

2015

Attention-deficit/hyperactivity disorder : experiences of diagnosis, treatment, and management by African American caregivers

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Lydie Helene Gnacadja
Attention-Deficit/Hyperactivity Disorder:
Experiences of Diagnosis,
Treatment, and Management
by African-American Caregivers

ABSTRACT

According to the diagnostic and statistical manual of mental disorders 5th edition, attention-deficit disorder is a childhood disorder in which symptoms of hyperactivity, inattention, and/or impulsivity are present for at least six months and must be present prior to a child turning 12 years old (American Psychiatric Association, 2013). Gapin & Etnier (2013) stated the following, ADHD “is one of the leading childhood psychiatric disorders in America and is a costly major public health problem” (p. 1). There is limited research on African American caregiver experiences (Miller, Nigg & Miller, 2009) and social workers would benefit by being familiar with African American caregiver experiences. My research attempted to understand African American caregiver’s experiences’ with diagnosis, treatment and management of their children’s ADHD symptoms.

The voices of twelve African American caregivers were captured through an online survey utilizing qualitative analysis. The survey focused specifically on their experiences with their children’s attention-deficit/hyperactivity disorder. The findings suggest that African American caregivers are advocates for their children, want to be acknowledged and invited in the process of diagnosis. In addition, they have different management strategies to help their children with their impulsivity, impatience and excess energy such as reading, making lists, and limiting television usage. Finally, the findings revealed the progress the children have made (i.e., being patient and self-advocates) and the caregiver’s undeniable love for their children.

**Attention-Deficit/Hyperactivity Disorder: Experiences of Diagnosis, Treatment,
and Management by African-American Caregivers**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

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2015

ACKNOWLEDGEMENTS

This thesis is made possible by being in the Holy Spirit, by constantly praying and seeking guidance from Jesus Christ. Prayers/positive thoughts came from family members, my church family, friends, faculty, staff and colleagues from Smith Council for Students of Color.

My mother, Cora Filomena Alves, and my sister, Colette Helene Gnacadja have been strong forces in my life and they continue to be supporters of my personal and professional pursuits. My son, Kasmir Danyan Barboza, has also been a source of inspiration for me to complete this thesis while remembering the present joys in my life. My grandmother, Joaquina Alves, always stressed the importance of education along with the possibilities that it can bring to a woman. She believed education could mean liberation for oppressed African people.

My pastor, my mentor and my adopted father, Reverend James Edward Dove, was also instrumental and supportive in my pursuit of becoming a social worker. He believed that I am capable of doing great work and worthy of all of God's blessings, even when I did not believe it and I was doubtful about having a successful career. Timothy 4:7-8 NLT "I have fought the good fight, I have finished the race, and I have remained faithful. And now the prize awaits me—the crown of righteousness, which the Lord, the righteous Judge, will give me on the day of his return. And the prize is not just for me but for all who eagerly look forward to his appearing."

My mother, sister, son, grandmother and pastor are the closest to my heart. They have been able to hold spaces for me to be my true self; the untarnished, raw and vulnerable parts of me. They have also celebrated the parts of me that are ambitious, strong, loving, caring and generous. During my most difficult and joyous moments, they have served as different anchors when I am floating by and not sure of where I should be going.

My thesis advisor, Dr. Debra Hull, has demonstrated to me that repairs are possible after an impasse and that a respectful relationship is necessary for people to work successfully together. In addition, Dean Marianne Yoshioka was instrumental in the completion of my thesis. She was confident in my abilities as she pushed me to successfully finish.

Sherri Love, Rita Smith Dove and Janae Peters have been amazing friends, colleagues and confidants. They pushed me when I was stuck in my work and reminded me not to let institutional racism dictate my path in life. Tanita Teagle is a new voice in my life. She became an advocate for my thesis and for my career (as a soon to be social worker). She reminded me that collaboration is vital in being a successful social worker; in our mission to dismantle oppressive systems while building and welcoming non-judgmental ways of being in the world.

Finally, I am extremely grateful to the caregivers who have given their time to my research. They have entrusted me with their voices and with the delicate care of their children's experiences. I am honored to have your stories and I have strived to gracefully let your voices be heard as LOUD AS POSSIBLE!

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CHAPTER I

Introduction

Definition of Attention-deficit/hyperactivity Disorder

Gregory Lester (2007) describes the three main markers of attention-deficit/hyperactivity disorder (i.e., inattention, impulsivity and hyperactivity). Children with ADHD struggle to attend to “dull, boring, repetitive tasks such as independent schoolwork, homework, or chores” (p. 12). These mundane daily tasks speak to the inattention part of ADHD. The second major part of ADHD symptomology is impulsivity. Impulsivity is displayed when children are too eager to get started (i.e., cannot wait for his/her turn or taking shortcuts). Hyperactivity is the final major marker of ADHD and is typically described as “Cannot sit still...talks excessively...acts as if driven by a motor” (p. 12). According to the diagnostic and statistical manual of mental disorders 5th edition, attention-deficit disorder is a childhood disorder in which symptoms of hyperactivity, inattention, and/or impulsivity are present for at least six months and must be present prior to a child turning 12 years old (American Psychiatric Association, 2013).

According to Gapin & Etnier (2013), ADHD “is one of the leading childhood psychiatric disorders in America and is a costly major public health problem” (p. 1).

The Importance of Including the Experiences of African American Caregivers

Even though ADHD has been extensively studied within the past twenty years (Mychailyszyn, dosReis, & Myers, 2008), there is minimal research on racial bias or disparities in diagnosis and treatment of ADHD symptoms (Miller et al., 2009). The literature also speaks to

the skepticism that African American parents have of an ADHD diagnosis “behavior problems exist in all races...I think we become suspicious as black people when we are constantly told that our kids [have] ADHD” (Olaniyan, dosReis, Garriett, Mychailyszyn, Anixt, Rowe, & Cheng, 2007, p. 228). In addition, African Americans parents’ are also reluctant to use medications for treatment of ADHD symptoms, “I think that it’s a control thing...most of our doctors are white...this stems all the way back to slavery...they couldn’t control us then...now they’re giving us medication” (p. 228). These previous studies show a need for research that attends to possible racial disparities in diagnosis and treatment as well as caretakers’ management of ADHD symptoms.

It is important that experiences of African American caregivers are heard. Racial prejudices are present in the minds of some White Americans due to the United States’ legacies of slavery, Jim Crow and mass incarceration (Tonry, 2011). For example, in “Punishing Race,” Tonry (2011) said the following “Whether whites care to admit it or not, they have a selfish interest in maintaining the categorical mechanisms that perpetuate racial stratification.” (p. 100). Slavery attempted to strip Africans of their beliefs, their culture and their families. By allowing African Americans a chance to be a part of research, they are able to be their own agents of change as they continue to be contributors to the United States economy.

In “Beyond Trickle-down Effects to Research Participants,” Bay-Cheng (2009) argues that social work research should allow participants to tell their own stories rather than be confined to preselected answers. This article speaks to the need for social workers to integrate social work research into their practices, which would also involve the use of social work

conceptual frameworks. I used narratives in order to understand the experiences of African American caregivers.

The Research Questions

Keeping the above framework in mind I explored the following:

- What are the experiences of African American caretakers as they pertain to their children's ADHD?
- What methods are African American caretakers utilizing to deal with their children's ADHD symptoms?
- Did caregivers experience racial or ethnic biases in mental health professionals?

CHAPTER II

Literature Review

Conceptual Framework

The conceptual framework that was applied to my study is one of narrative (Riessman & Quinney, 2005). The individual's story is seen as a co-construction with others. Narratives have imbedded within assumptions about why information was arranged in its specific pattern and the cultural resources it draws upon. The narratives that a person chooses to tell have significant meaning in that person's life at that time and it is what they feel comfortable sharing with the researcher. A narrative analysis is also helpful in that it can be a way to invite participants to share their stories in an open-ended fashion (Roscoe, Carson & Madoc-Jones, 2011) – thereby, allowing their joys, struggles, successes and humanities to be heard. The experience of authoring one's story and inviting others to be a part of it can be transformative. The author of the story gets to connect with others by sharing his or her experiences.

Working with narratives in research there are some limitations. As narratives are told to the researcher, the researcher may embed his/her/their own biases. Use of transference and countertransference may be a vital piece in working with narratives. Ehrenberg (1995) says "if we recognize our own vulnerability to unconscious responsiveness in the analytic interaction, then we must consider that anything we say or do, including remaining silent, can be a form of

countertransference” (p. 213). A challenge for the researcher is to be aware of one’s own feelings and possible biases towards the participant’s experiences. Guilfoyle (2015) speaks to the importance of “double listening” (p.37) when working with narratives. He argued that since people’s lives are complex the stories they choose to tell are complex and layered. Typically, the stories people tell when their lives are troubled are negative accounts of their experiences.

ADHD: What Have we Learned?

Miller et al. (2009) analyzed 73 studies completed since 2005 to identify gains made regarding African American children’s assessment, diagnosis and treatment of ADHD. They were looking at racial prevalence of children between 3-18 years old.

Across the studies, they found a higher rate of diagnosis among Caucasian youth even though African-American youth displayed more symptoms of ADHD: “African American children were also rated as having more problem behaviors by classroom observations” (p. 79). The authors suggested that this could be attributed to the parental beliefs regarding ADHD and lack of access to treatment “resulting in lower rates of identification, less treatment, and more classroom behavior problems in African American youth” (p. 80).

They also reported ADHD symptoms manifested differently in boys and in girls. For example, boys displayed more physical attributes (i.e., inattention and hyperactivity) and girls struggled with learning and emotional problems. Finally, the findings suggested a need for new assessment tools to properly capture ADHD symptoms in African American children.

The researchers wondered whether ADHD is portrayed differently across races. It is difficult to determine if symptoms manifest in the same manner across races due to African-

Americans reluctance to accept a diagnosis of ADHD (dosReis, Mychailyszyn, Myers, & Riley, 2007; Mychailyszyn, et al., 2008).

Bussing, Ljungberg, Noguchi, Mason, Mayerson, & Garvan (2011) conducted a study between 2007 and 2008 involving parents, adolescents, teachers and health care professionals (i.e., school nurses, psychologists, pediatricians and social workers). Participants were recruited from public school records across United States. White participants represented 72% (i.e., adolescents, parents and teachers) to 79% (health professionals) of the sample. Twenty-one percent of participants (i.e., health care professionals) to 28% (i.e., adolescents, parents and teachers) identified as African Americans/other. This study was deliberate about having an overrepresentation of female children due to the underrepresentation of female children within ADHD research. As referenced above, Miller et al. (2009) found ADHD symptoms manifested differently for boys when compared to girls.

A mixed methods approach was utilized to obtain information on five topics: short acting medication, long-acting medication, ADHD education, behavior therapy, and counseling therapy. Some of the participants did not like the use of medications as a form of treatment and parents, adolescents and teachers believed short acting medication should be used in conjunction with counseling and classroom adjustments. Interestingly, health professionals did not mention the use of the above alternatives in conjunction with short term medications.

Education was viewed favorably by the participants in conjunction with other alternatives, although, the other alternatives were not mentioned. According to the parents, behavior and counseling therapy were regarded as ineffective, especially if used exclusively. Teachers added “the importance of therapy and behavior modifications but at the same time

advocated for combining therapies with medical interventions” (p. 98). Overall, the study indicates medications, education about mental illness, behavior therapy and counseling therapy are not useful by themselves. The participants were more optimistic about the methods of treatment if used together.

Although the authors hypothesized that “Caucasian respondents express higher willingness than African Americans respondents to use medication interventions” (p. 93), the study did not yield a racial difference. What was discovered is willingness to seek treatment was increased once the participants felt educated about ADHD symptoms and treatment options (including medications). This was the same for both Caucasian and African American respondents.

ADHD: What have we learned? Call to action. Gregory Lester (2007) adds “Working with ADHD requires persistently disputing mistaken common ideas that frighten people unnecessarily about diagnosis and medication” (p. 11). How do social workers as agents of change and researchers work with African American caretakers? Also, how do social workers work with African American caretakers before their children’s symptoms become exacerbated? Could it be the same behaviors are diagnosed differently or there are racial differences in the type of behavior displayed, similarly to how ADHD appears differently across genders?

Parent and Youth Perspectives of ADHD

Some of the same researchers who conducted a mixed-methods research study from 2007 and 2008 (Bussing et al., 2011) were also interested in perceptions of ADHD among adolescents and their parents (Bussing, Zima, Mason, Meyer, White & Garvan, 2012). They found even though their participants believed they were familiar with ADHD symptoms and diagnosis, most

of them had false information. For example, some of the participants believed ADHD is induced by sugar and overuse of medications. Their research indicated African-Americans were more likely to believe ADHD was caused by a high sugar intake when compared to Caucasians.

In addition, parents were more likely to seek information from a number of sources as compared to adolescents. Adolescents were more likely to seek information from their peers. These findings were useful in my own data analysis. I was mindful of African American perceptions and was not surprised when someone mentioned that he or she believes that his/her child's ADHD symptoms were caused by a high sugar intake. Furthermore, when someone mentioned controlling or managing his/her child's ADHD diagnosis by reducing sugar intake I was open to understanding how that is or isn't working for that individual.

Teenagers' perceptions of their ADHD diagnosis are important. Researchers are seeking to understand how this age group construct their realities as they seek to understand and manage their ADHD symptoms (Koro-Ljungberg, Bussing, Williamson, Wilder & Mills, 2008; Bussing et al., 2011). In this longitudinal study by Koro-Ljungberg et al. (2008), the authors focused on teenagers that are at high risk for ADHD in the public school district in North Central Florida. The students were identified to be at high risk for ADHD based on school screenings. The researchers were interested in studying racial or gender disparities.

They targeted underrepresented groups (i.e., females and African Americans). They also included Caucasian participants as a comparison group. The authors chose to focus on four African American teenagers' perceptions of ADHD. They found some useful information for health care professionals to consider when working with African American teenagers.

We argue that African-American teenagers can be useful informants about their ADHD symptoms and they are capable of producing reliable self-reports when their self-reports are ‘translated’ and accurately interpreted by culturally sensitized providers. This translation and interpretation process requires that health care providers understand the teens’ communication styles and have familiarity with their non-medical discourse characteristics. (p. 481).

In addition, the authors found a small number of teenagers were concerned with ADHD symptoms and only a small number were concerned with seeking help for their ADHD symptoms. This was evidenced when teenagers did not make reference to ADHD symptoms and they did not contact their health care professionals. What is more shocking is none of the participants were in treatment with professionals and none were speaking to their primary physicians about their ADHD symptoms. In Bussing et al. (2011), their research also elicited a similar response from adolescents “adolescents were significantly less willing than adult respondents to consider medications or psychosocial treatments for their ADHD” (p. 92).

Another study aimed at ethnically diverse college students in the Northeast investigated adolescents’ views on their ADHD diagnoses and help seeking (Waite & Tran, 2010). The participants identified as Hispanic or African American and were single men and women ranging from 18-25 years of age. This study similar to the study conducted by Bussing et al. (2011) included an overrepresentation of females. What is interesting is that more than half of the participants were diagnosed in their teenage years. Could this relatively late diagnosis be related to access to services, skepticism of health care professionals or lack of knowledge of mental health or could it be all of the above?

The themes that emerged from this qualitative study regarding causation are: genetics, “ADHD runs in my family...I found out I was affected when I came to school...focusing and getting schoolwork and assignments completed” (p. 250); parenting style “My parents were very strict and had high expectations”; “Not having parents set limits and supervise...really contributed to my erratic behavior” (p.251); and environmental factors “Dyes and chemicals from food really caused me to be hyper when I was younger” (p. 251). Some students indicated inconsistent use of medications provided by health care professionals. Students also stated they did not use disability services that were offered at their colleges.

Parent and youth perspectives of ADHD-Call to action. The above results from authors Waite & Tran (2010) suggest a need for education about ADHD and management options available. The research results from Bussing et al. (2012); Bussing et al. (2011) and Koro-Ljungberg et al. (2008) call into question perceptions of teenagers with ADHD. Could it be these children are afraid of being seen as abnormal and so they do not wish to speak to professionals about their symptoms? Could it be their symptoms are viewed as part of a normal teenage trajectory, so there is no need to seek help for behaviors that they will grow out of?

Teenagers stated they seek advice regarding ADHD information from their peers rather than from other sources (Bussing et al., 2012). I believe teenagers turn to their friends for advice on many of their struggles. The concern is when they do so exclusively. This study was conducted years after Koro-Ljungberg et al. (2008), but it seems the findings are similar. How can we, as social workers, help teenagers to speak about their ADHD symptoms and other mental health concerns in addition to turning to their friends for advice?

This may be a call to action for social workers. We need to humble ourselves and make ourselves available where teenage conversations take place. For example, social workers should make themselves available in lunch rooms or outside the classroom.

Parents'/Caregivers' Perceptions about Diagnosis and Treatment

The first study conducted comparing parents' views on physical activity shows some promising results for management of ADHD symptoms (Gapin & Etnier, 2013). The participants were recruited via Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD) chapters (p. 3). Eighty-seven percent of respondents identified as Caucasian, 10% as African Americans and the remaining 3% identified as American Indian or Native Hawaiian/Pacific Islander. The authors did not code the responses based on racial identification.

The study asked questions relating to impulsivity, academics, inattentiveness and hyperactivity. Overall parents believed physical activity helped with management of ADHD symptoms. It should be noted 85% of the children were also on medication for ADHD. Therefore, the use of physical activity and medications might be useful for caretakers to consider when managing their children's ADHD symptoms.

Another study was conducted using participants whose children were associated with a teaching hospital in Baltimore City, Maryland (Mychailyszyn et al., 2008). The participants were single parents whose income levels were at or below poverty level. Eighty-eight percent were African Americans, 9% were White and 3% biracial. The study used interviews to gather information about parents' conception of ADHD and clinical treatment. The authors were interested in the following question "How do parents make sense of their child's behavior and how do they perceive the actual diagnosis of ADHD?" (p. 448). The study led to a theory of

making sense, which involved forming opinions of what was happening, how ADHD symptoms developed, and self-control of the symptoms.

The results stated parents had tried other alternatives prior to seeking medical care (i.e., relatives or friends to help with management of behaviors). Even though the answers given were not really clear, the researchers asked parents what made them seek medical care. Some of the participants indicated they knew their children had ADHD due to a prior experience with someone that has ADHD. After seeking medical care some themes appeared; parents looked for immediate resolutions, different management strategies (i.e., medical care and education), or they attributed their child's ADHD symptomology to environmental factors (i.e., children watching too much television or parents not engaging with their children).

African American parents/primary caregivers whose children were diagnosed with ADHD and receiving treatment from a pediatric facility in Baltimore Maryland were participants in a study that was aimed at parental views on medications in treatment of ADHD (dosReis, Butz, Lipkin, Anixt, Weiner & Chernoff, 2006). A limitation of this study pertains to the participants. Although the authors stated they were focused on African American families no further information regarding the racial background of the participants was provided.

The participants were drawn from a clinic that works with African American children from a low socioeconomic status. To be eligible, the children of the participants had to be younger than 19 years old and have received medication within the past twelve months. A survey was distributed and there was a high participation rate, over 80%. Eighty-three percent of the participants identified as single parents and 75% of the children with ADHD were male. These numbers represent a challenge for social workers.

This study displayed promising results. Eighty-eight percent of the participants felt the medication would be helpful and 90% trusted the recommendation for its use if it came from a physician, although, 71% were hesitant to use the medications (p. 427). Results also indicated non-White families when compared to White families were more concerned with side effects of medications and potential for drug dependency. Due to the above results, medication side effects and the potential for drug abuse might be contributing to African American caregivers' difficulty with attending appointments. Although, with the enormous demands of single parenting, it can be that scarcity of time and resources are also factors.

Parents'/caregivers'-Call to action. Single parents are already dealing with scarcity of finances and time. Lori Glass (2012) wrote about African American women and their perceived risks when asking for help. In her research she found the women (a majority of them single mothers) felt vulnerable when asking for help and asking for help “was in direct contrast to their need to be strong, independent and self-reliant” (p. 100). Another risk that was discovered

was the perceived cost of time associated with formal help seeking. The women viewed time as a resource. They consistently made decisions about how to best utilize what they already felt was insufficient time to meet their daily demands...The women perceived help seeking as a luxury. (p. 101).

According to the above study, after being physically assaulted African American single mothers found it too time consuming to have to schedule an appointment with their health/mental care providers. The time needed to attend a doctor's appointment added to their already demanding day to day activities (i.e., sole responsibility for working, taking care of the household and attending to the needs of their children). For African American single mothers,

help-seeking for their children might also be viewed as a luxury rather than a necessity. It becomes even more of a challenge for social workers/mental health providers to convey the importance of help-seeking for African Americans. How can social workers work with single parents of ADHD children without adding to their already enormous demands?

African American Families' Experiences

Previous studies conducted used qualitative methods in order to obtain detailed answers regarding ADHD. dosReis, Mychailyszyn, Myers & Riley (2007) were interested in exploring challenges urban African American families faced when they decided to seek medical care for their children's disruptive or inattentive behaviors. Upon seeking care during regularly scheduled physician appointments, parents were informed of their children's diagnosis of ADHD. A telephone interview was conducted with participants whose children were associated with a teaching hospital in Baltimore City, Maryland and this study reveals that racial disparities might have been present.

The average participants were nine years old and mainly male (65%). Ninety-six percent were African American. The researchers did not state the ethnic/racial backgrounds for the other 4% of the participants. The results indicated African Americans had a lower rate of attendance to appointments which may speak to their skepticism of mental health care professionals.

Skepticism about the benefits of mental health care has resulted in 49% lower odds of attending an appointment (10). Moreover, African American parents have less knowledge of ADHD, more concerns about psychotropic medication for children and lower use of psychotropic medication than white parents have" (p. 639).

Some African American parents in Baltimore City Maryland remained skeptical of their children's ADHD diagnosis even when it was diagnosed by a medical professional (i.e., primary care, pediatric specialist or specialized mental health clinicians). Some of the parents responses were "this little, problem, is what I am going to call it. I'm not going to call it a disease I'm going to call it a problem right now" and "he's not sick...it's not like he has cancer; he's not going through this treatment or AIDS that doesn't have a cure. It's a problem not a sickness" (Mychailyszyn et al., 2008, p. 454). In addition, African American parents will often use familial support systems in managing their child's ADHD symptoms rather than turn to medications because they are worried about the potential of drug dependency and are reluctant about the potential benefits (dosReis et al., 2007; dosReis et al., 2006).

African-American families, how do mental health professionals hear their stories?

Call to action. One of the limitations of a previously mentioned study (dosReis et al., 2007) was that it was a quantitative analysis. Although the results are informative, the participants had to choose from pre-selected responses rather than speak about their personal experiences. Qualitative analysis is necessary in order to allow people to tell their stories (Bay-Cheng, 2009) and is especially meaningful in African-American cultures.

Narratives serve various important functions also in the context of African-American cultural discourses. Historically, oral narratives preserved stories told about the homeland (Banks-Wallace 2002) as well as the "turbulent history of a people forcibly removed from their homeland and subjected to a variety of inhuman abuses both during slavery and following its 'official' demise" (p. 412). It affirmed "the ongoing commitment of a people determined to nurture a unique, spiritually based culture in the midst of an

oppressive environment” (Ibid, p. 413). Culturally accepted narratives could sometimes also turn into the scripts that communicate how children or other members of community should behave and what is expected from them (see Berne 1964).

Although there may be some differences in how to define African-American rhetoric tradition it could be argued that common characteristics of the tradition include: reaffirmation of African people as bearers of dignity with a right to speak to cultural truths; community focus in the way in which the rhetoric is intended to bring good to the community; and reflection on the constant resistance to a system of oppression (e.g., Karenga, cited in Jackson 2003). (Koro-ljungberg 2008, p. 470).

Quantitative analysis could have been just another tool used to silence the narratives of African Americans caregivers who are invested and seeking collaborative help with their children. I do not believe quantitative analysis was intentionally used to silence African American caregivers. I think it is more of an unconscious thought or lack of knowledge about the ways that African Americans tell their stories or how they interact with others “...giving voice to African American women by sharing their stories from their perspectives is a means of raising consciousness and transcending the limitations of race, class and gender” (Glass, 2012, p. 96).

Limitations of Previous Studies

One of the limitations of Mychailyszyn et al. (2008); dosReis et al. (2007) and dosReis et al. (2006) is that in all three studies the participants were selected from individuals who were seeking medical care for their children. African Americans are skeptical of health care professionals and are most likely to seek advice from family members and friends (dosReis et al.,

2007; dosReis et al., 2006) the above study most likely excluded African American caretakers who had not consulted with their childrens' health care providers.

Another bias is that children needed to have been diagnosed within a month of the beginning of the study. Caretakers who have been dealing with their children's ADHD symptoms for longer than a month were excluded although they may have been able to offer insight into treatment of their children's ADHD symptoms.

A theme in the literature available on ADHD is most studies were affiliated with a large teaching hospital in Baltimore, Maryland (Mychailyszyn, et al., 2008; dosReis et al., 2007 & dosReis et al., 2006). This raises a question regarding how the funding of this hospital and possibly staff available to conduct research on ADHD may be influencing findings. Additionally, it raises questions about the generalizability of their data?

CHAPTER III

Methodology

The purpose of this research is to learn more about the experiences of African American caregivers as they pertain to their children's ADHD diagnosis and treatment.

Research Design

I used a qualitative, exploratory research design to identify core themes in the experience of family caregivers of African American children who have a diagnosis of ADHD. Adler & Clark (2011) argued that exploratory research study is best utilized when there is little knowledge on a particular topic (i.e., racial disparities in diagnosis and treatment of ADHD). Koro-Ljungberg et al. (2008) has argued when conducting research within African-Americans communities it can be important to allow participants to be the narrators of their experiences. It is a link back to their historical tradition of stories being passed down by orators and also a way to reclaim in part, what was taken by years of slavery, their humanity and dignity.

In addition, data on demographic characteristics (i.e., age of participant, age of child at diagnosis, and gender of child) were collected for the purposes of describing the sample.

Research Instrument

Data were collected through an anonymous survey using open-ended questions to allow caregivers to author their stories. Even though the data are not generalizable due to the small

study, the participants are able to tell their stories and the results can be used in future research to develop new hypotheses or questions (Steinberg, 2004).

Specifically caregivers were asked the following questions:

- Tell me about your experiences when your child was in the process of being diagnosed with ADHD. What parts were helpful to you or your child? What parts do you wish could have been different?
- How do you view your child's ADHD diagnosis?
- Tell me how you are managing your child's ADHD?
- Do you believe that African American children have a higher diagnosis of ADHD when compared to Caucasian children?
- Are healthcare professionals (doctors, therapists, psychiatrists, social workers and counselors) culturally sensitive to African American traditions?

Institutional Research Approval

The flyer (see Appendix C), informed consent form (see Appendix D), and a list of questions (see Appendix E) were submitted for review to Smith College School for Social Work Human Subjects Review (HSR) Committee. The Human Subjects Review Committee approved this proposal upon modification to the recruitment process (see Appendix A).

Originally, I intended to utilize my first year field placement (The Metropolitan Regional Career and Technical Center-The MET) and the Rhode Island chapter for Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD). I had spoken to my contacts and they agreed to distribute my survey. The Smith HSR Committee asked for a letter from the agencies

tentatively agreeing to allow me to recruit participants from their organizations. The agencies were nonresponsive. I decided to seek other avenues, i.e., my professional contacts, to help in distributing my flyers for my research. I submitted a revised proposal (see appendix B) to the HSR Committee indicating a different recruitment method (i.e., professional contacts).

I called, emailed and had in person discussion with my peers, coworkers and professional contacts in which I described my thesis topic. I enlisted their help in the distribution of my survey by providing copies of my flyer and my informed consent form for review. The flyer briefly provided potential participants with a description of my study, including inclusion and exclusion criteria. The flyer gave potential participants the survey link in order to participate in the survey. In addition, the flyer invited potential participants to contact this researcher via email or telephone with any questions or concerns.

Sampling Method

Participants were recruited using nonprobability sampling procedures, snowball and convenience samples (Adler & Clark, 2011). Adler & Clark (2011) argued snowball sampling is best when members of a group are able to pass on the researchers study to other members. I have some professional relationships with basketball mothers. I asked them to pass on information about this research initiative to other caregivers who may have a child that has ADHD. In addition, I utilized classmates and my professional contacts from previous employers.

Specifically, I gave each participant a package of information consisting of the recruitment flyer which included the link to the data collection site and the informed consent form. There were occasions where an individual wanted to pass along information to another

person. In these cases, I also provided the list of questions so they were better prepared to explain the research process to their acquaintance.

Participants accessed the study site through the URL provided. The URL took the individual to a Survey Monkey site. Once they were at the site, they completed the online version of the informed consent form and if they provided consent, moved directly to the questions to be answered.

Inclusion of Diverse Populations

I chose to include all caregivers of children who had been diagnosed with attention-deficit/hyperactivity disorder. Since, my aim was to get perspectives from all African American caregivers, I did not specify gender, age, sexual orientation or ability. A caregiver for this study is defined as someone who has the primary responsibility of taking care of a child. This typically includes parents, grandparents, aunts and uncles. The child can be either biologically related or adopted. My study excluded foster parents because the focus was on caregivers who have permanent responsibility for a child.

Ethics of Research

To uphold standards of ethics of research (Engel & Schutt, 2013; Adler & Clark, 2011), I disclosed the purposes of my research to the potential participants through an informed consent form which stated the procedures, risks and benefits associated with their participation in the study while maintaining privacy and confidentiality (Engel & Schutt, 2013; Adler & Clark, 2011; Steinberg, 2004). I also disclosed in the informed consent form that no financial compensation would be provided to potential participants. In addition, the benefits associated with his/her/their participation were described as having a chance to tell his/her/their stories to

enhance the field of mental health and possibly helping health care professionals to be culturally aware and responsible in their collaborative work with clients. In addition, their participation might help to empower other caregivers in their pursuit of becoming advocates for their children.

Finally potential participants were informed of their options to withdraw at any point in the study (Engel & Schutt, 2013; Adler & Clark, 2011; Steinberg, 2004). Participants were informed all data will be retained for three years in a secure file and then will be destroyed.

Data Collection Methods

A survey was constructed via Survey Monkey. This is an online service allowing the creation and distribution of tailored surveys and the management of data collection.

Upon accessing the survey, the potential participant was able to view my flyer and proceed to my informed consent form. If the potential participant agreed to proceed then the caregiver was able to view 13 open-ended questions that could be answered within 10 to 30 minutes (depending on the length of the answers).

I collected information about my participants' identity but I did not collect their names which allowed the survey to remain confidential.

Data Analysis

The data were analyzed using Bryman's (2008) four stages method of thematic analysis as described by Gibbs (2011). The stages are described below:

1. Read the text as a whole and made notes while looking for major themes (i.e., ideas).
2. Read the text again while marking the text (i.e., highlighting, underlining, and marginal notes); labels that will be used for codes.

3. Coded the text (i.e., themes); reviewed the codes; eliminated repetition by combining similar codes.
4. Related theoretical ideas to the text; added my interpretation of the text; identified the significance of the text; searched for interconnections between the codes; searched for relationship between the codes and my literature review.

Text were sorted into conceptually similar buckets using this method. Initially 13 themes were identified:

1. can't sit still
2. strategies
3. tasks are hard to focus on
4. constantly on the go
5. you're not in trouble
6. the process of diagnosis
7. this is my child
8. are you listening to me?
9. healthcare professionals aren't the only ones that know best
10. ways to help my child succeed
11. the caregiver story
12. what narratives are being told
13. early interventions

In consultation with my research adviser, we collapsed these 13 themes into five overarching themes. My goal was to reduce redundancy, preserve parsimony, while ensuring conceptually discrete categories. These themes will be discussed below.

CHAPTER IV

Findings

The experiences of twelve participants were used in this analysis. Fourteen participants accessed my survey but two were excluded because they did not meet eligibility criteria (i.e., one participant did not complete all the questions and another did not identify as being African American).

The following data are organized based on demographic variables and five overarching themes which emerged during data analysis: (1) *Inadequate treatment*, (2) *strategies for my child*, (3) *concentration on the task at hand*, (4) *measurements of success*, and (5) *views of strength*. This researcher analyzed the data while attempting to allow the full voices of the caregivers to be heard. Subheadings are used within the themes and will be described within each theme.

Caregivers ranged from 29 to 56 years of age. Their children ranged from 4-14 years old at time of diagnosis. The mean age for diagnosis was 6.25 years old, the mode was 5 years old and the median age was also 5 years old. Of the children, two females and ten male were identified as having ADHD diagnosis.

Inadequate Treatment

Participants described their frustrations with the system. Inadequate treatment was described in different ways by all of the caregivers. Upon further analysis of the data, a couple of

subheadings have been used to more accurately maintain the voices of the caregivers. The subthemes that emerged were, *listen to me*, *medication is not the only option*, and *advice for healthcare professionals*.

Listen to me. Some of the participants (n=4) described not being heard when they were advocating for their children to be tested and gave some suggestions on how policy should be changed to allow for ADHD children to be their full selves. In particular, participant Nine added

It would be great if they took my advice without me having to flash my credentials. I feel that if I wasn't a PhD level patient with credentials in the arena of mental and emotional health the collaboration between myself and the healthcare professionals would be very different...though our doctor, likely because she is working in an urban setting did seem way more aware of the various institutions that may play a role in supporting positive behaviors and opportunities for my son.

The above caregiver expressed concerns of not being heard. This participant's voice was possibly recognized or validated after the mention of his/her/their credentials.

Participant Eight expressed similar concerns as the above participant adding “Learned sooner. Many doctors kept saying wait or he will grow out of this or he is being a typical boy. It was frustrating...practical things to do at home, normalize the situation and stop avoiding testing when they are young.” It seems that this caregiver's voice wasn't heard by the providers' either which possibly led to a lack of collaboration in developing strategies for the child.

Medication is not the only option. For some participants (n=4), it seemed as if their healthcare providers were strongly encouraging medications as their only option for management of their child's ADHD symptoms. Medication was recommended for participant number Eleven.

In addition, similar to participants Eight and Nine (described above) participant number Eleven also expressed frustration with healthcare professionals. Although, it manifested as a lack of communication, possibly between the caregiver and the healthcare professionals pertaining to the explanation of the child's ADHD symptoms

Continued understanding of why she has the behaviors she has, the tantrums, and I just did not understand why I could not get her to do what needed to be done. Why I had such a hard time with this. It just was not communicated to me by the professionals. It was only the medications will help...Taking the needed time and understanding the individuals as well as they do Caucasian children. No difference.

Advice for healthcare professionals. A third subtheme which emerged during analysis was *advice for healthcare professionals*. Twenty-five percent of caregivers (n=3) discussed ways that healthcare professionals can be more helpful in the diagnosis, treatment and management of their childrens' attention-deficit/hyperactivity disorder. Participant Two mentioned good and bad experiences as an employee in the healthcare industry working alongside other healthcare personnel. The following is an example:

I feel that health care professionals are quick to label and place patients in a category, when in actuality every case differs. Not one person is the same, every child comes from a different past, different circumstances... I've worked with and amongst numerous healthcare professionals and you can always tell who's there because they genuinely care and who is there just for a paycheck. I've had good experiences, where they understood and accepted certain traditions, and there have been others that have disregarded them, because of intentional or unintentional ignorance.

Participant One expressed a desire for collaboration amongst professionals, “Referral. I think if they can band together as a team to provide the best possible treatment for my child. Him and I would be able to deal with his disorder.”

One caregiver expressed a desire for healthcare professionals to receive education on ADHD and collaborate with parents during diagnosis. Responses given by other caregivers included the school’s desire to place the child in a special education program rather than help with his behaviors, a desire (by caregivers) for more educational programs pertaining to ADHD, a high school’s lack of concern/inability for testing the child, (this led the caregiver to seek a private assessment).

The subthemes of *listen to me, medication is not the only option and advice for healthcare professionals* speak to the caregivers concerns of inadequate treatment relating to the diagnosis of their children’s attention-deficit/hyperactivity disorder. As I analyzed the data, I kept hearing frustration from the caregivers regarding the treatment process. It seemed as if the process wasn’t successful which manifested as inadequate treatment for their children.

Strategies for my Child

This theme includes different strategies caregivers are using to help manage their children’s’ ADHD. Ninety-two percent (n=11) of the participants specifically mentioned strategies that are implemented. A couple of subheadings will also be used in this section to capture the full voices of the caregivers. The subheadings are *medication and other methods* and *other alternatives to medication*.

Medication and other methods. Thirty-three percent (n=4) are using medications with other management strategies. Participant number Two uses medications during the week for school and then employs other methods at home. For example,

I am managing his ADHD with different methods. During the school week he is given medication to control his impulsivity while in class. At home, tv is controlled and limited. Video games are granted only on the weekend and for short periods of time. He reads everyday anywhere from 30 minutes to an hour. I try different things, whether it be board games or outside activities, to expel his energy and keep his mind occupied. On occasions where it seems he can't control himself, he takes a few minutes to the side by himself to regroup.

Similarly participant number Seven uses medication on school days, "I manage his ADHD by giving him his medication on school days and on weekends, school vacations he does not take his medication. I deal with it and just be patient." Another caregiver also indicated non-use of medication during the summer as a strategy for the management of the child's ADHD symptoms. Participant number Ten was the only participant to mention the use of family support as a part of management strategies, "Medication, family support, and behavioral rewards system."

Other alternatives to medications. Thirty-three percent (n=4) of the participants did not mention medication as one of their management strategies. Participant number Fourteen described learning about ADHD as a helpful tool,

Because I work in the field, I've had to learn quite a bit about ADHD. The knowledge has helped me translate to my son an understanding of symptoms and management...Getting him to write things down, make lists, schedule, take breaks when he reaches a plateau...

For participant number Nine, medication is not warranted at this time and collaboration with the school was encouraged to make sure the child gets the support that is needed.

He was diagnosed just before the end of the school year, so we are not using any medications and the doctor doesn't think his case warrants that yet, but it was recommended that we work closely with the school to develop an intervention plan around areas where he may need some extra support and to communicate to the school the importance of him having time to move his body.

One caregiver expressed having better management strategies now than in the past which includes taking medication. Some of the other strategies mentioned by other caregivers were using medication, not using medications, setting limits, using time management techniques, allowing the child to be “hyper” by doing physical activities, no red dyes, and limiting sugar intake. The responses that I included under the theme of *strategies for my child* were ones which conveyed different ways caregivers are managing their children's ADHD symptoms. The subthemes of *medications and other methods* and *other alternatives to medications* are my attempts to honor and allow the voices of the caregivers to speak regarding different strategies they are employing for their children's ADHD symptoms.

Concentration on the Task at Hand

The next theme that arose for the caregivers was concentration on the task at hand. To different degrees, all of the participants wrote about their children's difficulties with school based activities and with tasks in the home. Two subthemes that will be addressed are *no longer interesting and cannot focus* and *being impatient*.

No longer interesting and cannot focus. Sixty-seven percent of the caregivers (n=8) described their children's rapid loss of interest and/or their inability to focus in certain activities. For example, participant number Ten added "Yes, he finds it difficult to maintain focus on school learning tasks...Yes, he tends to hum and sing a lot. He also asks a lot of questions." While participant number Five wrote about the length of time it takes for the child to complete tasks, "Yes it takes him a long time to complete any homework or chores and starts changing the subject or tries to do something else...Yes he gets frustrated.....sometimes when talking doesn't make any sense." For participant Fourteen, the difficulties were related to getting started on the task at hand rather than losing interest and focus after starting the task. The following is an example of the way it manifested for this caregiver,

His difficulty is in getting started. He has to be pushed and reminded of possible consequences, should he not finish. However, once in and he sees the progress, he'll finish...My child is rather laid back. However, he does tend to take short cuts. Example: He will look at the picture or diagram of something and then re-construct it. In reading, he scans.

Being impatient was the second subtheme that came up for caregivers under the theme of concentration on the task at hand. Twenty percent of the caregivers (n=3) discussed their children's impatience with activities or tasks they were taking part in. For example, participant Eight it manifested as always being on the go, "...he is impatient and interrupts all of the time... it's like he is always revved up. Everybody else can be calm and quiet and he is loud, jumping, running, laughing." Participant Eleven also expressed the child's impatience when interacting

with others, “ ...Yes, she interrupts others tries to jump or ask how long leaves the area does something else.”

For one of the caregivers the child is able to successfully accomplish familiar tasks (as a long as he is interested in it) but if it is a new task then he will experience difficulty.

Mathematics was a strength that was noted for this child. Other caregivers mentioned their children’s impatience when engaging with others. For some children it was difficult to control their bodies and for another child listening was the task that proved to be difficult, for another it was being patient while waiting for his turn, while other children it seemed they were always energized and ready to go.

For the above caregivers their children had difficulties with concentrating on the task at hand which lead to subthemes of *losing interest and focus* and *being impatient*. These subthemes manifested when their children were asked to engage in activities, such as chores, schoolwork, and homework.

Measurements of Success

The fourth theme that came up for caregivers was *measurements of success*. For this theme, I included comments which spoke to how the caregivers were able to measure progress in the management of their children’s symptoms. Fifty-eight percent of caregivers (n=7) elaborated on their successes. For participant Twelve, the child is removed from his activity and is offered an explanation on his behaviors

... At times he needs to be removed from the situation and sat down by himself. He is made aware that he's not in trouble, just that he needs a few minutes to himself to regain self control and conduct himself in a proper fashion.

Participant Nine waiting in line includes coming up with games to keep the child occupied. Also, having the child's physician explain the diagnosis seemed to have contributed to his successes. The following is an example to illustrate the success

He does fine with waiting his turn, but we have had to help him develop some strategies or games to do when he has to wait his turn in especially long lines....when not very fast he is just very persistent We found the way the doctor shared the information with him and us together helped him understand as something that wasn't about him being bad, but it was very much about helping him do better and have an easier time.

Finally, for participant Fourteen being in small classrooms was a part of the child's success. Although, during the beginning phases of the diagnosis the caregiver was in denial due to the child's early developmental milestones

As long as my child was in private schools with small classrooms, he excelled... At first, denial set in, because he was so smart, skipped a grade, talked and walked early. We kept the diagnosis from the rest of the family, because we were embarrassed by a disorder. For

For one of the caregivers the diagnosis of attention-deficit/hyperactivity disorder was welcomed along with medication as a form of management. For others studying the disorder, explaining the symptoms and diagnosis of ADHD to their children, the child growing older, the child asking lots of questions, reminding the child when they engaged in certain behaviors and watching television proved to be beneficial. I considered the above experiences as examples of success and that is why I placed them under the theme of *measurements of success*.

Views of Strength

The final theme that came up was *views of strength*. For some caregivers (n=6) the diagnosis of attention-deficit/hyperactivity disorder was not seen as a deficit. They described their children with a strengths perspective. Participant Two said the following “I view his diagnosis not as a disability, but as a character builder. This is who he is, and even through the adversities, I wouldn't change him.” Participants Seven and Eight felt similarly. They viewed their children's diagnoses as a hurdle they needed to overcome. The following are their responses, respectively, “I don't see it as a disease but a task that we need to hurdle over. I've taught him how to be conscious and how he needs to be very observant of himself and his actions” and “Just something to work with and or around. He is still smart and capable.”

Participants also spoke of not being ashamed of the diagnosis and of informing the child of others who have the diagnosis of attention-deficit/hyperactivity disorder. The responses I chose to place in this section exemplified a sense of strength as the caregivers described their views of their children.

CHAPTER V

Discussion

The purpose of this research was to uncover the experiences of African American caregivers of children with attention-deficit/hyperactivity disorder with a focus on diagnosis, treatment and management of their children's ADHD. The results were derived from the responses which twelve African American caregivers shared via an anonymous online survey that contained open-ended questions.

The major findings of this research project were African American caregivers experienced their children receiving inadequate treatment. They developed strategies for management of their children's ADHD symptoms and their children had difficulties with concentrating on tasks. The findings suggest African American caregivers view their children through the lens of success and compassion. The caregivers discussed their children's areas of successes such as learning to be patient, understanding ADHD symptomologies, and advocating for themselves. In addition, the caregivers viewed their children in a positive light that was reaffirmed as love in a non-shameful, non-judgmental and very compassionate manner.

This study contributes to the literature by allowing the voices of African American caregivers to be heard by those who are in helping professions. It also could help other caregivers become advocates by asking their providers to include them in the decision making process while asking for educational resources that can be accessed within the community.

Finally, this research may help children with attention-deficit/hyperactivity disorder relate to the difficulties and successes that other children are having.

The following sections elaborate on the five themes and their interconnections with the existing literature on African American caregivers and their perceptions of diagnosis and treatment, African American families' experiences and the progress that has been made thus far with research on attention-deficit/hyperactivity disorder. *Inadequate treatment* is considered first followed by *strategies for my child*, *concentration on the task at hand*, *measurements of success* and *views of strength*.

In this chapter I will also discuss recommendations for social workers, the strengths and limitations of this research, my possible biases, and areas for consideration in future research.

Inadequate Treatment

One of the major findings of this research was that caregivers struggled with feeling that their child received inadequate treatment. Although it manifested in different ways, inadequate treatment was described by all of the caregivers (12 out of 12). The caregivers expressed their frustrations with their children's providers. The caregivers painted a picture of screaming to their providers, "listen to me!" and "I know my child". The current literature (Mychailyszyn et al., 2008; dosReis et al., 2007 & dosReis et al., 2006) found African Americans are skeptical about medical professionals. It is vital that healthcare professionals and all helping professionals listen to their patient's and patient's family members and collaborate with them in order to deliver best possible care and outcome.

Another frustration that was expressed was medication was the only method of treatment offered. For example, participant Five added "...I personally thought this city needs more ways to

assist with ADHD instead of medicine...stop trying to just give him medication”; participant Eleven felt similarly “Why I had such a hard time with this. It just was not communicated to me by the professionals. It was only the medications will help” and “Show better alternatives instead of medication” was noted by participant Twelve.

The above caregivers expressed their desires to have their children’s providers offer alternatives to medication. Finally, the caregivers had advice for their healthcare professionals: desired collaboration amongst their providers, wanted to be included in the diagnosis process and desired information on attention-deficit/hyperactivity disorder for themselves, family and community members.

I was not surprised some caregivers wanted other alternatives than medication and education about ADHD. Bussing et al. (2011) found some participants did not like utilizing medication as a form of treatment. Overall, the respondents believed the best course of treatment involved a combination of medications, education about mental illness, behavior therapy and counseling. What was surprising is caregivers in this research project did not mention behavior therapy or counseling therapy as alternatives. Although, it was not enough to generate a subtheme, two of the caregivers mentioned a need for children to be able to channel their energy. For example, participant Seven added the following:

I believe they can help by having some type of programs in school's where kids with ADHD can leave there classes for about 10 mins have them run around to get there energy level down and they can focus better to what the teacher is teaching.

The above recommendation of allowing children to exert their hyperactivity via physical exercise could be useful for teachers.

Strategies for my Child

I was surprised caregivers did not directly mention the use of physical activity and medications. Gapin & Etnier (2013) in their research findings, parents believed physical activity and medication proved to be highly effective in managing their children's ADHD. I was also surprised that only one participant mentioned the use of family support. In the current literature (Mychailyszyn et al., 2008; dosReis et al., 2007; dosReis et al., 2006) family support before, during and after diagnosis was vital.

In the research conducted by Bussing et al. (2011), the authors found African Americans attributed their ADHD symptoms to too much sugar consumption. Waite and Tran (2010) focused their study on ethnically diverse college students and some of the students attributed their ADHD symptomology to environmental factors, for example "Dyes and chemicals from food really cause me to be hyper when I was young" (p. 251). I was not surprised one of the strategies listed by one of the caregivers was to limit sugar intake and to eliminate red dyes from the child's diet.

Concentration on the Task at Hand

The caregivers spoke to their children's lack of interest and focus during the school day, while doing chores at home and/or while doing homework. Some of the children were also impatient and had difficulties when waiting for their turn. Two of the caregivers for this research spoke to their children's need for supervision with tasks. In Waite & Tran (2010) one of the respondents view on diagnosis and help seeking added "Not having parents set limits and supervise...really contributed to my erratic behavior" (p. 251). It is interesting the above

respondent contributed his erratic behavior to lack of supervision so maybe it is a step in the right direction for the caregivers that are supervising their children during tasks.

Measurements of Success/Views of Strength

For some of the caregivers (n=7), they were able to see the progress their children had made. They described the ways they work with their children. For example, some of the caregivers had developed strategies to use before the child displayed signs of hyperactivity or inattentiveness. Although, it did not develop into a theme, participant Seven added

“...The part that was helpful was when they diagnosed him and when he started the medication I saw a huge difference instantly.”

For this caregiver diagnosis and medication was welcomed.

Half of the participants (n=6) described their children in a positive manner. They did not see their children as their illness. It seemed as if they were able to separate their children from their illness. This is encouraging for me as a future social worker.

The current literature does not speak to ways African American families measure success for their children with attention-deficit/hyperactivity disorder. The caregivers seemed to be intentional about having strategies ready to use if and when their children became impatient, impulsive or hyper energized. In addition, the caregivers were intentional about how and when their children moved about their environments (home, school and other public spaces). They attempted to make the experience as comfortable and non-judgmental as possible for their children. Finally, the current literature does not speak to the enormous respect the caregivers have for their children as people who are walking around with a mental illness diagnosis and still able to thrive in their environments.

Demographic Variables

Similar to the research results of dosReis et al. (2007) & dosReis et al. (2006) my research yielded a ratio of 1:5 of girls to boys diagnosed with ADHD. In the current literature (Miller et al., 2009) found in the Gershon (2002) research, ADHD symptomology manifested differently for boys and girls. For example, boys had more inattention and hyperactivity features and girls displayed more challenges with learning and emotion regulation. My research did not yield the above results, which I found interesting. I am wondering if ADHD symptomology for girls are being mislabeled under a different diagnosis or are not diagnosed.

Also, for a number of the respondents (n=6) their children were diagnosed at five years old. I wonder what was going on at that time. Could it have something to do with the children entering Kindergarten and maybe their teachers did not know how to handle the children's behaviors; therefore the caregivers were asked to seek treatment.

Considerations for Practice

Community supports. Inform caregivers of support systems in the community, i.e., local chapters of Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD). The CHADD website offers information on symptoms and management strategies for ADHD and the website also has information on community monthly meetings with different topics of discussion related to ADHD. In the research by Bussing et al. (2012), African American respondents were more willing to seek treatment once they felt knowledgeable about attention-deficit/hyperactivity disorder symptoms and treatment options. Gregory Lester (2007) found "Working with ADHD requires persistently disputing mistaken common ideas that frighten people unnecessarily about diagnosis and treatment" (p. 11).

Social workers-call to action. Social workers call to action pertains to educating and working collaboratively with individuals and families to dispel the myths about ADHD and to discuss different management strategies. For example, one caregiver from this research had successes with removing the child from the situation and explaining the behavior.

It is also vital for social workers to work in collaboration with African American families and *listen* to what the family is advocating for; this could help alleviate the skepticism and possibly the frustration African American families experience when working with mental health professionals. The following is an example of results obtained in a study by dosReis et al. (2006):

Skepticism about the benefits of mental health care has resulted in 49% lower odds of attending an appointment. Moreover, African American parents have less knowledge of ADHD, more concerns about psychotropic medication for children and lower use of psychotropic medication than white parents have” (p. 639).

Another caregiver’s provider suggested the school be advised of the diagnosis and collaboration between the school and the parent was encouraged in order to develop an intervention to help the child succeed. Social workers can be advocates as they facilitate collaboration between caregiver’s, the school system and healthcare/mental health providers. For example, a few caregivers (n=4) mentioned the need for children to be physically active during the school day in order to help them concentrate on the lesson.

In dosReis et al. (2006) the researchers had a high participation rate (over 80%) and 83% of the participants identified as single mothers. I wonder what contributed to the high participation rate considering Lori Glass (2012) found African American’s felt vulnerable when

asking for help and perceived help seeking as a luxury (that demanded too much time they do not have). The findings from dosReis et al. (2006) is promising for social workers, maybe there is a way they can work with single African American mothers.

Research Strengths

This study may be useful for caregivers of children with ADHD and it may further social workers' knowledge and practice with clients who have ADHD. This study may help teachers, doctors, other physicians, nurses and other people not in helping professions to begin to understand the many decisions caretakers of children with ADHD have to make. Will I be listened to? Will my child be labeled? How will this impact my relationship with my child? How do I get the school or my city involved? The above questions are examples of ways caretakers might be thinking about their children's ADHD diagnoses.

The above questions can also be helpful for educators and health care professionals who are working or attempting to engage with African-Americans families. This research shows African American families want to be included in the process of diagnosis, treatment and management of their children's attention-deficit/hyperactivity disorder. Some of the African American caregivers strongly voiced their children's progress and their strengths as people rather than view their children as a disorder.

Hopefully, these findings can help to ease the skepticism that African-American families have of health care professionals and allow African-Americans to seek professional care for their children before their symptoms became exacerbated (i.e., negatively affecting school performance during adolescence and work performance in adulthood). In addition, it might help educators and health care professionals to be empathetic to children with ADHD and to see them

beyond their diagnosis and to recognize their wish to be acknowledged, praised and comforted as human beings. For example, participant Ten and Two are quoted, respectively, "...Need to begin by understanding behavioral norms for black boys"; "I feel that health care professionals are quick to label and place patients in a category, when in actuality every case differs. Not one person is the same, every child comes from a different past, different circumstances."

Research Limitations

One of the limitations of this research pertains to the sampling method. I did not use a random sampling technique but used a snowballing method of recruitment. The use of snowballing limits the people who have access to the survey. For example, in order for someone to have heard about this research, they would need to know someone that I have a relationship with (since my method of recruitment involved using professional contacts). Another limitation to this study was the number of participants. Due to the study size, the results are not generalizable (meaning the results cannot be used to state that the themes are true across African American communities).

Another limitation of the study is that it was an online survey, which meant a person had to be able to read and write in English in order to complete it which is also connected to another limitation. The ability to access the survey. For example, one of my professional contacts had people that were interested in taking the survey but they did not have access to a computer.

Possible Biases of Author

As a future social worker, I will be involved with clients or caretakers of children with ADHD. I need to access any biases which may arise in my work as a social worker and as a researcher. I do have a bias for use of alternative methods for treatment rather than for

medication. I am aware this might impact my interactions with people who choose to use medication as a way of coping or healing.

Also, I am African and I am skeptical of mental diagnoses of people of color. I believe at times people of color are over diagnosed with mental illnesses or perhaps given more serious/severe diagnoses than their symptoms warrant. I am often left wondering why there is a pathologizing of the black body or of non-White bodies. Furthermore, due to some White professionals' lack of cultural awareness or sensitivity, they may turn to mental illness as a diagnosis rather than taking the time to get familiar with an individual and understand his/her/their difficulties which may be attributed to other factors (i.e., discrimination due to racism, gender, sexual preference, social class and immigration status). Throughout this research, I accessed my evaluation of the data to ensure that it is coming from a place of understanding rather than from judging.

Areas for Growth in Research

There are many areas to be explored that pertain to people who have attention-deficit/hyperactivity disorder. For example: Is there a correlation between the age of diagnosis and time of acceptance by the caregivers? One of the questions I asked in my survey was: Do you believe that African American children have a higher diagnosis of ADHD when compared to Caucasian children? I was trying to gauge the racial/ethnic disparities that might be present in diagnosis and treatment options for African American children in comparison to White children. I realized after analyzing my data my question was not open-ended and that it allowed for yes and no answers rather than examples to support or refute experiences of racial or ethnic

disparities. Future research can attend to racial/ethnic disparities with open-ended questions so caregivers can give examples of when and if it was present for them.

Upon analyzing my data, another question did not give caregivers enough space to elaborate on their experiences. For example, are healthcare professionals (doctors, therapists, psychiatrists, social workers and counselors) culturally sensitive to African American traditions? My question did not elaborate on the traditions I was speaking about and did not ask the caregivers to elaborate on their experiences. Finally, future research could look differently if different dynamics were concerned. For instance, how does the intersections of class, religion, gender, sexuality and disabilities affect the caregiver's views of the mental health system and of their children?

Three of the caregivers mentioned being in the medical/mental health fields. Their roles as advocates for their children manifested differently than the other caregivers who did not speak to being in the medical/mental health fields. More research could be conducted to find out if their roles as advocates for their children were largely impacted by their roles in the professional arena? If so, how? There are many other areas to be explored; the ones listed are just a few suggestions and definitely not meant to be all inclusive.

Conclusion

Being a caregiver of a child with a mental illness can be an added responsibility. The intersections of a school system, mental health/physical health facilities and the family can be tough to examine while being a part of it. Some of the caregivers have spoken about the frustrations they experienced with the above systems. They have also spoken about their children's progress and I imagine their progress (although not explicitly stated) before, during

and after the diagnosis of attention-deficit/hyperactivity disorder. Finally, for half of the caregivers, they have also added their positive reflections about their children's journey and how they would not change who they are.

I recognize the power I have in the analysis of the data. My findings and discussion sections have been a way for me to discuss and analyze the data while attempting to acknowledge the voices of those who asked to be heard. I hope I have done that. I invited the caregivers to share their stories with me as a way for me to step back and a way for them to step forward in their journey with their children with attention-deficit/hyperactivity disorder. The conceptual framework I decided to base my research was one of narratives.

The narratives the caregivers have decided to share with me were most salient in their lives at the time they took my survey (Roscoe et al., 2011). Narratives are seen as co-constructions between the author and someone else the author invites into his/her/their lives. I recognize the dangers of authoring someone else's life experiences. I am biased in that I needed to be objective in order to hear the voices of the caregivers.

Due to the objective work required in working with narratives, I kept Guilfoyle's idea of "double listening" (2015, p.37) in mind as I read and analyzed the data. The author argued people's lives are complex and multilayered and that it is necessary to listen/interpret what is being said and *what is not being said*. In thinking about what is not being said, what about the voices of the children? How do they conceptualize their attention-deficit/hyperactivity disorder? Also, why were a majority of the caregivers against medication as a form of treatment? What is the message about medication?

In the current literature, skepticisms around professionals and mental illness are addressed, “behavior problems exist in all races...I think we become suspicious as black people when we are constantly told that our kids [have] ADHD” (Olaniyan et al., 2007, p. 228). The skepticism about medication is also addressed “I think that it’s a control thing...most of our doctors are white...this stems all the way back to slavery...they couldn’t control us then...now they’re giving us medication” (p. 228).

As a researcher, I did not think I would be placed in the category with other professionals. Originally I thought I would be seen and received as a caring and future social worker, this was not the case. I had a difficult time with recruitment and it was not until people were able to learn more about me (via social events or other trusted professionals) that they trusted and allowed me to hear their stories. The quotes above which speak to being controlled either by a system or by medication became a reality as I ventured in search of participants. The participants did not know my motives for this research and they did not know me. For them, I could have represented the larger systems that benefit White people and oppresses anyone that is not considered White. As much as I am not that system, I recognize the power I have as author of this research.

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Appendix A: Human Subjects Review Application

Smith College School for Social Work

Project title: ADHD: Experiences of Diagnosis, Treatment, and Management by African-American Caregivers

Name of researcher: Lydie Helene Gnacadja

Check one: MSW PhD

Home phone: XXX-XXX-XXXX Email: LGnacadja@Smith.edu

Research advisor: Professor Debra Hull

The signature below testifies that I, as the researcher, pledge to conform to the following: As one engaged in research utilizing human subjects, I acknowledge the rights and welfare of the participants involved. I acknowledge my responsibility as a researcher to secure the informed consent of the participants by explaining the procedures and by describing the risks and benefits of the study. I assure the Committee that all procedures performed under the study will be conducted in accordance with those federal regulations and Smith School for Social Work policies that govern research involving human subjects.

Any deviation from the study (e.g.: change in researcher, research methodology, participant recruitment procedures, data collection procedures, etc.) will be submitted to the Committee in the form of a change of the study protocol for its approval *prior* to implementation. I agree to report all deviations to the study protocol or adverse events IMMEDIATELY to the Committee.

(For Committee Use)

REVIEW STATUS: Exempt Expedited Full Not Approved

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Board (HSRB).

Chair, Smith College SSW HSRB

Date

**IN THE SECTIONS BELOW WHERE DESCRIPTIONS ARE REQUESTED, BE SURE TO
PROVIDE SUFFICIENT DETAIL TO ENABLE THE COMMITTEE TO EVALUATE
YOUR PROCEDURES AND RESPONSES.**

DESCRIPTION OF RESEARCH PROJECT INVOLVING HUMAN PARTICIPANTS

Briefly summarize:

1. My research attempts to understand the diagnosis and treatment of ADHD symptoms, particularly with children of African diaspora. My use of African diaspora for this paper describes self-identified African descended people (Palmer, 2000). Another area I wish to explore within this paper is different management strategies that caregivers are utilizing for their children who have ADHD.
2. The overarching research question that I would like to address is: Do African American caregivers believe that they experience racial or ethnic biases pertaining to their children's ADHD?
3. Attention-deficit/hyperactivity disorder (ADHD) is a psychological disorder (Waite & Tran, 2010). Gregory Lester (2007) describes the three main markers of attention-deficit/hyperactivity disorder (i.e., inattention, impulsivity and hyperactivity). Children with ADHD struggle to attend to "dull, boring, repetitive tasks such as independent schoolwork, homework, or chores" (p. 12). These mundane daily tasks speak to the inattention part of ADHD. The second major part of ADHD symptomology is impulsivity. Impulsivity is displayed when children are too eager to get started (i.e., cannot wait for his/her turn or taking shortcuts). Hyperactivity is the final major marker of ADHD and is typically described as "Cannot sit still...talks excessively...acts as if driven by a motor" (p. 12). According to the diagnostic and statistical manual of mental disorders 5th edition, ADHD is a childhood disorder in which symptoms of hyperactivity, inattention, and/or impulsivity are present for at least six months and must present prior to a child being 12 years old

According to Jennifer Gapin & Jennifer Etnier (2013), ADHD "is one of the leading childhood psychiatric disorders in America and is a costly major public health problem" (p. 1). Even though ADHD has been extensively studied within the past twenty years (Mychailyszyn, dosReis, & Myers, 2008), there is minimal research on racial bias or disparities in diagnosis and treatment of ADHD symptoms (Miller, Nigg, & Miller, 2009). The literature also speaks to the skepticism that African American parents have of an ADHD diagnosis "behavior problems exist in all races...I think we become suspicious as black people when we are constantly told that our kids [have] ADHD." (Olaniyan, dosReis, Garriett, Mychailyszyn, Anixt, Rowe, Cheng, 2007, p. 228) The literature goes on to address African Americans parents' reluctance to use medication for treatment of ADHD symptoms. "I think that it's a control thing...most of our doctors are white...this stems all the way back to slavery...they couldn't control us then...now they're

giving us medication.” (p. 228). These previous studies show a need for research that attends to possible racial disparities as well as caretakers’ management of ADHD symptoms.

4. I plan to construct an online survey that asks closed-ended questions, in order to gather demographic information. I will also include open-ended questions to allow caretakers’ to author their stories. Koro-Ljungberg et al. (2008) writes about the importance of allowing African-Americans to be narrators of their experiences. It is a link back to their historical tradition of stories being passed down by orators and also a way to reclaim what was taken by years of slavery, their humanity and dignity.

Although the qualitative survey may not be generalizable, the participants will be able to tell their stories and the results can be used in future research to develop new hypotheses or questions (Steinberg, 2004).

PARTICIPANTS:

A). How many participants will be involved in the study?

X 12-15 ___ ≥ 50 ___ other (how many do you anticipate)

B). List specific eligibility requirements for participants, including inclusionary criteria and any specific exclusion criteria. For example, if including only male participants, *explain why*.

My plan is to gather information from caregivers that identify as African American. A caregiver for this study is defined as someone who has the primary responsibility of taking care of a child. Examples of caregivers are parents, grandparents, aunts and uncles. The child can be either biologically related or adopted. My study will exclude foster parents because I am interested in caregivers who have permanent responsibility for a child.

C). 1 & 2. The development of the survey and recruitment should be feasible. I plan to contact the Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) local chapter in Rhode Island, inform the organization of my research and ask for their help. **Contact them before gaining final approval and tell them about your study and get an email or some form of confirmation they will permit you to use in your application.** I can provide them with flyers (for the meetings) that explain my research purpose and designs. In addition, if allowed, I can attend a couple of meetings in order to talk about the research and answer questions. Finally, I plan on utilizing my previous internship site, The Metropolitan Regional Career and Technical School (The MET) to recruit participants. Once I receive permission from the directors, **same as above** I will visit each individual school and speak to their principals and ask if my flyer can be sent home to parents/caregivers. The flyers will direct caregivers to my survey monkey website. I will not recruit from the school that I was assigned to, I will only recruit from the other buildings.

3. Once the respondents start my survey and agree to participate in my research (by clicking yes after reading the consent form), the participant will be asked about his or her ethnic

identification. For example, do you identify as African American (meaning that you are an American with African ancestry). The next criteria for the survey will be if the anticipated participant is a main caregiver for a child that has ADHD.

4. By selecting yes to begin the Survey Monkey you are indicating that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided. You may print a copy of this consent form by selecting print from your internet browser before you continue.

5. You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, **Lydie Helene Gnacadja at LGnacadja@Smith.edu or by telephone at 401-365-2029**. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

6. Include copies of flyers, letters, announcements, email messages etc. that will be used to recruit.

D). One of the places that I plan on recruiting from is my previous internship site. There are six small schools at The Metropolitan Regional Career and Technical School (The MET). I will not be recruiting from the building that I did my placement at. I will be recruiting from four of the six schools.

E). Are study target populations any of the following federally defined vulnerable populations?

Yes No

If 'Yes', check all that apply:

- Minors (under 18 years of age)
- Prisoners
- Pregnant women
- Persons with physical disabilities
- Persons with mental disabilities
- economically disadvantaged
- educationally disadvantaged

If any of the above are anticipated participants in this study, state the necessity for doing so. Please indicate the approximate age range of minors to be involved. Participants under age 18 require participant assent AND written consent from the parent/legal guardian. Please use relevant forms.

The MET consists of adolescents between the ages of 13-19. The MET has an equal number of female and male students which is a drastic change from when The MET started almost 20 years ago (J. Bonilla, personal communication, January 23, 2014). The MET has an overrepresentation of students of color. GoLocalProv.com released a survey in June 2013. The survey was of “The Most and Least Diverse Schools in Providence”. Out of 51 schools, The MET ranked at number 3. At the time, The MET had 650 enrolled. 64% of the students were minorities (with Blacks representing 20% and Hispanics representing 36%). Similar results were shown in a brochure that The MET published in September 2013, with 15% of students identifying as African Americans and 42% identifying as Hispanics.

The student profile is representative of the larger community (Providence). In the census conducted in 2010, 38% of people living in Providence identified as Hispanics and 16% as African Americans. 28% of people met the criteria for living below the poverty line. The students enrolled at The MET are also of low socioeconomic status. Since the students come from low-income families, they often display difficulties that are associated with being raised in poverty, homelessness, and a racially discriminatory society. In a brochure that The MET published in September 2013, 64% of the students were eligible for free or reduced lunches.

Since I am mainly recruiting from The MET, I included the above information to give an idea of the area that I am recruiting from.

RESEARCH METHODS:(Check which applies)

Interview, focus group, non-anonymous questionnaire

Anonymous questionnaire/survey

Observation of public behavior

Analysis of de-identified data collected elsewhere

Where did these data come from originally?

Did this original research get IRB approval? Yes No

(Skip to BENEFITS section)

___ Other (describe)

Describe the nature of the interaction between you and the participants. Additionally, if applicable, include a description of the ways in which different subjects or groups of participants will receive different treatment (e.g., control group vs comparison group, etc.).

A). Participants will be directed from the flyer to fill out an online survey.

B). I will be meeting with the director for Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) local chapter in Rhode Island and ask to leave copies of my flyer. I will offer to come back and meet with the adults in the program (if they choose to) to answer questions.

C & D). This a one-time survey that should take between 15-30 minutes to complete depending on the length of the participants' answers.

E). Attachments A and B.

INFORMED CONSENT: *(If you are only observing public behavior, SKIP to next section)*

A). What categories of consent documentation will you be obtaining from your participants?
(Check all that apply)

written participant consent (online, prior to accepting to participate in the survey)

___ written parent/guardian consent

___ Child assent 14-17

___ Child assent, assent 6-13

___ Adult with guardian assent

B). Attach original consent documents. *note: be advised that, once the study begins, ALL consents/assents except those collected in connection with anonymous surveys will require [wet] signatures – no faxed or email/electronically signed copies.

COLLECTION /RETENTION OF INFORMATION:

A). With sufficient detail, describe the method(s) of recording participant responses (e.g., audiotape, videotape, written notes, surveys, etc.). The responses will be retrieved via Survey Monkey's secure website.

B). Include the following statement to describe where and for how long these materials will be stored and the precautions being taken to ensure the security and safety of the materials:

All research materials including transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.

C). Will the recordings of participant responses be coded for subsequent analysis? *If you are only observing public behavior, SKIP to next section.*

Yes

No

CONFIDENTIALITY:

A). What assurances about maintaining privacy will be given to participants about the information collected?

1. Anonymity is assured (data cannot be linked to participant identities)

2. Confidentiality is assured (names and identifying information are protected, i.e., stored separately from data).

3. Neither anonymity nor confidentiality is assured

B). If you checked (2) above, describe methods to protect confidentiality with sufficient detail. Describe how you will maintain privacy of the participant as well as the data

C). If you checked (3) above, explain, with sufficient detail, why confidentiality is not assured.

D). If you checked (3) above, provide sufficient detail that describes measures you will take to assure participants understand how their information will be used. Describe and attach any permissions/releases that will be requested from participants.

RISKS:

A). Could participation in this study cause participants to feel uncomfortable or distressed?

Yes

If yes, provide a detailed description of *what steps* you will take to protect them.

I informed the participants on the consent form. “The study has the following risks, this research attempts to uncover ethnic biases that may exist in diagnosis, treatment and management of your child’s ADHD. It may bring up uncomfortable memories of past or present racial and gender discrimination”. You can speak to family members, friends and/or health care professionals

about the discomforts that came up during and/or after taking the survey. If you are involved with a church you can speak to your pastor, minister, another church leader or church members. You can ask family members and/or friends for a referral to a counselor, therapist, psychologist or clinical social worker. You can also go online and research counselors, therapists, psychologists or clinical social workers in your area.)

B). Are there any other risks associated with participation (e.g. financial, social, legal, etc.)?

Yes

No

If yes, provide a detailed description of the measures you will take to mitigate these additional risks.

COMPENSATION: *(If you are only observing public behavior, SKIP to the next section)*

The participants will not receive any financial payment for their participation.

BENEFITS:

A). My goal is that my research might help educators and health care professionals to be caring and open to African American children with ADHD; to see them beyond their diagnosis; to recognize that they wish to be acknowledged, praised and comforted as human beings.

B). The benefits of participation are that you are able to have an opportunity to reflect on or think about your experiences with raising a child that has ADHD. My goal is as you write about your experience it may help you to advocate for yourself and for your child with educators and health care professionals that are working or attempting to engage with African-Americans families.

C). The benefits to social work and society are that this research can be used to further social workers' knowledge and practice with African American clients who have ADHD. I also believe that this study will help teachers, physicians, nurses and other people not in helping professions to begin to understand the many decisions that African American caregivers of children with ADHD have to make.

FINAL APPLICATION ELEMENTS:

a. Include the following statement to describe the intended uses of the data:

The data collected from this study will be used to complete my Master's in Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations.

b. There are no other researchers on this study.

c. TRAINING: I have completed the Collaborative Institutional Training Initiative (CITI) online training course prior to the Human Subjects Review (HSR) approval. The certificate of completion is on file at Smith College School of Social Work.

d. Your signature: LHGnacadja

RESEARCHER: Lydie Helene Gnacadja

DATE: 02/01/2015

Updated 8-6-14

**Appendix B: Human Subjects Review Committee
Approval Letter**



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

March 17, 2015
Lydie Gnacadja
Dear Lydie,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee
CC: Debra Hull, Research Advisor

Appendix C: Flyer for Participant Recruitment

“One day I realized I was living in a country where I was afraid to be black... We must change the system of education and instruction. Unfortunately, history has shown us that brotherhood must be learned, when it should be natural.”

Josephine Baker

Seeking African American caregivers to bring their experiences to research!!!

- ✚ Do you identify as an **African American**?
- ✚ Do you have a child who has been diagnosed with ADHD? Or a child who is in the process of getting an ADHD diagnosis?
- ✚ Are you the main caregiver for your child with ADHD?
 - A caregiver for this study is defined as someone who has the primary responsibility of taking care of a child. Examples of caregivers are parents, grandparents, aunts and uncles. The child can be either biologically related or adopted. My study will exclude foster parents because I'm interested in caregivers who have permanent responsibility for a child.
- ✚ Are you interested in sharing your experiences about your child's diagnosis, treatment and management of ADHD?
- ✚ How can healthcare professionals (doctors, therapists, psychiatrists, social workers and counselors) work with you to help with your child's ADHD symptoms?

Please consider participating in my study if the above speaks to your experiences. I am an African student and single mother pursuing my Masters in Social Work at Smith College School for Social Work.

This is a one-time ONLINE survey that should take between 15-30 minutes to complete depending on the length of your answers. Thank you for your time.

<https://www.surveymonkey.com/s/SmithCollegeADHDresearch>

Lydie Helene Gnacadja
Smith College MSW Candidate 2015
XXX-XXX-XXXX or LGnacadja@Smith.edu

“In order for us as poor and oppressed people to become part of a society that is meaningful, the system under which we now exist has to be radically changed... It means facing a system that does not lend its self to your needs and devising means by which you change that system.”

Ella Baker

Appendix D: Informed Consent Form



Consent to Participate in a Research Study Smith College School for Social Work Northampton, MA

Title of Study: ADHD: Experiences of Diagnosis, Treatment, and Management by African-American Caregivers

Investigator: Lydie Helene Gnacadja, Smith College School for Social Work student
Class of 2015, XXX-XXX-XXXX.

Introduction

- You are being asked to be in a research study to understand caregivers' experiences in diagnosis, treatment and management of child ADHD.
- You were selected as a possible participant because I plan to gather information from caregivers that identify as African American. A caregiver for this study is defined as someone who has the primary responsibility of taking care of a child. Examples of caregivers are parents, grandparents, aunts and uncles. The child can be either biologically related or adopted. My study will exclude foster parents because I'm interested in caregivers who have permanent responsibility for a child.
- I ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to learn more about the experiences of African American caregivers as they pertain to their children's ADHD diagnosis and treatment.
- This study is being conducted as a research requirement for my master's in social work degree from Smith College School for Social Work.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

If you agree to be in this study, you will be asked to do the following things: access my survey online from Survey Monkey and answer 13 questions related to your child's ADHD. This one-time ONLINE survey that should take between 15-30 minutes to complete depending on the length of your answers.

Risks/Discomforts of being in this Study

- This research attempts to understand your experiences in diagnosis, treatment and management of your child's ADHD. It may bring up uncomfortable memories of past or present racial and gender discrimination.

The study has the following risks, this research attempts to uncover ethnic biases that may exist in diagnosis, treatment and management of your child's ADHD. It may bring up uncomfortable memories of past or present racial and gender discrimination. You can speak to family members, friends and/or health care professionals about the discomforts that came up during and/or after taking the survey. If you are involved with a church you can speak to your pastor, minister, another church leader or church members. You can ask family members and/or friends for a referral to a counselor, therapist, psychologist or clinical social worker. You can also go online and research counselors, therapists, psychologists or clinical social workers in your area.

Benefits of Being in the Study

- The benefits of participation are that you are able to have an opportunity to reflect on or think about your experiences with raising a child that has ADHD. As you write about your experience it may help you to advocate for yourself and for your child with educators and health care professionals that are working or attempting to engage with African-Americans families.
- The benefits to social work and society are that this research can be used to further social workers' knowledge and practice with African American clients who have ADHD. I also believe that this study will help teachers, physicians, nurses and other people not in helping professions to begin to understand the many decisions that African American caregivers of children with ADHD have to make.
- My goal is that my research might help educators and health care professionals to be caring and open to African American children with ADHD; to see them beyond their diagnosis; to recognize that they wish to be acknowledged, praised and comforted as human beings.

Confidentiality

- This study is anonymous. We will not be collecting any information about your identity or retaining any information from the study once it is analyzed.
- All research materials including transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question and may withdraw at any point during the survey by not answering the question on the screen and by logging off of Survey Monkey. If you choose to withdraw, I will not use any of your information collected for this study.

Right to Ask Questions and Report Concerns

- You have the right to ask questions and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, *Lydie Helene Gnacadja* at XXX-XXX-XXXX (cell phone) or LGnacadja@Smith.edu. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

By selecting yes to begin the Survey Monkey you are indicating that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided. You may print a copy of this consent form by selecting print from your internet browser before you continue.

Form updated 9/25/13

Appendix E: Survey Questions

Demographic questions for survey

1. Do you identify as African American (meaning that you are an American with African ancestry)?
2. How old are you?
3. Is your child male or female?
4. How old was your child when he or she was diagnosed?

Qualitative questions for survey

1. Does your child have difficulties with dull, boring and repetitive tasks such as independent schoolwork, homework, or chores? Tell me about it.
2. Does your child have difficulties waiting for his or her turn or take a lot of shortcuts? Tell me about it.
3. Does your child talk excessively and operate as if driven by a motor? Tell me about it.
4. Tell me about your experiences when your child was in the process of being diagnosed with ADHD. What parts were helpful to you or your child? What parts do you wish could have been different?
5. How do you view your child's ADHD diagnosis?
6. Tell me how you are managing your child's ADHD?
7. Do you believe that African American children have a higher diagnosis of ADHD when compared to Caucasian children?
8. Are healthcare professionals (doctors, therapists, psychiatrists, social workers and counselors) culturally sensitive to African American traditions?
9. How can healthcare professionals (doctors, therapists, psychiatrists, social workers and counselors) work with you to help with your child's ADHD symptoms?