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# “You have to be Proactive with Your Child’s Health”: Learning and Health Literacy among Caregivers of Children with ADHD

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**Abstract:** This paper uses focus group data to examine health literacy among 26 low-socioeconomic status, minority caregivers of school-age children with ADHD. To cope with their child’s ADHD symptoms or diagnosis, caregivers used observation, gathered information from multiple sources, and discerned how to obtain services within confusing system healthcare and education systems.

In 2011, nearly 11% of children in the U.S. (6.4 million) had been diagnosed with attention deficit hyperactivity disorder, or ADHD; of these, 3.5 million (69%) were taking medication (Visser et al., 2014). To address children’s ADHD, parents need to seek information, understand diagnoses and treatment options, and discern how to obtain support services in complex healthcare and education systems, all vital aspects of health literacy. This can be a bewildering experience, especially for caregivers with limited income, education, or literacy. Most existing research on information seeking among parents of children with ADHD focuses on White, higher-SES adults—precisely those groups most likely to obtain and understand information about diagnoses and treatment (Bussing, Gary, Mills, & Garvan 1998). Moreover, adult education researchers have paid scant attention to parental learning and health literacy concerning ADHD. This paper addresses these gaps by using focus group data to explore how 26 racially diverse caregivers learned about ADHD and navigated the healthcare system.

## Literature Review

The National Library of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, qtd. in Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 2). This definition is aligned with the historically dominant “clinical” view of health literacy, which focuses on the functional skills that allow individuals to enact their role as a patient (Pleasant & Kuruvilla, 2008). From this perspective, individual health literacy can be measured using a variety of instruments (Nielsen-Bohlman et al., 2004). We align ourselves with critics (e.g., Nutbeam, 2008) who claim this view frames health literacy as a risk and unduly focuses on individual compliance with medical personnel.

By contrast, the more recent “public health” (Pleasant & Kuruvilla, 2008) or “asset” (Nutbeam, 2008) framework views health literacy as a resource that equips people to navigate healthcare systems, to critically assess information, and to take more control of their own health and that of family members (Nutbeam, 2008; Rudd, 2007; Sørensen et al., 2012). Rather than an individual, decontextualized skill, health literacy is a dynamic social practice situated in specific sociocultural settings (Nutbeam, 2008; Papen, 2009). For instance, the demands of different

situations shape how people navigate healthcare systems and novel health conditions (Villaire & Mayer, 2008). Health literacy is also a *shared* resource, meaning that people exchange knowledge, interpret health information, and make healthcare decisions with help from family and friends (Papen, 2009). The public health perspective of health literacy also holds healthcare practitioners responsible for communicating (orally and in writing) in ways that patients can understand. Currently, much healthcare information is available only in print and written at a reading level higher than many patients can decode or comprehend (Ronson & Rootman, 2012).

Parents of school-age children with ADHD may also struggle with health literacy. Raising a child with ADHD—seeking information and treatment, understanding diagnoses, making decisions about treatment, interacting with health care professionals—is a formidable challenge, especially for caregivers who lack access to social, economic, and educational resources and support. Research suggests that marginalized parents' preferred information sources and help-seeking behaviors differ from those of mainstream parents (Bussing et al., 2003). For instance, parents of low-SES, minority group children with ADHD are less likely than other parents to engage in empirically supported parenting interventions for childhood ADHD (Miller, Nigg, & Miller, 2009). Many low-income caregivers and parents of color tend to distrust medical (Rajakumar, Thomas, Musa, Almario, & Garza, 2002) and school (Bussing et al., 2003) professionals. Their health knowledge is shaped by preferred information sources such as churches, community centers, TV, and radio (Williams, Anstrom, Friedman, & Schulman, 2007). Thus, although functional health literacy skills such as reading comprehension are important, they are not sufficient to explain how marginalized parents learn about or address the health needs of their children or their own needs as caregivers.

### **Research Methods**

Since most information and materials on ADHD are derived from or created for middle-class, White parents (Bussing et al., 2003), we wanted to understand how racially/ethnically diverse caregivers with limited schooling and income sought to obtain relevant, comprehensible information concerning ADHD and made decisions about ADHD treatment.

The study was conducted in a small Pennsylvania city with a racially diverse population (at least 70% African American or Latino), high levels of socioeconomic disadvantage, and low educational attainment. This site was chosen because Penn State has an established community partnership and interdisciplinary research center in the city. We collaborated with community partners to recruit caregivers of color who had lower educational attainment, lower income, and at least one school-age child (Kindergarten to 5<sup>th</sup> grade) with ADHD symptoms or diagnosis.

We conducted 6 focus groups with 22 women and 4 men. Each participant received \$50 for attending two 90-minute focus groups. Participants were aged 24 to 65 (several women were custodial grandmothers), with an average age of 39. They identified as African American (n = 21), Latina (n = 3), White (n = 2), and/or multi-racial (n = 2). Twenty-two of the participants had annual household incomes of less than \$35,000; twenty had a high school education or less and five had some college but no degree. Nine had children with a formal ADHD diagnosis.

The focus groups, led by African American community facilitators, explored parents' experiences of raising a child with ADHD, including how they sought out information and made decisions based on information they received from medical personnel, friends, family members, literature, or other sources, and what assisted them in providing a constructive, supportive environment for their child inside and outside of their home. For this paper, we use a sub-set of data describing parents' learning about ADHD and navigation of the healthcare system.

The focus group recordings were transcribed and analyzed. Transcripts were coded using directed content analysis, which combines inductive and deductive analysis (Hsieh & Shannon, 2005). We then identified themes that related to our key questions: How do caregivers seek out and make sense of information about their children's ADHD symptoms or diagnosis? How do they make decisions about ADHD treatment? What are their experiences of interacting with professionals involved in diagnosing and treating their children? What kinds of supports do they need to raise a child with ADHD? Four team members independently coded the transcripts, met and discussed the results, and refined the codes. These team members then presented the main codes and findings to the full team for discussion, which led to additional analyses.

### **Findings**

We identified key themes that revealed how participants sought information about ADHD and learned to navigate a labyrinth of insurance regulations, city and school support services, and healthcare providers to help their children. Participants revealed that they began this process by requesting a referral if there was a behavior concern ("I know that something is not right here") or because a professional recommended an ADHD evaluation. All participants stated that the system for diagnosing and treating ADHD was cumbersome and impeded effective and timely services. Participants felt that they were left on their own to "figure it out," and had varying levels of trust in the helpfulness of medical professionals. For most participants, their child's ADHD symptoms or diagnosis initiated a learning process that relied on observation; gathering information from personal experiences, social networks, the Internet, and other sources; and discerning how to obtain the services they needed in a confusing system.

#### **Observation**

Observation of child behaviors was a key strategy for gathering information about ADHD and deciding how to address concerns or symptoms. For example, a mother stated:

When my son was on the meds, everything bother him. If he hear a little noise, he start fightin'. Like he just, irritate....That's why I have to take him off the meds. When I take him off the meds, there was nothing. He just calm, come back like a normal little child.

Another mother mentioned taking notes to keep track of her son's reaction to medications, while another participant used school records to track and learn more about her child's behavior.

Similar to participants' seeking a referral because they sensed their child was not functioning as expected, parents used personal knowledge and childrearing experiences to inform how to work with their child. For example, one parent stated, "I think [I trust] my own personal experience and I would just go with my instinct." Personal knowledge included examining family incidence of ADHD, illustrated by the mother who explained, "You always look at the grandparents" to understand the child.

#### **Social Networks**

Through their social network of family, friends, acquaintances, and other trusted sources such as pastors (Williams et al., 2007), participants learned about managing behavior, accessing support services, navigating insurance and school systems, and medication options. Many of these caregivers were eager to find explanations for their children's symptoms and alternatives to medication such as structured activities. For example, one mother said, "My pastor last week, he told us some of these children got energy, they just need to go do something."

Participants assessed the advice they received in terms of trust and the person's experience of raising a child with ADHD. Trust was based on reliability of information and perceived integrity, as when one mother stated, "I knew that she wouldn't be as biased as some

people that might have been trying to give me information.” Parents gave more weight to people who had experience dealing with ADHD, like the mother who commented, “[I trust] people who actually have dealt with it, or been through it or who are going through it.... I’m going to the person who I feel as though had that experience and can help.” For one mother, having a parent advocate (a professional who helps parents obtain appropriate special education services) was instrumental for learning her rights within the school system. Interactions among the focus group participants evidenced these findings; they supported and commiserated with each other and shared experiences, resources, and strategies for getting information and services, highlighting the shared nature of building health literacy knowledge (Papen, 2009).

### **Books, Internet, and Other Resources**

Parents learned about new interventions (for example, diet modification, medications, or tactics to help children focus on schoolwork) from a variety of sources, such as brochures and television programs. Parents listed examples such as creating “be-bop” rhymes or eliminating gluten or sugar. They enhanced their knowledge and assessed doctor’s advice by seeking second opinions and conducting their own research. One mother elaborated on her strategy for understanding and establishing herself as knowledgeable when interacting with professionals:

I work in the medical field and so...when they throw a medication at me, I go get my reference handbook and I’m already looking at medications. And I’ll come back and like when they was saying, “Well, we’re going to put him on Methylin?” I was like, “Well, you know, that’s similar to Concerta,” you know what I mean? And then they was like, “Well, yes.”...And so I do that. And I’ve got doctors readily accessible to me, so I ask them. And that’s just been one advantage that I have had, being in the medical field.

Participants primarily mentioned using medical books, accessing websites, and contacting people listed on informational brochures. Although parents did not express difficulty reading informational literature, they stated that such literature was often out-of-date or run of the mill, and therefore not useful in learning more about managing their child’s behavior, medical treatment, or understanding ADHD more fully.

### **Persistence and Perseverance**

Learning to navigate the healthcare system is a recently recognized component of health literacy (Nutbeam, 2008). Participants described “fighting” with schools and insurance providers that gave them the “runaround,” making it difficult to know which services they were eligible to receive and then to access them. In particular, parents had to figure out how to work around insurance regulations that governed the referral process, the number of allowable sessions, obtaining a second opinion, appealing denials, and so on. Asking questions and doing their own research were key strategies both for navigating the system and learning about their child’s ADHD symptoms or diagnosis. For instance, a mother commented, “You have to ask questions. I was taught to ask questions. You don’t just accept everything that’s told to you. You have to check it out for yourself.” Similarly, they navigated the system by being persistent and “proactive,” as illustrated by the following remarks: “I’ll keep going until I get my answer;” “You have to fight with the insurance. You have to be proactive with your child’s health.”

These strategies signal the development of *critical* health literacy, which includes the ability to advocate for one’s needs and to question and assess information accuracy (Nutbeam, 2008). Although some parents were able to utilize the system and obtain useful information, they all expressed a view akin to this mother, who did not want the doctor “just leaving me in a box with one option and [me] leaving the office with just some sort of understandin’, and I truly don’t understand what it is.” Instead, they wanted to be presented with more than “one option”

for treating their child and have a thorough understanding of how to treat and work with their child's behavior or diagnosis.

Some examples of non-formal learning emerged, such as the mother who reported that a mental health practitioner explicitly taught her how to restrain her son and another woman who participated in a university-sponsored parent education program. Regardless of how parents came across information, they reported that learning was difficult: "I became more educated about it. I recognized it [ADHD] for what it was, and I came through the storm." Their experiences of interacting with schools and service providers evidenced that muddling and persevering through numerous appointments, onerous insurance claim paperwork, and confusing medical language was key to learning more about how best to help (or not help) their child.

Parents provided specific examples of information, resources, and activities that they thought would support their learning. For example, they desired accessible printed information about ADHD that would provide in-depth explanations or engagement that would "break it down for them [parents], so they could understand it." Parents noted a need to raise their awareness of supportive programs and services. However, they also signaled that health literacy is not simply a requirement for caregivers by noting that school personnel, school boards, and the public at large also needed to be better informed about ADHD (see Nutbeam, 2008; Pleasant & Kuruvella, 2008) to ensure that children's and parents' needs were met. Referring to the public awareness of autism spectrum disorders, a participant stated, "I think we need a color and a ribbon because people don't really understand the mental drain and ADHD awareness."

### **Discussion**

The findings elucidate how caregivers developed health literacy concerning their child's ADHD. They used a constellation of strategies to learn about ADHD and access services from insurance companies, providers, and schools. Importantly, they emphasized the need to persist, question, and advocate for their needs, which contrasts with the emphasis on passive, compliant patients implied in some health literacy research. Participants had questions about what causes ADHD and the most effective ways of treating it. They were not interested in prescriptive solutions, but rather in understanding and communicating with professionals about solutions, further dispelling the notion that health literacy is an individualistic competency.

Medication is considered the most effective method of treating ADHD (Visser et al., 2014), yet this was also the most complicated and questionable treatment for these parents, in part because information they received from medical professionals was unexplained or they were unable to win their "fight" with the system. Thus, advice from trusted sources and treatments with little or no empirical support were often sought out (Miller et al., 2009; Williams et al., 2007) because the information was accessible and they encountered it through their own research (e.g., reading websites, viewing television programs, talking with experienced parents).

Furthermore, although they may not have reported difficulty *reading* information about ADHD, it is clear that the information they have encountered to date has not answered all of their questions about topics such as the origins and growth of ADHD diagnoses over time, the role of diet and activity in treating ADHD, use of medication, and more. These findings indicate that health literacy does include functional skills; however, it also includes the ability to access information, navigate the supportive services system, and form relationships with professionals and providers who communicate in understandable terms (Paasche-Orlow & Wolf, 2007).

Our findings suggest that information and non-formal education opportunities such as workshops for caregivers should be offered by people whom the intended audience considers

trustworthy and knowledgeable. In addition, caregivers need coaching and support to become advocates for their child's needs; this includes explanations of locally available services and how to access them, parental rights, the insurance system, and interacting with professionals—in sum, how to “fight” to get what they need, or critical health literacy (Chinn, 2011). Adult educators are poised to provide these types of support, along with learner-centered health literacy curricula.

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