentration and improve their grades, and helped them become more behaved. "I'm really hyper, but I can control it with a pill." "I always take my medicine. It calms me down, so I don't get wild."

When asked what helped the most with dealing with ADHD, the majority of the child and adolescent participants said it was the medicine. Others talked about it in terms of what happened when they did not take their pills. One 13-year-old boy said, "When I don't take (my pills) I have a bad time concentrating at school and sometimes I talk a lot and I can't like focus on my work. The hardest thing about ADHD is that sometimes I forget to take (the pills) and then I can't concentrate."

Negatives

The participants also talked in terms of what they did not like about taking pills. Frequently heard was that Ritalin tasted bad. In addition, some mentioned problems with side effects of the pills, primarily headaches and stomachaches. Of greater concern was the fear and shame associated with taking pills to control behavior.

"I don't want anybody to know that I take pills . . . because they would laugh at me."

"I'm scared to take it because my Mom was taking drugs when I was a little kid . . . . and I'm a drug baby. So I could get hooked on that kind of stuff very easy." Her aunt, with whom she was living, had similar concerns and this 13-year-old girl was taken off Ritalin and her aunt placed her on a herbal medication instead.

In addition, several participants talked about not wanting to take pills because they

did not like the change the pills made in them. As one 14-year-old boy said, "I don't like it. I just want to be myself. My Mom makes me take it so I can focus. . .but I just want to be myself."

Another participant said, "It just like changes me . . . it makes me awful, like this way. . .. It's like, I don't like to play that much anymore."

"Ritalin. I don't take it anymore. I didn't like how I felt on it. I felt real depressed on it."

It appeared that although the medications these children and adolescents were on were helpful to many, there were also drawbacks to the medications, indicating the need for health providers to listen to the children and adolescents for whom they prescribe and not to use only parents' or teachers' reports on evaluating the appropriateness of medication use.

Mom

Although many of the participants did not think that ADHD affected their family and seemed to lack insight on the effects of their problems on family life, the importance of their mothers to them was clearly visible. The most frequent response to the questions of who helps you the most and what support do you need to help you with your ADHD, was Mom. These children often talked about how important their families were to them, and without question, the most important person in the family to them was their mothers, or when mothers were absent, the primary caregivers in the mother role, ie, grandmothers and aunts. Family life, of which Mom was central, was mentioned throughout the interviews.

"My Mom keeps me safe."

"My Mom understands me."

"My Mom's the best."

"My Mom does good with my ADHD."

"My Mom helps me the most."

"My Mom is the only one who helps me with my homework."

These children also worried about their mothers, both in terms of the effects of ADHD on them and the family, and because of their mother's health problems.

"I feel bad for my Mom because she doesn't know how to help me and she tries hard."

"Sometimes I get in trouble at school and the school calls and my Mom has to come and take me back to work with her, and she's not suppose to. I worry she'll get in trouble, but she says she won't, but she don't like it, but she loves me so she do it."

"The hardest thing about ADHD is what it does to my Mom. I mean, she doesn't say it, but I know it's frustrating for her because I pull out my paper late at night and she gets frustrated because she's so tired. She goes to school too and she told me after last night to bring out my homework while she is doing hers while she is still energizing. She's tired a lot."

"The thing I worry most about is my Mom. She's sick a lot. She has diabetes. I worry about her and don't want to be too much trouble on her."

Causes

Of the 39 children interviewed, 23 responded to the question of what they thought was the cause of ADHD. The other 16 children did not want to answer the question, were unable to focus enough to answer it, or ignored the interviewer. Needless to say, interviewing children whose primary difficulties involved problems with focusing, concentrating, and paying attention posed significant challenges to the interviewers.

Nine children stated that they did not know the cause of their ADHD. "I don't know what causes it, but I know its bad." Five said they were just born with it, that it was just the way their brain worked. "My brain just works that way. One half of my brain works and the other half doesn't." Four stated it was "in the genes" and hereditary. Two believed they had ADHD because their mother used drugs and alcohol during pregnancy, 1 said ADHD was related to an accident at birth, and another said going through many family tragedies caused her difficulties. One 7-year-old girl said ADHD was

caused by sports, but was unable to explain what she meant by that. Although this category of data is sparse, it is indicative of some of the perceptions children have about ADHD and the overall lack of information they have regarding their illness.

Ethnicity/race/racism

In concert with Glaser's analytical strategy[44] of not raising demographic variables to the level of conceptualization unless their importance demands it, let us mention here that we did not see differences in the data related to gender, age, or income. While it makes intuitive sense that older children would have more insight and verbal skills than younger children, and that families with higher levels of income would have more resources and so their children might have fewer problems and less severe symptoms, our analysis did not demonstrate this. Two of the highest income families had children with the most severe symptoms of ADHD and many of our 9-year-old and 10-year-old participants verbalized and shared insights at a higher level than did the teenagers. In relation to gender, we were often surprised to find that some of the stories regarding aggression and fighting came from girls, breaking the stereotype that boys were more aggressive than girls, even with ADHD present. In fact, one of the participants whom we were most worried about in relation to aggression and fighting was a girl.

However, in relation to ethnicity and race, we did find some interesting differences. As stated in the "Meaning and Identity of ADHD" section, African American children used the word "bad" much more frequently than did the Hispanic or Caucasian children when describing themselves in relation to ADHD. Hispanic children more frequently discussed the meaning of ADHD in terms of "trouble" and "getting into trouble" and Caucasian children were the only ones to mention being "weird" or "whacko." While we will not draw conclusions based on this, it is an interesting difference and one that needs further follow-up regarding ADHD children's self-appraisal.

Because ethnic and racial minorities bear a greater disability burden from unmet mental health needs relative to whites, and in line with previous work on the importance of explicitly asking participants about their culture, as well as their experiences with racism and discrimination,[45,46] we asked all participants who self-identified their ethnicity as African American, Hispanic, or biracial what their ethnicity meant to them, and if they had experienced any episodes of discrimination or differences in how they were treated from white Americans. The most frequent answer to these questions was that they did not think they were treated any differently from white people. The response from a 9-year-old Hispanic boy was typical of most of the responses, "We're no different from anybody else. No one treats me any differently. I get the same stuff at school as everybody else." One 16-year-old Hispanic girl added a bit more dialogue to this perspective, "I'm not discriminated against, but we are different from White America. It's hard to explain. But they have more money and can get the help they need—they can pay for whatever they need. We don't have that kind of money and we have to get help wherever we can. Yes—life is different for us than for White Americans—because life is more difficult for us and it's not that difficult for them. It's easier for them to learn. We come from over there and we have to learn the language, to learn English and it's just more difficult for us. And we don't have the money for everything we need."

Although few reported episodes of discrimination, 4 participants did talk about specific incidents that had happened to them. A 9-year-old Hispanic boy said, "Yea—kinda (referring to discrimination)—people lying about me" and a 13-year-old Hispanic girl said, "There is a teacher at our school that is racist to Mexicans. He hasn't really done anything that much to me, except yell at me all the time, but that's not that bad. At first he was really nice. He wouldn't do anything and then he heard me speaking Spanish . . . . And

he just acts different now and always writes down my name and gives us detention and stuff."

Two African Americans boys, aged 11 and 12, also spoke of incidents of discrimination. "There was this one teacher in 4th grade. She would give all the African American kids F's and stuff and all the white kids, like a bunch of A's and that kind of stuff." I think white people try to bully us because they are still prejudiced."

These reports are hard to evaluate and further work needs to be done on developing methodological strategies for obtaining rich data about racial experience with children and adolescents. As researchers we need to figure out how to ask these questions of children, taking into account the developmental appropriateness of asking about experiences of broader social context when children may not yet have the verbal skills, trust, or context to understand the intention of those doing the asking.

DISCUSSION

Recognizing that the meaning of ADHD is both culturally and medically defined and that ADHD as a postmodern illness is surrounded by controversy, these data demonstrate that affected children and their families suffer from real problems and that biological treatments (ie medications) are often viewed as effective and helpful. These data indicated that these children were socialized to believe that they should "be good," which created a constant internal tension, or dissonance, between what they believed they should be doing and what they, in fact, were doing as they tried to account for the many difficulties they were having. Thus, participants attempted to deal with "getting into trouble," being "bad," and feeling "weird" as they came to know more about ADHD. They struggled with symptoms and their own adequacy as they faced a constant dissonance between what they had to do and what they were doing.

The participants in this study knew they had problems, although it was not always clear to them what accounted for those problems or what ADHD was. They saw themselves as different from their peers and knew life would be easier for them and their families if they did not have ADHD. Although some of the children mentioned that they thought they were "normal, but just different," none of them denied having ADHD-associated problems. Some of the children also thought of themselves as abnormal, using words such as "retarded," "bad," "weird," or "whacko." It is clear that ADHD interfered with the kinds of social and academic tasks children are expected to perform and that it was not that they were just more exuberant children, further supporting the argument that ADHD truly exists and that they and their families are in need of intervention. Helping families who have children with ADHD by focusing on ADHD as an illness and helping them manage the symptoms, serves to replace blame and criticism with understanding and support, thereby helping to stabilize the family, which, in turn, helps to decrease the symptoms of the ADHD itself.[19] The idea that ADHD is a bogus disorder smacks of ignorance and naiveté among those who do not live with its sequalae. Clearly, these data indicated that these children are in need of a compassionate society looking out for them, rather than being victimized by further debate of the authenticity of the diagnosis.

These data support the perspective that children are aware that they have problems related to ADHD and that it is not just a figment of their imagination or a condition placed on them unreasonably. We believe that the national debate about ADHD reflects the ambiguous and frightening nature of childhood behavioral and mental health problems and speaks to the poor understanding that we have, as a society, when faced with the challenge of how best to provide services to our young people and their families. Findings from this study indicate that ADHD exists and that many of these children suffer from real problems. Given these discoveries, the

continual debate about the authenticity of ADHD only further victimizes families who are in desperate need of services.

Clinically, we have witnessed children and parents become overwhelmed with the academic, behavioral, and social problems associated with this disorder and have talked to parents distraught with worry and fear over the disturbing nature of their child's difficulties. It is our contention that the problems these children have are a day to day experience of pushing up against the norms society expects, falling and struggling to get back up again. While clearly there are multiple ways in which to name these difficulties, and in fact these data demonstrate a variety of ways these children indicate what ADHD means to them, none of the participants in this study denied that they had difficulties and many of the difficulties they described corresponded to *DSM* criteria and the scientific literature. One could claim that this correspondence is related to the scientific persuasions of the researchers interpreting this data; however, it seems a far stretch to think that the struggles these children endure on a daily basis are the fault of overzealous educators, physicians, or researchers. The continual debate about the authenticity of ADHD only further victimizes families who are in desperate need of community support. ADHD and its manifestations are a health problem that has enormous consequences for society and implications for social policy, given the rates of incarceration for this population. We suggest that the tenor of the discussion change from whether or not ADHD exists, to recognizing that these problems are real for these children and that we, as a society, should hear their needs and provide them with better services. While ADHD may be viewed as a postmodern illness, embedded in controversy reflective of contemporary values and culture, we believe that ADHD is not a hoax, myth, or distortion of lived reality.

"Conservatives are sure it's a sign of parental laziness. Liberals are sure it is big business, in the form of drug companies conspiring to ensnare large numbers of American children. Observers of no particular outlook are nonetheless likely to believe ADHD is either a fraud or an invention. . .The idea of ADHD as a myth fits our suspicions about contemporary America—excuse seeking, shortcut finding and irresponsibility. But on closer examination, it turns out the myth is a myth."[47]

The ongoing debate regarding the authenticity of ADHD as a legitimate medical/ behavioral disorder circumvents the resources and energy needed to provide these children and families with the services they need. Schools are required to evaluate students for eligibility of specialized services under Section 504 of the Rehabilitation Act of 1974 and to assess the extent of the child's educational problems and to develop and implement needed services. Yet, the continuous debate surrounding the diagnosis of ADHD impedes progress toward meeting these goals. Schools are not meeting their obligations to provide services to these children and too often the relationship between parents of children with ADHD and their teachers is adversarial.[48] School nurses are in a unique position to address the medical, behavioral, social, and educational concerns parents and teachers raise specific to the problems children with ADHD have from the perspective of the state of the science in ADHD research today. Nurses in primary care settings can refer these children and families to specialty mental health services where providers have the knowledge and skill to help them. "The burden of suffering experienced by children with mental health needs and their families has created a health crisis in this country. Growing numbers of children are suffering needlessly because their emotional, behavioral, and developmental needs are not being met by those very institutions which were explicitly created to take care of them."[40(p3)] By promoting awareness of the issues related to ADHD and reducing the stigma surrounding mental and behavioral disorders, child and family-centered mental health services can become an integral part of a child's overall health plan. Nurses need to identify

potential behavioral and academic indicators of ADHD to provide early intervention services to these children and families before the disorder threatens child and family psychological stability and academic progress. Families are central in the care of children with mental health needs. Efforts to promote culturally appropriate mental health services must include strategies to strengthen families and to decrease barriers to care by providing services that are affordable and effective.

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Appendix

Interview Questions for Child/Adolescent With ADHD

Establish rapport by spending some time getting to know the child and talking about things of interest to him/her. This initial content also assists the researcher in establishing a contextual understanding of the child's life. Use "warm up" questions as a way to build trust and rapport with children.

I. Warm-up Questions: Spend some time getting to know the child and talking about things of interest to him/her. Ask questions in a way that is developmentally appropriate and individualized for each circumstance. Tell me about yourself. How old are you? What grade are you in? What's your favorite thing to do in the whole world? What is your favorite subject in school? Spend some time talking about what the child is really interested in. Develop trust and rapport.

II. Description of ADHD
   - How would you describe yourself?
   - Tell me what it is like having ADHD. What's is it like for you? What's easy/hard about it?
   - How would you describe ADHD? What is ADHD? Do you have a name for it?

III. Beliefs About ADHD
   - What do you think ADHD is?
   - How do you know you have ADHD? What do you think ADHD does to a person?
   - Where does it come from?
   - Do you think you have ADHD?
   - What do you think causes ADHD?

IV. Help
   - What helps you the most?
   - Is ADHD an illness? Does it have anything to do with health? Why, or why not?
   - What kinds of support are most helpful?

V. Treatment Issues
   - What treatments are you currently on?
   - Do you think these treatments are helpful? Why, or why not?

VI. Contextual Issues: Because ethnic and racial minorities bear a greater disability burden from unmet mental health needs relative to whites, we asked only African American, Latino and biracial children these questions in order to better understand their specific health service needs and experiences.
   - What should researchers and clinicians know about what it means to be African American/Latino.
   - Is your life different from white Americans? How? Tell me about that.
   - What has your experience with your school, or doctor, or nurse been like? Tell me about that.
   - What would you like doctors/nurses/counselors/teachers to know about you and your family? What do they need to know about what it means to be African American or Latino?
   - Do you think that being African American/Latino affects how you or your family are treated? How?
   - Have you ever experienced what you thought might have been discrimination from your teacher or doctor or school nurse? Tell me about that.
   - Where do you get most of your support and help when something goes wrong for you?
   - Who provides you with the most support? What kinds of support are most helpful?

VII. Closure: Is there anything we haven't talked about that you think is important for me to know?