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Minoritized Student Experiences with Psychoeducational Service Provision for Attention-Deficit/Hyperactivity Disorder

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MINORITIZED STUDENT EXPERIENCES WITH PSYCHOEDUCATIONAL

SERVICE PROVISION FOR ATTENTION-DEFICIT/HYPERACTIVITY

DISORDER

by

Megan E. Golson

A thesis submitted in partial fulfillment

of the requirements for the degree

of

MASTER OF SCIENCE

in

Psychology

Approved:

_____   _____
Maryellen McClain Verdoes, Ph.D.   Renee V. Galliher, Ph.D.
Major Professor   Committee Member

_____   _____
Melanie M. Domenech Rodríguez, Ph.D.   D. Richard Cutler, Ph.D.
Committee Member   Interim Vice Provost of Graduate
                                          Studies

UTAH STATE UNIVERSITY

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ABSTRACT

Minoritized Student Experiences with Psychoeducational Service Provision for

Attention-Deficit/Hyperactivity Disorder

by

Megan E. Golson, Master of Science

Utah State University, 2021

Major Professor: Dr. Maryellen McClain Verdoes
Department: Psychology

Attention-deficit/hyperactivity disorder (ADHD) can impact students' academic,

social, and behavioral outcomes. To improve student outcomes, schools regularly identify

students with ADHD and develop relevant educational programming. However, the

extant research that supports these practices underrepresents racially/ethnically

minoritized students. Due to the influences of discrimination and stereotypes

racially/ethnically minoritized students with ADHD may experience ADHD differently

than their White peers. Unfortunately, the literature that addresses such issues is sparse.

To address this gap, we seek to understand racially/ethnically minoritized students' ($N =$

35) experiences with ADHD and related school-based services. Results from the

phenomenological investigation revealed 16 themes and 28 corresponding subthemes

surrounding symptom experiences, the academic and social impacts of ADHD,

community and personal perceptions of ADHD, parent roles, the intersection of

race/ethnicity and ADHD, student roles in service provision, school-based services, and

assessment. These findings support the importance of diverse sampling, involving students in treatment planning, increasing ADHD knowledge, and school-community collaboration in service provision.

(76 pages)

PUBLIC ABSTRACT

Minoritized Student Experiences with Psychoeducational Service Provision for

Attention-Deficit/Hyperactivity Disorder

Megan E. Golson

Due to the impact of attention-deficit/hyperactivity disorder on students' academic,

social, and behavioral outcomes, it is important students receive supportive interventions.

Federal regulation requires schools identify students with disabilities like ADHD and

provide them with accommodations and supports as needed. Unfortunately, the research

that supports these interventions does not adequately include students from

racially/ethnically minoritized groups. Due to factors like discrimination and

stereotyping, racially/ethnically minoritized students may experience ADHD and ADHD

services differently. This study included 35 minoritized adolescent students who receive

ADHD services. Through an online survey, students reported their symptom experiences,

the academic and social effects of ADHD, community and personal perceptions of

ADHD, and parent roles. Students also wrote about their role in school services, what

services they receive at school, and their assessment experiences. These findings support

the need for diversity in ADHD research, student involvement in treatment planning, and

increased knowledge and collaboration.

ACKNOWLEDGMENTS

CONTENTS

CHAPTER I

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) has an approximate 5%

prevalence rate for children (American Psychiatric Association [APA], 2013) and is

comorbid with several behaviors (Barkley, 2015), mood (Jarrett & Ollendick, 2008), and

other neurodevelopmental disorders (Casey et al., 2000). ADHD is associated with a

variety of challenges, including reduced academic performance (APA, 2013), peer

rejection (Weiner & Mak, 2009), stigma (Mueller et al., 2012), substance abuse,

involvement with school discipline or the justice system (Bussing et al., 2012; Robb et

al., 2011), sleep problems (Owens, 2005), and occupational deficits (Barkley & Fischer,

2011). Since the effects of ADHD are wide-ranging and pervasive, implementation of

interventions to promote positive outcomes is crucial. Schools are an ideal setting for

such interventions since it is where children and adolescents spend the majority of their

time and ADHD can significantly impact school performance. Furthermore, the federal

mandate (Child Find) to identify and provide services to students with disabilities

includes those with ADHD (Individuals with Disabilities Educational Improvement Act

[IDEIA], 2004).

Assessment and identification must precede intervention for ADHD. Within the

school, ADHD assessment includes direct assessment, observation, interviews, record

reviews, and the administration of rating scales (DuPaul & Stoner, 2014). Following

successful identification, assessment results inform the intervention process by

identifying treatment targets (Roach, 2008). Most common among these is the use of

stimulant medication, which reduces ADHD symptoms and related behaviors and thereby

results in increased academic performance (DuPaul & Stoner, 2014). However, the side effects and lack of long-term improvements support the conjunct use of school-based psychosocial interventions and medication (Barkley, 2015). Furthermore, school teams and parents should develop an educational plan that uses a variety of interventions, personalized to the student (DuPaul et al., 2006).

Part of intervention personalization requires consideration of one's racial/ethnic background. Research suggests that there are notable differences in the knowledge and beliefs regarding ADHD (Bussing et al., 2012; Lawton et al., 2014), identification rates (Morgan et al., 2014), and engagement with, or availability of, interventions (Bussing et al., 2012) between racially/ethnically minoritized students and their White peers. Despite this, research often fails to include diverse participants (Visser & Lesesne, 2003), leading to a skew in the extant data that disadvantages racially/ethnically minoritized students. Since research supports and informs practice and training of service providers, a lack of research focused on racially/ethnically minoritized students limits culturally responsive care.

Because there is a high degree of variability and nuance to the experiences of ADHD, especially due to the systemic and educational factors that impact service provision for racially/ethnically minoritized students, qualitative research is recommended to supplement the representation of this population in the literature. By employing a qualitative strategy, students can voice their experiences with a greater depth of information than discrete measurement designed by the investigator has the potential to provide (Richardson et al., 2000). Despite the utility this method has for providing information about underrepresented groups, qualitative research with racially/ethnically

minoritized populations remains lacking; there are only two qualitative studies of racially/ethnically minoritized students with ADHD to the best of our knowledge. We begin remedying the lack of research by informing researchers and practitioners of the experiences that racially/ethnically minoritized students with ADHD have related to service provision in schools.

CHAPTER II

LITERATURE REVIEW

ADHD is characterized by a consistent pattern of inattentiveness and/or hyperactivity-impulsivity that interferes with daily functioning. Examples of inattentive behaviors include difficulty sustaining focus and disorganization. The hyperactivity-impulsivity grouping includes such behaviors as excessive motor activity (e.g., inability to sit still, fidgeting), hasty actions, and lacking forethought. Individuals may present with symptoms representing one type more than the other or receive the identification of a combined type (APA, 2013). The prevalence rates of ADHD vary, with estimates ranging from a lifetime rate of 2.2% (Erskine et al., 2013) to 5% for children and 2.5% among adults (APA, 2013). Prevalence studies indicate Black children are identified at two-thirds the rate of their White peers, with Latinx and other minoritized groups equally less likely to be identified (Morgan et al., 2014). ADHD is often comorbid with oppositional defiant disorder (ODD), conduct disorder (CD; Barkley, 2015), substance use disorders (Charach et al., 2011), anxiety and depressive disorders (Jarrett & Ollendick, 2008), and learning disabilities (Casey et al., 2000). Further problems related to ADHD include externalizing tendencies (e.g., aggression) and increased risk-taking (Nigg & Barkley, 2014).

Individuals with ADHD often experience a variety of challenges, especially in school settings. Teachers report difficulty managing students with ADHD in their classrooms (Poznanski et al., 2018; Dennis et al., 2008), which in some cases results in increased encounters with school discipline (Robb et al., 2011). Furthermore, teachers have reported limited knowledge of the disorder and its associated behaviors (Arcia et al.,

2000), which may inhibit their ability to effectively identify, manage, and support students with ADHD. Aid from teachers and other school personnel is integral in mitigating lower academic attainment (e.g., college entrance) and reduced school performance, especially in math and reading (DuPaul et al., 2006) students with ADHD may otherwise experience. Given these challenges, many students with ADHD may benefit from special education services. Unfortunately, students with ADHD often receive special education classification when they are older (ages 12-17; Pastor & Reuben, 2008), further delaying intervention in the school and placing them at-risk for academic underperformance.

Negative long-term outcomes associated with ADHD stretch beyond the scope of the classroom. Students with ADHD experience greater peer rejection, especially when they exhibit higher rates of hyperactivity (Nigg & Barkley, 2014). Weiner and Mak (2009) found that students with ADHD were more likely to report being victims of bullying. For students that remain unidentified and untreated into adolescence, the risk for substance abuse and involvement with the justice system increases (Bussing et al., 2012). Unidentified students with ADHD have also been shown to exhibit occupational deficits (Barkley & Fischer, 2011) and poor driving ability (Fischer et al., 2007) into adulthood. Sleep problems are also consistently reported by individuals with ADHD (Owens, 2005). Considering these possibilities, preventing aversive long-term outcomes and promoting educational attainment and positive social-emotional development should be treatment goals. To further increase the likelihood of positive outcomes, early identification and intervention are crucial.

Although the symptoms, related behaviors and disorders, and outcomes associated with ADHD occur across settings, the school is an ideal setting for assessment and intervention for the disorder for several reasons. First, many students with ADHD experience significant difficulty with the behavior expectations of the traditional classroom (e.g., sitting still, remaining on task, answering questions when called upon) and with maintaining academic performance (APA, 2013; DuPaul & Stoner, 2014). Intervention at the site of the problem is a logical and targeted treatment choice (DuPaul et al., 2014). Second, since the symptoms of ADHD are evident within the classroom, evidence-based assessment can occur at the school. Third, due to the Individuals with Disabilities Educational Improvement Act (IDEIA, 2004) and Section 504 of the Rehabilitation Act (Rehabilitation Act, 1973) schools are required to identify and provide services or accommodations to students with disabilities and disorders, such as ADHD, without cost to the parent, such as is reasonable in providing the student with an education. Because of this, school-based assessment and intervention enable students, including those from diverse and/or disadvantaged backgrounds, to services to which they may not otherwise have access.

However, it is important to make the distinction between school identification and medical or clinical diagnosis of ADHD. For a medical or clinical diagnosis of ADHD, children must meet criteria outlined in the DSM-5 (APA, 2013), including a minimum of six specified symptoms in the inattention or hyperactivity/impulsivity categories, the presence of symptoms by 12 years of age, and multiple contexts in which symptoms occur. On the other hand, schools follow IDEIA guidelines for the identification of ADHD, which falls under the Other Health Impairment (OHI) category. These guidelines

require only that the disability impair the student's education and require special

education services, with relevant medical history on file. Yet, OHI also includes other

medical conditions, such asthma, diabetes, sickle cell disease, and other related concerns

(IDEIA, 2004). For many children with ADHD, a 504-plan has been deemed more

appropriate than special education services as accommodations and classroom or task

modifications are sometimes sufficient to meet their educational needs (DuPaul & Stoner,

2014). This broad and diverse OHI category and the frequent utilization of 504-plans

makes it difficult to assess the incidence rates of ADHD within the school. Furthermore,

the vague requirements for identification within the school provide for great variability

between school districts and states in methods and rates of ADHD identification.

Assessment of ADHD

Identification of ADHD begins with assessment. School-based ADHD assessment

consists of a multi-method process that includes direct assessments, observations,

interviews, and a review of education records (DuPaul & Stoner, 2014). Direct

assessment for ADHD can take a variety of forms, including the computerized Conners

Continuous Performance Test (CPT-3; Conners, 2015) which asks that students who are

at least 8-years-old to respond by pressing the spacebar when certain stimuli are

displayed on a screen, measuring attention and impulsivity. This can be used in

conjunction with the Connors Continuous Auditory Test of Attention (CATA; Conners,

2015), which measures similar domains of auditory attention using aural stimuli.

Executive functioning (EF) is also frequently assessed as many students with

ADHD exhibit deficits in this domain (APA, 2013). EF broadly refers to higher-order

cognitive processes that includes skills such as (but not limited to) inhibition, working

memory, and attentional control (Lezak, 2012). Neuropsychological and psychological

assessments of EF deficits may aid in the identification of ADHD. Equally as helpful are

behavioral observations. Witnessing some of the symptoms enumerated in the DSM-5

(APA, 2013), such as fidgeting, can aid in identification, especially if the referral

question concerns multiple disorders. Behavior observations can occur during the

administration of direct assessments or in naturalistic settings (e.g., during class time).

Using behavior observations can further corroborate referral questions, interview

statements, and direct assessment results. To make behavior observation more objective,

schedules like the Behavioral Observation of Students in Schools (BOSS; Shapiro, 2011)

may be employed. This schedule, like others, outlines the frequency of observation and

provides codes to apply to behaviors the students in question may be performing.

Interviews and a record review further support or inform the identification and

assessment process. Interviews may be conducted with parents or children, commonly

through the Diagnostic Interview Schedule for Children (DISC-IV; Shaffer et al., 2000)

which uses diagnostic criteria to guide interviews for either parents or children to screen

for more than thirty childhood and adolescent psychiatric disorders, including ADHD.

Additionally, investigation of the records can help identify the onset of the disorder and

related behaviors (DuPaul & Stoner, 2014). A structured approach through the School

Archival Records Search (SARS; Walker et al., 1998) can be employed in reviewing

absences, achievement, grades, behavioral referrals, and other variables.

Despite being more common in the literature than in practice, rating forms are

another method of assessment for ADHD. Both parents and teachers may complete these

forms (DuPaul & Stoner, 2014). Common rating forms include the Behavior Assessment

System for Children (BASC-3; Reynolds & Kamphaus, 2015) and the Child Behavior

Checklist (CBCL; Achenbach & Recorla, 2001), which are broadband measures designed

to identify a variety of internalizing and externalizing behaviors. These measures may

provide evidence for differential diagnoses if ADHD is not the most appropriate

designation. Specific to ADHD and related issues, the Conners-3 (Conners, 2008) is a

narrowband measure that may aid in the assessment process due to its focus on

attentional issues. However, teachers' perceptions of appropriate behavior across groups

(e.g., racial/ethnic groups, gender) can skew ratings on these and similar forms (Chang &

Sue, 2003; Hosterman et al., 2008). This further emphasizes the importance of using a

multi-method approach. By utilizing multiple informants, perspectives, and tools, the

likelihood of timely and accurate identification increases.

Interventions for ADHD

Schools require assessment as a prerequisite to special education eligibility per

IDEIA regulations; however, assessment results also inform intervention plans and

educational programming. Though interventions have varying intervention validity (i.e.,

application to intervention planning; Roach, 2008), observations and skills analyses can

aid in personalizing education and behavior plans. To this end, there are a variety of

evidence-based treatment and intervention strategies for students with ADHD.

Perhaps the most well-known intervention for ADHD is stimulant medication.

Since the 1990s the use of stimulant medications to manage ADHD symptoms has

increased (Zuvekas & Vitiello, 2012). Recent estimates suggest that 69% of children

identified with ADHD in the United States have prescribed stimulant medications (Visser

et al., 2014). Considering its widespread usage, it is little surprise that research supports

the reduction in hyperactivity/impulsivity, increased attention, and decreased aggression as a result of these medications. Due to this reduction in symptoms, particularly related to attention, students are better able to perform academically (DuPaul & Stoner, 2014). Furthermore, these benefits typically satisfy the parents of children with ADHD (Dosreis et al., 2003).

Stimulant medication as a treatment option is associated with potentially serious side effects including appetite suppression, weight change, and sleep disturbance (Oehrlein et al., 2016). Additionally, the common twice-daily dosage may be difficult to manage within the school environment and frequently subsides before the student arrives home for the day (DuPaul & Stoner, 2014). Furthermore, the medication fails to provide compensatory skills for the symptoms of ADHD in the long-term; its effects last only as long as it is prescribed. Since a large portion of parents seek medication because they desire symptom management and the subsequent academic improvements (Dosreis et al., 2003), long-term positive outcomes may be more effectively achieved when stimulant medication is used in conjunction with school-based intervention plans (Barkley, 2015).

School-based intervention plans often include behavioral interventions, of which there are many options. Some behavioral interventions, such as contingency management procedures (e.g. token economy and response cost) can be effective in reducing problem behaviors associated with ADHD through reinforcing preferred behaviors (Carlson et al., 2000; Coelho et al., 2015). Alternatively, schools can teach students to self-monitor their performance and attention, which can elicit large gains in these domains without continued external reinforcement (Harris et al., 2005). Interventions may also be academic in focus, such as peer tutoring or study skills instruction (DuPaul et al., 1998).

At a minimum, most students with ADHD receive modifications to tasks, instruction, or both (e.g., preferential seating, additional time on assignments, DuPaul & White, 2006) as these are available to students through Section 504 of the Rehabilitation Act even if they do not qualify for an Individualized Education Plan (IEP) through special education (DuPaul & Stoner, 2014). Whether one or many of these interventions are employed is determined by the school and parents. However, evidence suggests that tailored and individualized intervention plans yield better outcomes than domain-general interventions (DuPaul et al., 2006). Therefore, whatever intervention plan the school develops should consider educational classification as well as individual factors.

Race/Ethnicity and ADHD

An integral aspect of this personalizing assessment and intervention process is the consideration of a student's racial and/or ethnic background. In addition to cultural and linguistic differences unique to each group, racially/ethnically minoritized students with ADHD have membership within two traditionally disadvantaged groups (e.g., racially/ethnically minoritized and with a disability) that impacts their experiences. Biases that arise from perceptions about ADHD and racially/ethnically minoritized students can impact teacher response on rating forms (Chang & Sue, 2003). For example, some teachers and evaluators that hold stereotypes that Latinx students are loud and disruptive are more likely to attend to hyperkinetic and disruption than their attentive behaviors, resulting in identification of behavior disorders over ADHD (Arcia & Fernández, 2003). Asian American students who are subject to the model minority myth may be held to higher academic expectations than students from other racial/ethnic groups, causing significant distress when they fail to meet these standards (Thompson et

al., 2016). Belief in this myth may also impact teacher ratings and student experiences of ADHD. Related to these perceptual biases in rating, Morgan and colleagues (2014) found that racially/ethnically minoritized students are more likely to be identified with ADHD later than their White peers with similar symptoms.

However, once minoritized students are identified, there are still notable differences in their intervention experiences compared to their White peers. As mentioned before, stimulant medication is one of the most well-known treatments for ADHD. Racially/ethnically minoritized families, however, have less access on average to these medications than White families (Graves & Serpell, 2013). Factors such as disparities in medical access due to socioeconomic status, insurance, transportation, bilingual medical providers, and inequitable health systems inhibit racially/ethnically minoritized students from participating in this treatment. As a result, the provision of school-based services for ADHD is increasingly necessary to serve racially/ethnically minoritized students.

Although interventions should be evidence-based, if they are not sensitive to cultural beliefs and endorsed by parents just as much as the school team proposing them, they may fail to meet the needs of students to which they are being provided. The beliefs a person has about the etiologies of a psychological disorder impact the services they seek for it (Eiraldi et al., 2014). Accordingly, the spiritualism and familism more common in Latinx households are associated with greater participation in religious and alternative medicine practices to treat ADHD (Lawton et al., 2014). Black parents are more likely to endorse the sugar etiology of ADHD or believe it is a result of poor discipline, decreasing the likelihood that they would seek medication or other school-

based services (Bussing et al., 2012). Noting this, school professionals should actively seek to know and understand the beliefs, values, and preferences of the racially/ethnically minoritized families they are working with when developing intervention plans.

The disparities in experience spread beyond assessment, intervention, and beliefs. The research on ADHD overrepresents the experiences of White, male, and privately insured individuals over any other group (Visser & Lesesne, 2003). Although some research has investigated Black and Latinx populations, nearly no data has been collected on Asian American, Native American or Middle Eastern students. The overrepresentation of White individuals and underrepresentation of racially/ethnically minoritized groups skews the understanding of, and intervention for, ADHD that does not favor the latter group. In particular, although some have researched treatment response to stimulant medication among Black children (Arnold et al., 2003), there is a lack of research on intervention response within the school context. The assumption that students from all racial and ethnic backgrounds will have the same experiences with ADHD invalidates the cultural, systemic, and personal contextual factors that produce variety across and within these groups. Therefore, further research is needed to increase scholarly and professional understanding of all experiences to provide high-quality services to all groups.

Qualitative Research

Qualitative research complements quantitative findings and allows members of the population of interest to volunteer information the researchers may not think to investigate (Richardson et al., 2000). This is especially helpful when there is limited information on a topic as is true here. Nuanced topics such as experience or working with populations as broadly defined and heterogenous as racially/ethnically minoritized

students, quantitative research methods are ill suited to capture the variability and complexity of the phenomenon. Findings from qualitative study can inform future quantitative study (Creswell & Poth, 2018). As such, qualitative research can help to elucidate ideas and meanings yet unknown to researchers and practitioners regarding ADHD and service provision. Consistently, some researchers have begun to employ qualitative methodologies to better understand the ADHD experience generally (e.g., Haack et al., 2018; Moore et al., 2017). However, there remains little research on this topic, and the majority of studies fail to focus the research on the students, especially minoritized students. Although teachers and parents can provide a valuable and unique perspective, especially while students are still minors, it is an oversight within the field that very few researchers have investigated the experience of ADHD and related provision of services from the perspective of the recipient: the student.

My review of the literature only yielded two qualitative studies of racially/ethnically minoritized students with ADHD. One of these studies involved analysis of four narratives produced by Black teens through a modified experience sampling method (ESM), where participants periodically called researchers as they had relevant experiences with ADHD (Koro-Ljungberg et al., 2008). The data suggested that students are valuable informants into their own experiences of the disorder. The narratives they expressed were at times contrary to or masked the prototypic ADHD manifestation familiar to service providers. This may contribute to the delay in identification of the disorder for racially/ethnically minoritized students and influence treatment decisions made by health and educational professionals unaware of these differences. Waite and Tran (2010) also conducted a qualitative investigation of ADHD

experience of ethnic minority women attending university. Thematic analysis of the

resulting interviews suggested that individuals experience ADHD classification as an

identity-salient event and describe the experience of the disorder as internalized chaos.

Women who received later identification more commonly expressed experience of chaos.

These results further emphasize the importance of timely identification and intervention

as it may aid in greater positive outcomes.

The Current Study

Overall, the culturally situated narratives expressed through these studies together

emphasize the necessity of qualitative investigation of experience. Though both studies

focus on experiences of racially/ethnically minoritized students with ADHD, neither

focus explicitly on intervention or assessment practices. Knowledge about how

racial/ethnic minorities experience service provision can be equally as useful for

practitioners as the quantitative outcome data. As such, we conducted a

phenomenological investigation of experiences of racially/ethnically minoritized students

with ADHD specific to school-based identification and intervention processes that is

guided by two central questions. First, how do racially/ethnically minoritized students

experience ADHD? Second, how do they experience service provision for ADHD?

Relevant to their experience, this study will relate the feelings, events, and meanings

associated with ADHD and service provision. Insight into these experiences may help

remedy the gap in the research and further inform treatment, improving the likelihood of

positive outcomes for racially/ethnically minoritized students with ADHD.

CHAPTER III

METHOD

Theoretical Orientation

Phenomenology is the study of experience (Moustakas, 1994). At the root of phenomenology is consciousness, divided into the perception of an experience and its meaning. Theoretically, phenomenology occurs through three processes. First is the epoche, where the researcher sets aside their own experiences and biases to study the topic of interest with new eyes. Second, the researcher uses transcendental-phenomenological reduction to describe the experience. Third, the process of imaginative variation integrates the factors surrounding the experience that give context into the description. Though all these parts are essential to the method of inquiry, phenomenology is chiefly concerned with the internal or subjective experience of a phenomenon over the object or event itself (Moustakas, 1994). In this case, my research focuses on the experience of ADHD and related service provision rather than these phenomena themselves as can and have been investigated through quantitative means. Furthermore, phenomenology is appropriate over other qualitative approaches (e.g., narrative analysis, grounded theory) because the identification of, living with, and intervention for ADHD are all, at their root, experiences. Understanding the meanings attributed to and the perceptions of these provides insight for research and practice yet undiscovered through quantitative methods (Moustakas, 1994).

Researcher Orientation

I am particularly passionate about this work after working in multiple school districts where I watched many racially/ethnically minoritized students receive

inappropriate placements in self-contained classrooms. Alternatively, some racially/ethnically minoritized students I worked with were denied needed special education services because their behavior was interpreted as a disciplinary problem rather than a disability. By contrast, White students in the same schools did not experience these same difficulties as frequently. After doing what I could to support racially/ethnically minoritized students as a practitioner in training, I sought to find answers to improve the cultural responsivity of services through research.

As school psychologists we are positioned to interact with students from various racial/ethnic backgrounds who have disabilities. Working with students who have ADHD in both assessment and intervention contexts is common for professionals in our discipline. However, most students identified with ADHD are White, thereby leading to a gap in training and experience that does not favor students from other racial/ethnic backgrounds. To compound this problem, many of our colleagues in school psychology are White neurotypical females who likely share this lack of understanding, leading to questionably accurate supports for racially/ethnically minoritized students with ADHD.

Thus, the research team was developed to both reflect the state of the field and ensure an authentic analysis of the data. The first author identifies as a White, neurotypical (i.e., without a neurological or neurodevelopmental disability) woman, similar to the majority of school psychology practitioners. I am joined by a coding partner who identifies as Native American, and final themes and codes were reviewed by her biracial (Black/White) committee chair. The resulting team represents a diversity of experiences and knowledge related to the intersectionality between race and disability, minoritization, and school-based services for ADHD.

Participants

Thirty-five students participated in the current study. Traditionally, phenomenology accepts a maximum of 20 participants (Creswell & Poth, 2018). However, due to the method of data collection (see below), over recruitment is ideal to supplement potential poor response quality. Participants' ages ranged from 14-17 years old (M = 15.8 years). Twenty participants identified as male, 14 identified as female, and one elected not to respond. A significant portion of participants identified as biracial (n = 19). For 3 of these, participants did not disclose the two races included in this identity and are identified using the term Biracial only. Two additional participants identified as multiracial, operationalized as identifying with three or more races/ethnicities. The remaining 14 participants identified with a single race or ethnicity. Participants represented a variety of backgrounds, including Black, Native American, Latinx, White, Asian, Middle Eastern/North African, and Pacific Islander. Eight participants reported comorbid conditions such as ASD, anxiety, depression, post-concussive disorder, and developmental coordination disorder. By parent report, 26 participants had a formal diagnosis of ADHD, qualifying them for a 504-plan in the school. The majority of participants also received special education services (n = 26) per parent report, but 15 participants did not receive services for ADHD through this program.

Individuals who met the following inclusion criteria were eligible to participate. First, participants had to be students who receive some form of services for ADHD, as reported by their parents. Second, they must identify as racially/ethnically minoritized. Since the research question specifically concerns students who are racially/ethnically minoritized, those who personally identified as White only, regardless of their parents'

reported race/ethnicity, were excluded. In keeping with phenomenological tradition, the sample was derived of individuals with similar experiences (racially/ethnically minoritized student with ADHD who receives related school-based services) that are otherwise heterogeneous (Creswell & Poth, 2018).

Third, participants were excluded if they or their parents did not speak English fluently due to potential translation conflicts and language barriers. This exclusion was implemented to limit confounds to the phenomenon of interest since linguistic differences in school impacts the evaluation and intervention process for students with disabilities. For example, parents who are not fluent in English are likely to participate in the evaluation and intervention process for their children differently than parents who do speak the language fluently. IDEIA mandates consent be given to parents in their language, involving interpreters and/or translation services, stipulates that assessment should be administered in the child's native language (defined as the language their parent speaks most at home), and may require further or different assessment strategies to test in the student's native language and ascertain whether or not language level is impacting the referral (IDEIA, 2004). In practice, school psychologists employ a wide variety of strategies for working with parents and children who do not speak English fluently (Ochoa, et al., 2004). Furthermore, children who are not fluent in English may experience different assessment and intervention strategies that confound the phenomenon under study. Students were also excluded if they were younger than 14 years of age. Not only has previous research indicated that a greater number of older students have been identified with ADHD than younger students (Pastor & Reuben,

2008) but this age restriction is included to increase the likelihood that participating students are mature enough to meaningfully contribute.

Materials

Parent Demographic Questionnaire

Participating parents completed a demographic questionnaire (Appendix A) through the survey hosting website, Qualtrics (Qualtrics, 2018). The questionnaire asked for information such as the parents' racial/ethnic identity, family history of ADHD, and ADHD-related services their child receives at school to provide contextual information for analysis.

Student Demographic Questionnaire

Student participants completed an additional brief demographic questionnaire (Appendix B) on Qualtrics to gather information about their racial/ethnic identity and confirm their knowledge of their diagnosis or classification. The latter was asked to elucidate whether students were aware of their diagnosis or classification and could provide useful information about the phenomenon in question.

Phenomenological Questionnaire

Students also completed a survey through Qualtrics, which consisted of 20 open-ended questions (Appendix C), to prompt responses related to ADHD, assessment, and school-based intervention. These questions did not explicitly prompt responses related to race/ethnicity to ensure that responses related to this topic were organic in nature. Imbedded logic in the survey required participant responses to contain at least 60 characters to reduce nonsense or single word responses.

Procedures

Participants were recruited through Qualtrics Panels. An assigned representative from the company sent the survey to a panel of qualifying individuals to access the necessary diverse response pool. Parents of potential participants received a link to the survey, prefaced by the informed consent document. Parents completed the informed consent and parent demographic questionnaire before their child was granted access to the survey. The student then completed the assent form, student demographic questionnaire, and the phenomenological questionnaire. Similar qualitative research conducted through online surveys has been used previous in the literature (e.g., Fogarty et al., 2016; Harris et al., 2019)

Data Analysis Plan

Participant survey responses varied significantly in length. The shortest response to a question was one word, bookended by random characters to meet the character requirement. By contrast, the longest question response was 90 words. The average response to a single question was 22 words. We analyzed data following the tradition of transcendental phenomenology outlined by Moustakas (1994). First, I and one other trained coder (Roanhorse), independently read each participant's responses to gain familiarity with the data and make preliminary notes. Second, we met over the course of 6, 2-hour sessions to review the data together. During each session, meaningful and relevant statements were identified and sorted per the two central research questions. We removed irrelevant, overlapping, or repetitious ideas from the final collection by coder consensus. For example, one participant wrote several sentences about their experiences in the foster care system. Because no connection was made between foster care and the

experience of ADHD or services in the statements, these were excluded from the analysis. By doing following this exclusion process, variation in the experiences of ADHD and service provision for the disorder form the core of themes. Additionally, the focus on imaginative variation enabled a richer picture of the experience to emerge. This procedure also allowed for opposing statements and contradictory experiences to coexist.

Third, following the sorting of unique statements, we met again to cluster the statements into themes. Over the course of 2, 2-hour sessions, we identified and named themes regarding the two central research questions. We then wrote descriptions for each theme, which were evaluated by the committee chair (McClain) for descriptive value and compared to the comprising statements for accuracy and validity. Themes that did not connect to the original statements, overlapped with other themes, or were too broad were revised based on this feedback. Finalized themes and their descriptions were then organized into the essence of the experience discussed in later chapters.

Validity

Validity, as it pertains to transcendental phenomenology, is best understood as the evaluation of the accuracy and authenticity of the resulting description of the essence of the experience (Creswell & Poth, 2018). The goal of the project, then, is to present a description of ADHD and related school-based service provision as experienced racially/ethnically minoritized students that is as rich, informative, and faithful to the participants' experience as possible. Three techniques were employed to increase validity: (1) bracketing in the form of the researcher positionality statement, (2) a clear description of methods and results for review, and (3) evaluation of themes by the research team and committee chair.

Bracketing, as explained earlier, delineates my experiences with and perceptions related to the subject of inquiry (Moustakas, 1994). By explaining these to the reader, the audience can evaluate my position and relationship to the study. Any biases we have can be more easily identified and may potentially be counteracted by engaging in this practice. Furthermore, the use of bracketing at the beginning of the research allows the reader to focus on the experiences and perceptions of the participants rather than my own. Thus, the research yields a more authentic expression of the experiences studied rather than one muddied by researcher agenda (Creswell & Poth, 2018).

On a related note, since psychology is a predominantly quantitative field (Richardson, et al., 2000) a clear and thorough description of data collection and analysis methods is included for peer researcher audit. Further, the themes and the participant statements that comprise them were subject to review by the two coders following analysis. Additionally, the committee chair reviewed the themes before finalization. Thus, the concern of validity is shouldered not just by the primary investigator, but also involved the other research members, committee, and readers of the final product.

CHAPTER IV

RESULTS

The qualitative analysis process elucidated 10 themes with 28 subthemes. These themes are separated by the central research question to which they pertain. Of these, 6 themes and 17 subthemes emerged to answer the first question: how do minoritized students experience ADHD? An additional 4 themes and 11 subthemes emerged in the data related to the second question: how do minoritized students experience school-based service provision for ADHD? The following sections describe each theme and relevant subthemes in greater detail.

Experiences of ADHD

Use of Narrative and Metaphor

A significant theme in the data is the recurrent use of metaphor and narrative strategies to communicate the internal experience of ADHD and related frustration. These strategies helped participants communicate the internal experience and symptoms of ADHD. For example, one participant, a 16-year-old Latinx female, described her experience of ADHD with the following:

> "It's like having 5 puppies and trying to keep them all inside of a small circle, but the puppies just keep wandering off and the more you chase them the further they run and while you are chasing one, more of the puppies run off until all of the puppies are running and playing in every direction."

Similar statements from participants also capture the frustrations of symptom management in the face of teacher or social expectations. The use of these narrative strategies allowed participants to communicate symptom experiences and perceptions of ADHD simultaneously.

Symptoms of ADHD

Participants reported symptom experiences that correlated with, or echoed, the diagnostic criteria for ADHD as well as other related disorders or behaviors. The comprising subthemes reference each of the symptom criteria or related behavior referenced by participants. The result was four subthemes: (1) *Inattention*, (2) *Hyperactivity/Impulsivity*, (3) *Sleep Problems and Exhaustion*, and (4) *Anxiety*.

Inattention. Participants mentioned several inattentive symptoms when discussing their experience of ADHD. They reported difficulty sustaining attention, disorganization, problems starting and completing tasks, and forgetfulness. Overall, across the complete sample, each of the inattentive symptom criteria from the DSM-5 was reported at least once. Of the symptoms described, difficulty concentrating and completing tasks were the most common. Participants described these symptoms in the context of their impact on daily life, schoolwork, or relationships. For example, one participant, a 17-year-old Asian male, wrote that people "get tired of repeating themselves" because he does not attend to whole conversations. Another participant, a 16-year-old biracial (Black/Latinx) female, described how inattention interferes with chore completion and said, "When I am doing my daily chores and someone in the house asks me something, I would go and answer their question but then forget about the chores I was doing until hours later when someone else remembered or saw it."

Hyperactivity/Impulsivity. Participants also described behaviors and experiences that reflect symptoms of hyperactivity/impulsivity such as having high energy, restlessness, talkativeness, and limited impulse control. Of these, restlessness, or the need to move around was the most commonly reported by participants. One

participant, a 15-year-old biracial (Native American/White) male, described it as "having a lot of energy that I don't know what to do with." Impulsivity was also a significant feature of ADHD noted by the participants. A 15-year-old multiracial (Native American/Black/Latinx/White) male wrote, "I say the first thing that comes to mind without thinking. I do things without thinking." Indeed, several participants connected their hyperactive/impulsive symptoms to speech as well as motor movement.

Sleep Problems and Exhaustion. Participants reported experiencing sleep problems and subsequent exhaustion related to ADHD. This presented in one of two ways in the data set. In some cases, participants reported difficulty falling asleep or staying asleep. In other cases, participants connected their ADHD to a sense of exhaustion and a need for additional sleep or naps throughout the day. A 15-year-old Biracial male, who falls in the second of these categories, described having ADHD as "exhausting." Another 15-year-old biracial (Native American/White) male wrote, "I have a really hard time falling asleep."

Anxiety. Participants connected the experience of anxiety with ADHD. They reported anxiety and nervousness generally, while others noted more specific associated behaviors such as dwelling on stressful thoughts or catastrophizing outcomes. For example, one participant, a 17-year-old Latinx female wrote, "I overthink a lot which causes me to stress." Another participant, a 17-year-old biracial (Native American/White) male, described feeling like "even the smallest mistake can snowball into an avalanche."

Navigating Life with ADHD

Aptly put by one participant, a 16-year-old Black male: "It affects every part of my life." Participants in this study reported several impacts of ADHD, including those on

their education and social relationships. They also discussed the ways they have adapted to these impacts through self-management strategies and social behaviors. This theme includes three subthemes: (1) *ADHD at School*, (2) *Social Relationships with ADHD*, and (3) *Learning to Manage ADHD*.

ADHD at School. Participants reported a variety of experiences ADHD has engendered within the school environment. Academically, participants reported inattention and hyperactivity present additional challenges to focusing on instruction. Frustration with lower grades or difficulty with specific subjects, such as math and reading, was expressed. A 15-year-old biracial (Native American/White) male stated, "Without ADHD, I can guarantee I would have straight A's." In addition to academic difficulties, participants reported school disciplinary experiences for being out of seat, disruptive, or impulsive. Teachers also treated participants differently from other students. For some, teachers are more attentive and offer more support. For others, participants reported a lack of understanding from teachers or stigmatizing classroom discipline. A 15-year-old biracial (Black/White) female wrote: "In 4th grade, when I would talk too much the teacher had this giant blue box she would put around me. It was humiliating."

Social Relationships with ADHD. Fitting in, developing a support network, peer rejection, and loneliness were key experiences participants discussed in relation to their ADHD. Participants indicated that they isolate themselves to avoid ridicule or bullying. Feeling out of place or lonely was also common for these participants. Some participants directly attributed their difficulty building or maintaining friendships and victimization to ADHD. Symptoms such as high energy and difficulty sustaining attention on

conversations were among those mentioned as causing relationship problems. Other participants cited self-deprecating reasons for friendship difficulties, including being a "loser" or "weirdo." However, the social landscape of participants was not wholly negative. Participants reported finding support from friends with ADHD as well and prioritizing healthy friendships.

Learning to Manage ADHD. A 16-year-old biracial (Black/Latinx) female said, "Over the years as I got older I think the ability to work by myself and gain independence helped me a lot in managing my ADHD." Navigating life with ADHD for many participants in this study includes learning to manage the disorder, whether through conscious efforts to improve or personal strategies and hobbies. The methods participants use to accomplish this vary widely from artistic expression (e.g., drawing, singing) to study strategies (e.g., chunking work) to wellness behaviors (e.g., exercise, yoga, deep breathing exercises).

Perceptions of ADHD

Perceptions of ADHD from participants and their communities were markedly varied. While some participants were able to find positivity in ADHD and its associated behaviors, others characterized ADHD as a daily struggle. Stigma, internalized and echoed from community and family members, was a recurring theme. Further, participants noted the portrayal of ADHD in media and community dialogue affected the ways people respond to them and their diagnosis or educational classification. Due to the variety in experience and the complexity of this theme, it is divided into five subthemes described below: (1) *Finding Positivity in ADHD*, (2) *Daily Internal Struggle*, (3)

Internalized Stigma, (4) *Communicated Stigma*, and (5) *Mainstream Understanding of ADHD.*

Finding Positivity in ADHD. Participants reported that ADHD has advantages, such as unique or positive qualities. One participant, a 14-year-old Black male, said, "It's what makes me unique and outstanding. I see it as my own gift and I try to challenge myself to do things that people say is impossible." Other participants mentioned specific characteristics or abilities that they attribute to ADHD. For example, a 15-year-old biracial (Black/White) female wrote, "I think my ADHD makes me an outgoing person." Notably, not all participants described ADHD as a consistently positive experience. As one participant, a 16-year-old biracial (Black/Latinx) male reported his positivity toward ADHD "really depends on how I am feeling at the time." While having ADHD may be viewed as beneficial or positive to some, this interpretation of, or the identified advantages may not be consistent for all participants.

Daily Internal Struggle. Although some participants described positivity related to ADHD, many participants described their internal life with ADHD in a consistently negative way. Participants used words such as "chaotic, overwhelming," "frustrating," and "scary" to describe their internal experience with ADHD and its symptoms. The terms participants used evoke a sense of loss of control and strong, negative emotions. One participant, a 17-year-old Latinx female wrote, "I feel like it makes everything difficult. It takes over." To these participants, coping with ADHD is a difficult and challenging experience.

Internalized Stigma. The stigma of ADHD is apparent in many of the participants' descriptions of themselves, the disorder, and their experiences. Many

participants expressed a desire to be "normal" or to outgrow or be cured of ADHD. An association between ADHD and intelligence was also expressed. Participants indicated they felt ADHD or related interventions made them seem less intelligent than those without ADHD. A 16-year-old Black male wrote, "I feel stupid compared to other kids my age." Due to this association and others, participants reported they did not want to receive interventions or accommodations to help them cope. Other participants wrote, "I don't want special treatment," and "I did feel bad that I was considered a 'special student' because I felt that made me seem less intelligent." Additionally, negative associations and stigma related to ADHD prevented participants from discussing their experiences with others.

Communicated Stigma. Related to the stated negative beliefs of participants, the participants also reported several of negative perceptions, statements, and behaviors teachers and community members have engaged in due to their ADHD. Here, the perception that people with ADHD are less intelligent was again expressed. Additionally, participants reported people believe they are "trouble maker[s]," "weirdo[s]," or a "handful" because of ADHD. Participants described how teachers and other adults are warier around them or voice hurtful jokes related to these beliefs. For some, stigma is communicated through outright rejection by community members. One participant, a 17-year-old biracial (Black/White) male, wrote, "Sometimes people don't want to deal with you, even before they get to know you."

Mainstream Understanding of ADHD. Participants reported the ways lay awareness and media representation of ADHD influences others' responses to and perceptions of ADHD. Discourse surrounding ADHD and the prevalence of ADHD has

led to the reduction in its perceived severity. One participant, a 17-year-old biracial (Native American/White) male wrote, "I get it because it's so common, but I wish people took it a bit more seriously. . . . They usually say 'Same,' even if they don't have it." Another participant echoed the sense that ADHD is perceived as a "trend" or as "quirky" rather than a disorder with significant impairments and consequences. Conversely, a lack of understanding about ADHD resulted in the following experience for a 16-year-old biracial (Black/White) female: "Some stupid people think it's a disease or something, as if they're going to catch it if they're near me."

Parents and ADHD

When describing their experiences with ADHD, participants discussed their parents' perceptions of ADHD, concerns about outcomes, and support in managing the disorder. Within this theme, three subthemes emerged: (1) *Concern for Child Outcomes*, (2) *Support from Parents*, and (3) *Lack of Understanding*.

Concern for Child Outcomes. Participants in this sample perceive their parents to be concerned about them and their futures related to ADHD. These concerns included academic achievement, future occupations, and transitioning to adulthood. A 17-year-old Asian female wrote, "They wish I didn't have it. Four of us have ADHD and they know it's hard for us at school." Another participant, a 17-year-old biracial (Asian/Black) male, stated, "I don't think they like to see me struggle. . . . They worry about how I will do in a job in the future." Participant statements capture both an understanding that their parents worry about them as well as a perceived desire to help their children.

Support from Parents. Understanding, help with symptom management, and patience from parents have helped these participants to navigate the disorder. Participants

described how their parents' understanding of ADHD and its impacts on their life and functioning helps them. A 16-year-old biracial (Black/Latinx) male said this understanding from his parents "makes things easier." Further, many participants reported the ways their parents help them to manage ADHD at home. These supports include setting reminders, making to-do lists, setting personal deadlines, rearranging the home environment, and giving chores and instructions one at a time. Even patience with ADHD symptoms is helpful, according to these participants. Participants described the process of their parents developing greater patience for symptoms and behaviors associated with ADHD. One participant, a 17-year-old Asian male wrote, "My parents try to be more patient when I don't pay attention."

Lack of Understanding. Participants described some of their parents as lacking understanding about ADHD, their experience of the disorder, or how to help them. This lack of understanding is expressed as frustration toward the participant or through minimization of the disorder. One participant, a 15-year-old biracial (Black/White) female wrote, "They downplay it a lot which really hurts the way I cope with it." Other participants reported their parents thought their ADHD symptoms were signs of their "misbehaving" or being "wild." This minimization and lack of understanding invalidates the participants' experience and, in some cases, reduced their ability to cope with ADHD.

Race/Ethnicity and ADHD

Participants reported their experiences as members of minoritized communities as well as the intersections, or lack thereof, between ADHD and race/ethnicity. Common experiences with bias emerged. Participants had varied knowledge and experiences regarding the intersections between race/ethnicity and ADHD. Thus, the two subthemes

within this theme capture these two facets: *Experience of Bias* and *Intersection of Race/Ethnicity and ADHD.*

Experience of Bias. Stereotypes, differential treatment, and lower expectations due to their racial/ethnic backgrounds permeated the experiences participants reported. Though the stereotypes and expectations varied from participant to participant, they shared a common thread of frustration on the part of the participant. For example, a 17-year-old biracial (Asian/Black) male reported, "People have joked that because I am part Asian, I should do better." Conversely, a 17-year-old Middle Eastern / North African male noted people in his school and neighborhood "think everyone from my family's country are the same." Performance stereotypes and out-group homogeneity biases were just some of the experiences reported by the participants, contributing to a lack of patience and differential treatment.

Intersection of Race/Ethnicity and ADHD. For some of the participants, differential treatment was not solely a factor of bias. Participants had a variety of experiences with the intersectionality between ADHD and race/ethnicity. A 15-year-old Biracial male stated, "I get treated like the minority and then on top of it having the learning disabilities on top of it make it even worse." For him and others, the experience of being minoritized is compounded by their disability status. One participant, a 15-year-old biracial (Black/White) female noticed differences in perceptions of ADHD between the two races she identifies with:

> "What's funny is that the White community has been more accepting of my ADHD than the Black community. I don't think that has to do with my own race. I think it has to do with their own culture and the way they were raised."

Conversely, a portion of the sample reported there was no intersection between race/ethnicity and ADHD.

Experience of Service Provision for ADHD

Student Role in the Process

This theme captures the degree of involvement, or desire for involvement, in school-based services and the relevant decisions reported by participants. Though school-based services do not require student participation in decision making, participant responses reflected a desire for a greater role or to be better informed about the process. This theme is comprised of three subthemes: (1) *Student Service Recommendations*, (2) *Lack of Information*, and (3) *Benefits to School-Based Services.*

Student Service Recommendations. Participants consistently reported a desire to help plan the interventions used and even noted some of the accommodations or interventions they believed would be most helpful to them. These recommendations and preferences ranged from changes to the learning environment to adapted assignments to professional development and trainings for teachers regarding ADHD and other learning disorders. One participant, a 17-year-old Biracial female wrote she would like to have "someone who was with me at school who would help me stay on task." Another participant, a 14-year-old Native American female reported that they wished she had a "computer in each class. I can type faster than I can write." The majority of requested accommodations and modifications are readily available options through IEPs and 504-plans. Further, participants were able to provide rationales for their recommendations, such as a 15-year-old biracial (Black/White) female who said, "For me personally, the more structure an environment has, the better I am able to function in it."

Lack of Information. Despite the desire to be involved in the process and recommendations for their services, participants were unaware of the service provision

process especially while it was ongoing. Students were unaware of why they were being tested or in some cases that an assessment was ongoing at all. Additionally, some participants reported no knowledge of any interventions or supports implemented in the school following their identification with ADHD. A 17-year-old Asian male surmised: "I did not understand what was going on."

Benefits to School-Based Services. This subtheme captures the benefits participants were able to identify in response to the school-based services they had received. Thus, despite limited knowledge of the process, participants were able to recognize and articulate the various improvements and advantages of the services they received. These benefits include improvements to academic performance, increased focus, and patience from teachers previously unaware the participant had ADHD.

School Services and Collaboration

Service provision for ADHD varies widely across participants in the use of accommodations and modifications as well as the degree of collaboration with outside stakeholders. This theme encapsulates the participation of parents in services, school-based interventions and accommodations, and the role of professionals in other disciplines in these services. Four subthemes emerged: (1) *Parent Coordinated Services*, (2) *Accommodations*, (3) *Modifications*, and (4) *Interdisciplinary Stakeholders*.

Parent Coordinated Services. For some participants, receiving school-based services for ADHD that meets their needs required advocacy from their parents or nontraditional arrangements with schools. Parent involvement in school-based was precipitated by a variety of conditions, including denial of services from the school or outside diagnosis. One participant, a 16-year-old Latinx female, wrote, "I was struggling

in school and my mom kept talking to my teacher and principal but was not having any luck. She took it upon herself to get me tested because the school didn't think I needed to be tested." In her case, though testing occurred outside of the school, she received intervention services from the school following diagnosis. Another participant reported that their parent shared an outside report of their diagnosis to trigger school-based services. Parents of these participants also took nontraditional actions to ensure appropriate services for their students, such as transferring them to specialized charter schools.

Accommodations. Participants reported a variety of accommodations provided through 504-plans or IEPs to help them manage ADHD within the school. The reported accommodations include preferential seating to reduce distractions, additional time on tests or assignments, visual cues and schedules in the classroom, separate classrooms for test-taking, and scheduled breaks. The majority of the accommodations participants mentioned are passive in nature, such as changing to the seating chart, classroom environment, or deadlines. Accommodations that require additional personnel, changes to schedule, or behavior contingencies were less common. Participants stated they benefit from these accommodations. For example, a 16-year-old Black female wrote, "I received a 504 plan this year and the accommodations have helped tremendously."

Modifications. Participants also reported modifications to instruction or tasks to help them in school as part of their IEP. Modifications and interventions participants in this sample reported included specialized instruction outside of the general classroom, changes to assignment content or length, and additional support staff, such as tutors or

aides. Some participants were unaware of the extent of their services beyond the knowledge that they were "on an IEP."

Interdisciplinary Stakeholders. Schools do not provide services to these participants in a vacuum. Their responses clearly identify the involvement of other professionals outside the school in providing additional services or assessing for ADHD. These professionals were involved in the participant's identification with ADHD. Participants reported seeing therapists, neuropsychologists, behavioral psychiatrists, and doctors to this end. One participant alluded to collaboration between these professionals, stating, "I was tested by doctors and my therapist." Beyond identification, participants also benefit from services outside of the school to help manage ADHD and its comorbid conditions. Participants reported seeing therapists outside of the school to help them cope.

Prompts to Assess

Although all the participants receive interventions in the school, who initiated the evaluation process and where it took place varied for participants. The two subthemes *Assessment Initiated Privately* and *Assessment Prompted by School* comprise the two avenues through which participants reported their assessment process began.

Assessment Initiated Privately. For some participants, identification with ADHD was preceded by parent or personal concerns. These participants reported their parents initiated assessment due to a family history of ADHD, suspicions they may qualify for diagnosis, testing for other health concerns, or a desire for a label. A 16-year-old biracial (Black/White) female said related to being tested for ADHD, "My parents said I just have to do it so that people will leave me alone." Other participants reported

they were assessed for possible ADHD after noticing behavioral differences or changes in mood in themselves. A 15-year-old biracial (Black/Latinx) male described, "I started noticing mood swings and irritability, later I noticed lack of focus and irritability."

Assessment Prompted by School. In other cases, the school or school staff initiated assessment for ADHD for the student. Participants reported their grades or behavior at school were often the catalysts to these referrals. A 16-year-old Black male stated, "My grades started slipping at school and I was having trouble paying attention in class." The participants recalled their teachers as those who referred them for assessment most commonly. A 16-year-old biracial (Black/Latinx) female reported that they were referred by "a school counselor who thought ADHD could be the reason I was acting out so much."

Assessment

Assessment is a necessary prerequisite to identification with ADHD. Though participants in this sample had widely varying experiences that prompted assessment and examiners, the core feelings about testing and testing activities are more similar. Thus, this theme contains two subthemes: *Feelings About Testing* and *Testing Activities*. The names of these themes remain broad to encapsulate the diversity of experiences reported by participants related to assessment for ADHD.

Feelings About Testing. The testing process for these participants was characterized by indifference toward the process or negative emotions. As one participant, a 17-year-old Biracial female stated, "I felt indifferent." Another participant explained that it "never bothers me when I have to get tested for things." However, this indifference is in contrast to the negative emotions reported by other participants,

including feeling "annoyed," "trapped," and "awkward." A 14-year-old Black female

described how the experience of being assessed made her feel "different from everyone

else."

  Testing Activities. Many participants were identified with ADHD at a young age

and do not remember much of the assessment process. For example, a 14-year-old Black

male reported he was identified when he was "around 5 years old." Despite the lapse in

time between assessment and this study in addition to the participants' young age at

identification, the participants were able to report some memorable elements of the

process. One of the most common mentions was the experience of answering questions

asked by doctors or psychologists. A 17-year-old biracial (Black/White) male recalled

that he "played games and toys." One participant, a 15-year-old Black male, who was

identified in early adolescence, stated he had to take several breaks during the testing

experience, which included neuropsychiatric assessments.

CHAPTER V

DISCUSSION

This phenomenological investigation sought to elucidate the experiences, feelings, and meanings racially/ethnically minoritized students make of having ADHD and school-based service provision for ADHD. The participants wrote about their perceptions of and experiences with ADHD, its intersection with race/ethnicity, parent support, and impacts on education and socialization. Specific to services, participants discussed their experiences with and preferences for services, the role of community professionals, and the assessment experiences that led to their identification with ADHD. Though the reported experiences varied across participants, the identified themes were largely consistent with the extant research on ADHD.

Given the extremely limited research specific to racially/ethnically minoritized youth with ADHD, the study sought to give voice to this underrepresented group. Previous qualitative research in this area has found students to be reliable reporters on their own experiences with ADHD through narrative (Koro-Ljungberg et al., 2008). This study similarly found students were able to communicate their experiences with ADHD and their related feelings and thoughts. The participating students reported identifiable ADHD symptoms, services they receive through schools, and, notably, were willing and able to articulate when they did not know something, such as when asked to recall being tested for ADHD.

The experiences participating students shared aligned with much of the extant ADHD research. The behaviors and experiences the students mentioned in describing ADHD correlate with or describe ADHD symptoms from the DSM-5 (APA, 2013),

including disorganization, difficulty concentrating, hyperactivity, restlessness, and impulsivity. Both domains of ADHD symptoms were represented in the descriptions provided by participants. The students also reported experiencing comorbid anxiety (Jarrett & Ollendick, 2008), and sleep disturbances (Owens, 2005), both of which commonly cooccur with ADHD. Additionally, participants reported several difficulties in school and with social relationships related to ADHD that are consistent with prior research, including academic difficulties in math and reading (DuPaul et al., 2006), social isolation (Nigg & Barkley, 2014), bullying (Weiner & Mak, 2009), and school discipline referrals (Robb et al., 2011).

The reported experiences students shared regarding their school-based services for ADHD suggests they can be informed decision-makers in their own service planning. Participants reported their current services if they were made aware of them, including 504-plan accommodations, visual schedules and cues, specialized instruction, and support staff. The reported services were largely consistent with research-supported practices for ADHD, such as preferential seating (DuPaul & White, 2006), behavior contingencies (Carlson et al., 2000; Coelho et al., 2015), and tutoring services (DuPaul et al., 1998). Additionally, many participants reported they understood the benefit of the services they received. Many also expressed a desire for additional or alternative accommodations or interventions. Unfortunately, the lack of knowledge about some of their services and the process related to receiving them suggests these students are excluded from the IEP and 504 planning processes.

In addition to the needed involvement of students in treatment planning, the experiences reported by participants highlight the involvement of interdisciplinary

providers outside of the school. Participants mentioned teachers, school counselors, doctors, psychologists, and other specialists as key players in their assessment and service provision. Further, participants reported both assessments initiated by their parents and by the school. To accommodate the multitude of avenues that lead to students receiving ADHD services, interdisciplinary collaboration with schools is essential.

The significant limitation to students' ability to report on their service experiences is their memory of assessment. Many of the participants reported their evaluation for ADHD occurred when they were approximately 5 years old. Because of this, much of their report was limited to their negative feelings and general activities. This trend is contrary to previous research that suggests minoritized children are identified later than White peers (e.g., Morgan et al., 2014; Pastor & Reuben, 2008). Notably, students in this sample reported their parents and caregivers were significantly involved in facilitating their identification and services within and without the school. This may contribute to their earlier reported identification. However, further research is needed to understand the identification disparities in ADHD and related factors.

Parents and caregivers played a significant role in the daily life, services, and experiences of students with ADHD. The participants reported their parents have several misconceptions about ADHD, which is consistent with previous direct assessments of parent ADHD knowledge (Bussing et al., 2012). Despite limited or incorrect understandings of ADHD, parents of students in this sample communicated concern to their children about their outcomes as well as supported them through at-home management strategies and advocated for their services. Additional research is needed to

further understand the roles of racially/ethnically minoritized parents in school-based services.

Finally, the perceptions of ADHD communicated by students both confirm and refute extant research. While many participants reported a daily internal struggle with ADHD, which echoes findings from Waite and Tran (2010), some participants also described positive aspects of ADHD. This aspect of the ADHD experience is lacking in the current research. Unfortunately, participants also reported experiencing and internalizing stigma related to ADHD. Previous research supports this experience (Mueller et al., 2012). The racially/ethnically minoritized status of participants places them in double jeopardy for negative prejudice. In addition to stigma related to ADHD, participants reported the impact of racial/ethnic stereotypes. Previous research has documented student distress in response to stereotypes (Thompson et al., 2016) and their effects on the ADHD assessment process (Arcia & Fernandez, 2003). Notably, participants varied in their perceptions of the intersection of race/ethnicity and ADHD. Additional research is needed to better understand this phenomenon.

Implications

This study contributes meaningfully to the ADHD literature principally through its exploration of racially/ethnically minoritized perspectives. The findings highlight the necessity for researchers to include diverse and minoritized populations in investigations of ADHD. As mentioned previously, students proved reliable reporters of their experiences. However, their use of narrative strategies may require further interview for researchers and practitioners to interpret. Increased recruitment of this population is encouraged. Additionally, practitioners should consider students as team members in IEP

team meetings and intervention planning. Soliciting their preferences and feedback may improve fidelity and response to intervention. However, this research emphasizes the ongoing lack of knowledge about ADHD and school-based services on the part of students and their parents. Practitioners need to prioritize informing affected parents and students about ADHD, possible services, and ongoing developments in their treatment. Finally, though all participants in this study reported school-based services, it is clear assessment and intervention occur outside the school for many families. Schools, clinics, and community providers should develop collaborative partnerships with doctors, therapists, and other professionals to best serve students with ADHD.

Limitations and Future Directions

Despite notable contributions to the literature, this study is not without its limitations. First, due to the online format of data collection, no proof of diagnosis or educational classification and related services were solicited. Participants were included or excluded from the study based on parent report of these two criteria. It is recommended future research seek documentation of identification with ADHD or confirm eligibility through review of school records. On a related note, the second limitation is the survey nature of the study. Because the phenomenological investigation was presented as an online questionnaire, follow-up and clarifying questions could not be asked of participants. This was accounted for through multiple-part questions (see Appendix C), a longer survey, and increased sample size. However, future research should pursue qualitative investigations through in-person or telephone interviews that allow for a semi-structured format. Third, as is true of most qualitative research, this study is limited in its generalizability (Creswell & Poth, 2017). The findings here

demonstrate the utility of adolescent reporters and are consistent with prior qualitative and quantitative findings. However, to further support the presented claims, quantitative and mixed method inquiries are needed.

Conclusions

Overall, the phenomenological inquiry regarding experiences with ADHD and related service provision, as voiced by racially/ethnically minoritized students elucidated several findings. Racially/ethnically minoritized students report experiencing ADHD, school-based services, and related school and social challenges consistent with previous research. Additionally, students shared narratives used to communicate ADHD, the positive aspects of having ADHD, and challenges, including stigma, racial/ethnic bias, lack of knowledge, and lack of participation in school-based intervention planning.

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APPENDICES

APPENDIX A

Parent Demographic Questionnaire

Parent Demographic Questionnaire

Are you a parent?

    __ Yes

    __ No

Which categories describe you? Select all that apply:

    __ Native American or Alaskan Native

    __ Asian

    __ Black or African American

    __ Latino/a, Hispanic, or of Spanish origin

    __ Middle Eastern or North African

    __ Native Hawaiian or Pacific Islander

    __ White or European American

    __ Some other race, ethnicity, or origin. Please specify: _____

    __ I prefer not to respond

Do you have any disability or impairment?

    __ Yes. Please describe: _____

    __ No

    __ I prefer not to answer

If yes, have you received special education or 504 services while in school for this

disability or impairment?

    __ Yes, under the category: _____

    __ No

    __ I don't know

__ I prefer not to answer

Do you have biological, adopted, foster, or stepchildren?

__ No

__ No, but I or my partner(s) are pregnant or in the process of adopting

__ Yes, one child

__ Yes, two children

__ Yes, three children

__ Yes, four or more children

Have any of your children been diagnosed with a disability or impairment?

__ No

__ Yes, one child. Please describe: _____

__ Yes, more than one child. Please describe: _____

__ I prefer not to answer.

If yes, does this child or children receive special education or 504 services through the

school for this disability or impairment?

__ Yes, under the category: _____

__ No

__ I don't know

__ I prefer not to answer

Are you currently in a romantic relationship with a partner or partners?

__ Yes, with one partner

__ Yes, with multiple partners

__ No

__ I prefer not to answer

If you answered yes, please mark all that apply:

__ Married or in a civil union, living together

__ Married or in a civil union, living apart

__ Not married or in a civil union, living together

__ Not married or in a civil union, living apart

If you answered yes, which of these describes your partner or partners:

__ Native American or Alaskan Native

__ Asian

__ Black or African American

__ Latino/a, Hispanic, or of Spanish origin

__ Middle Eastern or North African

__ Native Hawaiian or Pacific Islander

__ White or European American

__ Some other race, ethnicity, or origin. Please specify: _____

__ I prefer not to respond

(If you have multiple partners, please respond for your other partners as needed) If you answered yes, which of these describes your partner or partners:

__ Native American or Alaskan Native

__ Asian

__ Black or African American

__ Latino/a, Hispanic, or of Spanish origin

__ Middle Eastern or North African

__ Native Hawaiian or Pacific Islander

__ White or European American

__ Some other race, ethnicity, or origin. Please specify: _____

__ I prefer not to respond

(If you have multiple partners, please respond for your other partners as needed) If you answered yes, which of these describes your partner or partners:

__ Native American or Alaskan Native

__ Asian

__ Black or African American

__ Latino/a, Hispanic, or of Spanish origin

__ Middle Eastern or North African

__ Native Hawaiian or Pacific Islander

__ White or European American

__ Some other race, ethnicity, or origin. Please specify: _____

__ I prefer not to respond

Is your partner or partners diagnosed with a disability or impairment?

__ Yes, one of my partners. Please describe: _____

__ Yes, more than one of my partners. Please describe: _____

__ No

__ I don't know

__ I prefer not to answer

If yes, did your partner or partners ever receive special education or 504 services for the disability or impairment?

___ Yes, under the category: _____

___ No

___ I don't know

___ I prefer not to answer

Do you or your partner(s) have a family history of attention-deficit/hyperactivity disorder?

___ Yes

___ No

___ I don't know

___ I prefer not to respond

What best describes your family's income?

___ Less than $20,000

___ $20,000 to $34,999

___ $35,000 to $49,999

___ $50,000 to $74,999

___ $75,000 to $99,000

___ Greater than $100,000

Please answer the following questions about your child who will be participating.

Does your child have ADHD?

___ Yes

___ No

Does your child receive services through their school for their ADHD?

__ Yes, my child has an Individualized Education Plan (IEP) and associated special education services.

__ Yes, my child has a 504-plan that provides accommodations for ADHD.

__ No

Thank you for your responses, please pass this survey for your child to complete. Once your child is at the computer or device, please allow them to continue.

APPENDIX B

Child Demographic Questionnaire

Child Demographic Questionnaire

How do you currently describe your gender identity?

      Please describe: _____

      __ I prefer not to respond.

What is your age in years? _____

What grade are you currently in?

      __ 6th

      __ 7th

      __ 8th

      __ 9th (Freshman)

      __ 10th (Sophomore)

      __ 11th (Junior)

      __ 12th (Senior)

      __ Another grade

      __ I have graduated or dropped out.

Which categories best describe you? Please select all that apply:

      __ Native American or Alaskan Native

      __ Asian

      __ Black or African American

      __ Hispanic, Latino/a, or of Spanish origin

      __ Middle Eastern or North African

      __ Native Hawaiian or Pacific Islander

      __ White or European American

__ Some other race, ethnicity, or origin. Please describe: _____

__ I prefer not to respond

If you chose White or European American, is this the only racial/ethnic category that

applies to you?

__ Yes

__ No, I am biracial or multiracial

Do you have a diagnosis of a disability or impairment?

__ Yes. What is it? _____

__ No

__ I don't know

__ I prefer not to respond

If yes, do you currently receive special education or have a 504 plan for this disability or

impairment?

__ Yes

__ No

__ I don't know

__ I prefer not to respond

APPENDIX C

Phenomenological Questionnaire

Phenomenological Questionnaire

On the next page, the questionnaire will begin. Please answer the questions as honestly

and completely as you can. No one but the researcher will see your responses and they

will be kept confidential.

Experience of ADHD

1. **What is it like to have ADHD?**

2. How would you describe ADHD to someone?

3. How does ADHD affect your daily, school, and social life?

4. What do your parents think about ADHD?

5. What experiences have you have because of ADHD?

6. Tell me about ADHD at home versus ADHD at school. Are these experiences
   different?

7. How do people react if they know you have ADHD?

8. What things does ADHD make difficult? OR Tell me about a time when ADHD
   made something more difficult.

9. Do you feel like people treat you differently than other students with ADHD?
   What was it like? Why do you think you were treated differently?

10. Have people treated your ADHD differently because you come from a different
    culture? In what ways?

Experience of Assessment

11. How did you find out you had ADHD?

12. Did you wonder if you had ADHD before you found out?

13. How did you feel while they were testing you for ADHD?

14. What led up to you being tested for ADHD?

Experience of Intervention

15. Tell me about what has changed at school to help you deal with ADHD? Are

these things helpful?

16. What things do you think would help you succeed in school?

17. What things do you do to help manage ADHD?

18. What things have changed at home related to ADHD?

19. If you have ever taken medication for ADHD, what is it like?

20. What do you think about medication for ADHD?

Thank you for your participation. We are very grateful for your time and look forward to

learning from your responses.