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Understanding The Role Of Family Management In Ethnically Diverse Children With Adhd From Urban Philadelphia

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Abstract

Attention Deficit Hyperactivity Disorder (ADHD) is the most common neurodevelopmental condition of childhood. Prior research shows improvement in ADHD outcomes with parental and family engagement. What is less known, however, is how caregivers from diverse families manage childhood ADHD on a daily basis and how family management factors correlate with child functioning. Guided by the family management framework, the purpose of this study was to understand how ethnically diverse caregivers manage childhood ADHD in their everyday lives and how family management is related to children's level of functional impairment.

This mixed methods study used a concurrent nested design (QUAL [quan]) to independently analyze and integrate cross-sectional qualitative and quantitative data from caregivers of children with ADHD recruited from diverse families living in urban Philadelphia (N=50). Semi-structured qualitative interviews were conducted to explore how caregivers managed ADHD in their everyday lives and identified barriers and facilitators of family management. Quantitative questionnaires were completed by caregivers to describe child, caregiver, and environmental characteristics and understand how family management factors influenced children's functional impairment. The qualitative and quantitative data were then integrated and transformed at the level of analysis to further understand the experience of families whose children are higher and lower functioning.

Qualitative results (from directed content analysis) revealed robust and descriptive themes within family management, including the child's daily life, condition management effort, condition management ability, and view of condition impact. Barriers and facilitators were also described, including those within immediate and extended families, educational and healthcare systems, financial, policy, and insurance issues, and mental health stigma within communities. Quantitative results (using descriptive and inferential statistics) confirmed these themes in a diverse sample of caregivers and children. Family management factors and children's functional impairment were significantly correlated (<.05; weak to moderate) in hypothesized directions. Qualitative themes were complemented by quantitative results and elucidated the daily work of families who are managing ADHD at higher and lower levels of functional impairment. Findings from this study have implications for research, practice, and policy related to the complexities of treatment, experiences of caregivers, and stigma regarding in developmental and mental health conditions among children.

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UNDERSTANDING THE ROLE OF FAMILY MANAGEMENT IN ETHNICALLY DIVERSE CHILDREN WITH ADHD FROM URBAN PHILADELPHIA

Cynthia P. Paidipati

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UNDERSTANDING THE ROLE OF FAMILY MANAGEMENT IN ETHNICALLY DIVERSE CHILDREN WITH ADHD FROM URBAN PHILADELPHIA

Cynthia Priya Paidipati

Dedication

This dissertation is dedicated to children with ADHD (Attention Deficit Hyperactivity Disorder) and their devoted caregivers, who help them survive and thrive in a world that has yet to fully understand children with mental health conditions and their families.

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ABSTRACT

UNDERSTANDING THE ROLE OF FAMILY MANAGEMENT IN ETHNICALLY DIVERSE CHILDREN WITH ADHD FROM URBAN PHILADELPHIA

Cynthia P. Paidipati

Bridgette Brawner, PhD, APRN

Attention Deficit Hyperactivity Disorder (ADHD) is the most common neurodevelopmental condition of childhood. Prior research shows improvement in ADHD outcomes with parental and family engagement. What is less known, however, is how caregivers from diverse families manage childhood ADHD on a daily basis and how family management factors correlate with child functioning. Guided by the family management framework, the purpose of this study was to understand how ethnically diverse caregivers manage childhood ADHD in their everyday lives and how family management is related to children's level of functional impairment.

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Chapter 1: Introduction and Specific Aims

Introduction to the Problem

Attention Deficit Hyperactivity Disorder (ADHD) is the most common neurodevelopmental condition of childhood with a prevalence rate of 5 to 11% within the United States (Centers for Disease Control and Prevention [CDC], 2015; Froehlich, 2007; Spencer, Biederman, & Mick, 2007). From a biomedical perspective, this chronic neurodevelopmental disorder is caused by a complex interplay between genetics, changes in brain development, and environmental influences (Spencer, Biederman, Wilens, & Faraone, 2002). Standard, evidence-based treatments for childhood ADHD include psychopharmacology and behavioral therapy (American Academy of Child and Adolescent Psychiatry [AACAP], 2007; American Academy of Pediatrics [AAP], 2011). Literature suggests, however, that parents and caregivers (hereafter, caregivers) may have differing views on the causes of ADHD, which may diverge from traditional biomedical explanations (Bussing et al., 2012; Carpenter-Song, 2009; Lawton, Gerdes, Haack, & Schneider, 2014). Caregivers also may have different care-seeking behaviors and treatment preferences as compared to caregivers who view ADHD as a neurobiological condition (DosReis et al., 2006; DosReis, Mychailyszyn, Myers, & Riley, 2007; Mychailyszyn, DosReis, & Myers, 2008; Pham, Carlson, & Kosciulek, 2010).

Major health disparities exist for children with ADHD in regards to symptom recognition, diagnostic rates, treatment acceptability, and service use within the United States. Historically, these disparities have been created by a variety of socioecological and political influences, which are present in children's lives including family, school, healthcare, and community level factors (Eiraldi, Mazzuca, Clarke, & Power, 2006). In the literature, health disparities regarding childhood ADHD are pronounced for racially and ethnically diverse families, including: 1.) minority children are less likely to be identified and/or diagnosed with ADHD; 2.) minority children are less likely to be treated with medications for ADHD; and 3.) minority children and their families have a lower use of services for ADHD despite persistence of symptoms or behaviors (Paidipati, Brawner, Eiraldi, & Deatrick, 2017). In addition, issues of health equity magnify these disparities for children and families, especially for those living in resource poor communities with fewer opportunities to seek and access health care due to a variety of social, economic, and political influences. A review of current research in this area highlights the issues of health equity for racially and ethnically diverse children with ADHD, including: 1.) lack of access to high quality evaluation, care, and services for ADHD; 2.) lack of culturally-appropriate interventions (i.e., in some cases, caregivers may prefer behavioral and/or social interventions over pharmacologic treatment for their child); 3.) lack of resources and supports within schools, especially in low-income neighborhoods; and 4.) fragmented care and poor communication and coordination between systems and services (e.g., healthcare, school, community, family; Paidipati, Brawner, Eiraldi, & Deatrick, 2017).

The relationship between race and ethnicity, socio-economic positioning, and health care is complex but has become increasingly relevant today as we recognize the importance of the social determinants of health (Braveman, Egerter, & Williams, 2011).

From this perspective, our health and well-being is affected by the areas we live, work, and play (Marmot, 2008). For children, this also includes where they receive their education, and the condition of their respective school systems. Families from racial and ethnic minority backgrounds, especially African-American and Hispanic/Latino heritages, historically and presently are affected by institutional policies, long-standing racial discrimination, and other socio-political influences in American society that constrain economic opportunities and health-related resources potentially available to them. Because of decades and even centuries of economic oppression, a high proportion of racial and ethnic minority families in the United States have lower educational attainment and income levels; are geographically segregated to poorer neighborhoods (often in urban areas); are limited to resource-poor school systems, and have less access to high-quality health care as compared to White, middle-class families (Williams & Sternthal, 2010).

The intersectionality of race and ethnicity, socio-economic opportunity, and health care becomes even more complex when we integrate childhood mental health into the lives and stories of families from diverse cultural backgrounds. For example, Rivera (2014) highlights the research "on externalizing behavior among disadvantaged African American youth and how it may be a response to structurally embedded stressors and inequities within the home, school, and community" (pg. 202). He reflects on how inadequate resources may lead education and health care professionals to focus primarily on children's behaviors (often labeled negatively or pejoratively) without addressing the potential underlying issues, such as poverty, lack of safe and appropriate housing, childhood abuse, trauma, or neglect, neighborhood or family violence, parental mental illness, or depression (Rivera, 2014). Similarly, racial and ethnic minority children who exhibit symptoms of hyperactivity or impulsivity may be identified by school or health care professionals as having primarily externalizing or disruptive behavior problems, like oppositional defiant or conduct disorders, without recognizing the underlying attentional or executive functioning issues, like ADHD. As opposed to stereotypes in the popular press and non-ethnic communities, African-American and Hispanic or Latino children are actually less likely to receive a diagnosis of ADHD, even when symptoms are present, as compared to their White counterparts (Rowland et al., 2002). A variety of factors have been implicated as possible reasons for this, including less awareness of the condition, differing beliefs on the causes of childhood behavioral problems, and the impact of racism and discrimination in ethnic minority communities (Bussing, Gary, Mills, & Garvan, 2007; Bussing et al., 2012; Carpenter-Song, 2009; Lawton, Gerdes, Haack, & Schneider, 2014; Olaniyan et al., 2007).

The relationship between socioeconomic status (SES) and childhood ADHD has been explored extensively in the literature with mixed findings. Authors, such as Morley (2010), propose the distribution of the ADHD diagnosis falls along socioeconomic lines with trends moving in the exact opposite direction from those who are at highest risk for ADHD. In other words, children from relatively wealthier neighborhoods and from families of higher socioeconomic positions are more likely to receive a diagnosis of ADHD, and subsequent treatment, whereas children from lower socioeconomic positions are less likely to receive diagnosis and treatment. These children, without diagnosis or treatment, are then at greater risk for functional impairment and downstream sequelae to their overall development (Morley, 2010).

This disparity in ADHD diagnosis and treatment often conflicts with other theoretical positions and empirical evidence, which suggest that children from lower socioeconomic families are at higher risk for mental health problems, including ADHD (Butler, Kowalkowski, Jones, & Raphael, 2012). Over the last 10-years, the moderating effects of socioeconomic status on the development of ADHD have been studied from a gene-environment perspective in children identified from lower SES families at higher risk for ADHD (Lasky-Su et al., 2007; Nobile et al., 2010; Nomura et al., 2012). Neurological impairments in cognition, learning, memory, attention, and executive functioning are proposed as resulting from environmental influences acting upon the genetic preposition for ADHD in children.

When examining how socioeconomic factors, such as family income, caregiver education level and occupation, and neighborhood influences, affect children with ADHD, the concept of epigenetics surfaces in the literature. Studies exploring ADHD and family income have theorized a variety of factors to explain the negative relationship between income level and ADHD risk, including insurance status, access and quality of health care screening and assessment, parental stress, and resources within the family (Larsson, Sariaslan, Långström, D'Onofrio, & Lichtenstein, 2014; Martel, 2013). In addition, neurobehavioral conditions, such as ADHD, can be genetically inherited by a child who has a parent with ADHD (Law, Sideridis, Prock, & Sheridan, 2014; Tillman & Granvald, 2014). For these families, both children and their parents may be experiencing neurodevelopmental deficits and difficulties navigating the systems or systems to treat their child's ADHD. Furthermore, according to the "enriched environments" theory, parents with higher education levels may have more opportunities to provide their children with experiences and circumstances that will likely enhance prefrontal cortex development and advance key neurocognitive processes (Law, Sideridis, Prock, & Sheridan, 2014; Tillman & Granvald, 2014; Rieppi et al., 2002).

While the latter finding requires more evidence to make a sound argument, the evidence surrounding neighborhood and physical environmental factors on childhood ADHD is more robust. The "social determinants of health" framework has increasingly become relevant to discussions on health inequalities and childhood health disparities (Butler, Kowalkowski, Jones, & Raphael, 2012). For example, a recent study by Kim and colleagues (2013) finds postnatal lead exposure to be associated with higher risk for clinical ADHD near environmental sites with accumulated hazardous waste. The harmful neurotoxic effects of lead have been documented with mandates for homes built after 1978 to be free of all lead-based paint. Unfortunately, children and families living in homes built prior to 1978, many of whom have little control over their housing conditions, may have a higher risk for lead exposure and subsequent adverse effects on neurodevelopment (Kim et al., 2013).

Neighborhood conditions have also been explored specifically in the epidemiology of childhood ADHD. Researchers suggest both the physical aspects (e.g., housing quality, recreational resources) and the social aspects (support, trust, and safety) of a neighborhood may have an impact on childhood mental health. In a large, national, cross-sectional study with over 64,000 participants, researchers found children living in neighborhoods with poorer physical qualities and lower parent-perceived social support and trust in neighborhoods were associated with greater odds of ADHD and other mental health concerns, like anxiety and depression (Butler, Kowalkowski, Jones, & Raphael, 2012).

Because of the complex relationship between race and ethnicity, socio-economics, and mental health, children from diverse families may be at higher risk for undiagnosed, untreated, or undertreated ADHD. This may have dire consequences on children, including poor academic achievement, negative peer relationships, conflict in family life, psychiatric co-morbidities, such as depression, anxiety, severe mood and behavioral disturbances, and oppositional-defiant and conduct disorders, and poor self-esteem (Eiraldi, Power, & Nezu, 1997). For a subset of children, the lack of appropriate care and treatment for ADHD may lead to substance abuse, risk-taking behaviors, or involvement in the juvenile justice system later in adolescence or young adulthood (Fletcher & Wolfe, 2009; Molina & Pelham, 2003; Rowland, Lesesne, & Abramowitz, 2002). From a social justice perspective, this has serious implications for children and families.

Family, especially parents or family caregivers, are considered an important and integral aspect to the care, management, and well-being of children with ADHD (Bussing & Lall, 2010; Cunningham, 2007; Davis, Claudiu, Palinkas, Wong, & Leslie, 2012; DeMarle, Denk, & Ernsthausen, 2003; Dishion & Stormshak, 2007). The literature suggests that the behavioral management by families is a key determinant in treatment outcomes (Bussing & Gary, 2001). In fact, prior research has shown greater improvement in childhood ADHD outcomes with active family engagement and participatory collaboration between health care providers and family caregivers as compared to children without strong family involvement (Power, Soffer, Cassano, Tresco, & Mautone, 2011). There is a paucity of research, however, on: 1.) how caregivers from diverse families view ADHD, and 2.) how their views relate to the behavioral management of childhood ADHD and its subsequent outcomes, including children's level of functional impairment.

One approach for understanding how caregivers view and manage ADHD is by using the family management framework (Knafl, Deatrick, & Havill, 2012). Family management is a concept that combines family processes with condition management (Knafl & Deatrick, 1990). Family management describes how the family and its members incorporate condition management into family life, including the child's daily life, condition management effort, condition management ability, parent mutuality, family life difficulty, and view of condition impact (Knafl & Deatrick, 2006; Knafl et al., 2011; Knafl, Deatrick, & Havill, 2012; Knafl et al., 2013). Guided by the family management framework, the purpose of this study was to understand how ethnically diverse caregivers manage childhood ADHD in their everyday lives and examine how family management factors relate to child functioning. This study aimed to investigate the impact of caregiver management on childhood ADHD and the challenges and successes experienced by caregivers regarding the management of children across a spectrum of childhood functional impairment. By identifying the family management factors which were related to higher and lower levels of children's functional impairment, this study extended previous research on family management and ADHD in diverse populations and built upon existing knowledge about cultural and family perspectives of children with neurodevelopmental conditions.

Significance

Health disparities and issues of health equity impact children from diverse families, who are at risk for undiagnosed, untreated, or undertreated ADHD. In the United States, clinical identification rates of ADHD for African American and Latino populations tend to be lower than Caucasian populations (APA, 2013). In the literature, African-American and Latino youth are less likely to be identified and/or treated for ADHD than Caucasian youth, despite evidence indicating similar prevalence of the condition across race, ethnicity and socio-economic status (Morgan, Staff, Hillemeier, Farkas, & Maczuga, 2013; Vierhile, Robb, & Ryan-Krause, 2009). Differences in ADHD diagnosis rates, treatment, and service use, especially for racial and ethnic minority families, may have significant and long-lasting effects on children, including poor academic achievement, negative peer relationships, conflict in family life, and psychiatric co-morbidities, such as depression, anxiety, severe mood and behavioral disturbances, and oppositional-defiant and conduct disorders (Eiraldi, Power, & Nezu, 1997). For a subset of youth, the lack of appropriate care for ADHD may lead to illegal substance use, abuse of prescription medications, risk-taking behaviors, or involvement in the juvenile justice system during adolescence and young adulthood (Fletcher & Wolfe, 2009; Molina & Pelham, 2003; Rowland, Lesesne, & Abramowitz, 2002).

Furthermore, inner-city youth may be disproportionally exposed to fragmented and disorganized care within health, school, and community service organizations (Guevara et al., 2005; Morgan, Staff, Hillemeier, Farkas, & Maczuga, 2013). The literature suggests children and families from urban communities may experience poor communication and coordination within their interactions with health care and school service providers. Furthermore, caregivers may experience significant barriers and challenges when navigating the complex systems related to ADHD care for their child (Kendall, Leo, Perrin, & Hatton, 2005). Inadequate access and support to available resources may impede initiation or maintenance of ADHD treatment. In addition, caregiver concerns about ADHD medications and negative experiences with past or present services may account for the low service utilization and mental health follow-up for ADHD, which may further the disparities in ADHD care and treatment for these already disadvantaged children (Berger-Jenkins, McKay, Newcorn, Bannon, & Laraque, 2012; Larson, J. J., Yoon, Y., Stewart, M., & DosReis, 2011; Mychailyszyn, Dosreis, & Myers, 2008).

Specific Aims

This study aimed to understand how ethnically diverse caregivers manage childhood ADHD in their everyday lives and how family management related to children's level of functional impairment. Using a concurrent nested mixed methods study design, we independently analyzed and integrated cross-sectional qualitative and quantitative data from caregivers of children with ADHD recruited from ethnically diverse families residing in urban Philadelphia (*N* = 50).

The Specific Aims of this study were:

Aim 1: To qualitatively examine via in-person interviews (using family management as a guide) how ethnically diverse caregivers manage ADHD in their everyday lives and to understand the barriers and facilitators of family management for their child's ADHD.

Aim 2: To quantitatively describe child, caregiver, and environmental characteristics and examine how family management factors (e.g., child's daily life, condition management effort, condition management ability, view of condition impact) are related to children's level of functional impairment.

> **Hypothesis 1:** Higher scores for child's daily life (higher scores more positive) and condition management ability (higher scores more positive) would be correlated with lower levels of children's functional impairment.
>
> **Hypothesis 2:** Higher scores for condition management effort (higher scores more negative) and view of condition impact (higher scores more negative) would be correlated with higher levels of children's functional impairment.

Aim 3: To use a mixed methods approach to integrate the qualitative and quantitative findings explicating overlapping complementary themes and family management factors that influence children with ADHD at higher and lower levels of children's functional impairment.

The long-term goals of this research were consistent with the mission and priorities of pediatric, neurodevelopmental, and health equity research (AAP, 2011; AACAP, 2007; Braveman, 2006), namely, to capitalize on emerging family science (Eccleston, Palermo, Fisher, & Law, 2012) to develop or adapt evidence-based interventions that support child health and caregiver well-being in diverse communities. Furthermore, the knowledge gained from this study supports a larger program of research that aims to improve family management for caregivers of ethnically diverse children with ADHD and to ensure the health, well-being, and full potential of children with neurodevelopmental conditions.

Chapter 2: Substantive Review of The Literature

Key Definitions

For clarity and consistency, these definitions will be used throughout the paper:

- **Attention Deficit Hyperactivity Disorder (ADHD)** is a chronic neurodevelopmental condition typically first seen in childhood and characterized by the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition [DSM-V]* as having 3 core features, including inattention, hyperactivity, and impulsivity (APA, 2013). Children with ADHD are classified as having the predominantly inattentive presentation, predominantly hyperactive/ impulsive presentation, or the ADHD combined presentation, which is the most common.
- **Caregiver(s)** are defined, in this study, as parents (i.e., biological, adoptive, or step), legal guardians, or other family members of a child with ADHD that assumes a profile of: (a) residing in the same household as the child, and (b) viewing him or herself as assuming major responsibility for the child's care (Deatrick et al., 2014). By this definition, caregivers may be parents, legal guardians, grandparents, or other extended family members, who are caring for a child with ADHD and meet both criteria (a) and (b).
- **Family Management** describes the key family processes involved in how the family and its members incorporate condition management into family life (Knafl & Deatrick, 1990; Knafl et al. 1996).

- **Family Management Styles Framework (FMSF)** is a theoretical framework that expands the family management concept into a theoretical model. The FMSF is comprised of three major components: Definition of the Situation, Management Behaviors, and Perceived Consequences. Each component is composed of conceptual dimensions that reflect more specific aspects of the component. The eight dimensions are: child identity, illness view, management mindset, parental mutuality, parenting philosophy, management approach, family focus, and future expectations (Knafl & Deatrick, 1990; 2003; Knafl et al. 1996).
- **Family Management Measure (FaMM)** was developed to measure how families manage caring for a child with a chronic condition or illness and the extent to which they incorporate condition management into everyday family life (Knafl et al., 2015). The FaMM includes non-summative Likert-type scales, including *"child's daily life", "condition management effort", "condition management ability", "view of condition impact",* "family life difficulty", and "parent mutuality", which reflect dimensions of the FMSF.
- **The Family Management Factors** chosen for this research are consistent with the aims of this study and reflect corresponding scales on the FaMM. These include:
    - ***Child's Daily Life*** - caregiver perceptions of their child and his/her everyday life.
    - ***Condition Management Effort*** - caregiver perceptions about the time and work needed to manage the condition.

    - ***Condition Management Ability*** - caregivers' perceptions of the overall manageability of the child's condition.
    - ***View of Condition Impact*** - caregivers' perceptions of the seriousness of the condition and its implications for the child's and family's future.

  The ***family life difficulty scale*** aims to determine the impact of a child's ADHD condition on family life. In this study, we were primarily focusing on the impact of families on childhood ADHD. We did not include the family difficulty scale, as it examines the reverse relationship (i.e., how ADHD impacts the family). We recognize this relationship exists, but requires a separate study to fully explore.

  The ***parent mutuality scale*** measures the degree to which parents from two-caregiver households are aligned with care management. For this research, we need not want to exclude families with a sole primary caregiver (vs. a two-caregiver household) as single-caregiver families were thought to contribute valuable insight and understanding in this study. Therefore, the parent mutuality scale was not included as a primary measure in this study, merely a secondary observation.

- **An Ethnically Diverse person** is defined as a person who self-identifies as Hispanic or Latino, American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, Middle Eastern White, North African White, or European/Caucasian White. These categories were derived and modified from the *NIH Policy on Reporting Race and Ethnicity Data* (NIH, 2001). In this study, a person may self-identify with more than one ethnic or racial group or country of origin, such as "Chinese American", "Puerto Rican", "Brazilian", "Lebanese", "Ethiopian", or "Jamaican". The term ***"ethnic minority"*** is used to describe children and families, who do not self-identify as European/Caucasian white, to reflect the minority of views in the literature regarding cultural and ethnic perspectives of childhood ADHD.

- **Health Disparities** are differences in the incidence, prevalence, morbidity and mortality, survival rates, and burden of diseases and other adverse health conditions that exist among specific population groups (Dankwa-Mullan et al., 2010). In the United States, many different populations are affected by disparities including racial and ethnic minorities, residents of rural areas, women, children, and persons with disabilities (Carter-Pokras & Baquet, 2002).
- **Health Inequities** are avoidable inequalities in health between groups of people within and between countries and societies that reflect social and economic conditions linked to issues of social justice (Maddox, 2014). These may adversely affect groups of people, who have systematically experienced greater obstacles to health or health care based on their racial or ethnic group, religion, socioeconomic status, gender, age, mental status, cognitive, sensory or physical disability, sexual orientation or gender identity, geographic location or other characteristics historically linked to discrimination or exclusion (World Health Organization [WHO], 2010).
- **Health Equity** relates to the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage or disadvantage—that is, different positions in a social hierarchy (Braveman & Gruskin, 2003). Inequities in health systematically put groups

of people who are already socially disadvantaged (for example, by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic, or religious group) at further disadvantage with respect to their health (Braveman & Gruskin, 2003).

- **Health Equity Research** is an active approach that aims to understand and decrease health disparities and health inequities caused by an unjust social system (Braveman, 2006).

ADHD and its Treatment

ADHD is the most common neurodevelopmental condition of childhood in the United States with prevalence rates from 5% to 11% in youth ages 4 to 17 years old (CDC, 2015; Froehlich, 2007; Spencer, Biederman, & Mick, 2007). Advancements in science have led researchers and clinicians to conceptualize ADHD as a chronic neurodevelopmental disorder caused by a complex interplay between genetics, changes in brain development, and environmental influences (Biederman & Faraone, 2001; Spencer, Biederman, Wilens, & Faraone, 2002). ADHD is often depicted as a triad of inattention, hyperactivity, and impulsiveness (Swanson, 2003). Symptoms of attention are attributed to deficits in neurocognitive processes and executive functioning, such as selected and sustained attention, concentration, organization and planning, time management, learning and memory, and sensory-motor integration (Mahone et al., 2002). Symptoms of hyperactivity and impulsivity are common in childhood and often persist into adolescence and young adulthood (Wilens, Biederman, & Spencer, 2002). See *Table 2.1* for common symptoms and behaviors for children with ADHD (APA, 2013).

Table 2.1

Common ADHD Symptoms and Behaviors

ADHD Symptom Type	**Common Behaviors**
Inattentive	Fails to give close attention to details or makes careless mistakes Difficulty sustaining attention Does not seem to listen Does not follow through on instructions or fails to complete tasks or activities Difficulty organizing and planning Struggles with prioritization and time management Loses things, forgetful Easily distracted by extraneous stimuli
Hyperactive	Fidgety or squirmy Gets up out of seat or station frequently Runs around, climbs, constantly moving Difficulty playing or engaging in pleasurable activities quietly Always on the go", like a race car Talks excessively, a "motor mouth"
Impulsive	Blurts out answers before questions have been completed Difficulty waiting turn Reactive (acts without thinking first) Interrupts or intrudes into other's conversations or activities

Children with ADHD usually experience difficulties and potential impairments in their functioning across multiple domains and settings, including school and academics, family and home life, in peer relationships and friendships, and in their psychological and emotional well-being (Weiss, 2014). In the academic setting, children with ADHD often struggle with paying attention in the classroom, focusing on schoolwork, following instructions, and completing tasks set forth by their teachers and other school workers.

They are also likely to be forgetful, disorganized, easily distracted, and experience fatigue and frustration with activities that require sustained mental effort. Due to these deficits in attention and executive functioning, children with ADHD are at increased risk for academic impairment, including poor grades, lower test taking ability, grade retention, decrease in academic achievement, and other learning difficulties (Biederman et al., 2004; Raggi & Chronis, 2006).

Symptoms of hyperactivity, like difficulty sitting still, moving around the classroom, and an excess of unproductive energy, all complicate the ability for children with ADHD to be successful in the academic setting. In children with ADHD, potential disruptive behaviors, conflicts with teachers, and behavioral challenges in the classroom are associated with an increased use of school-based services, increased rates of detention, suspensions, and expulsion from school, and relatively low rates of high school graduation and postsecondary education (Loe & Feldman, 2007; Raggi & Chronis, 2006). Symptoms of impulsivity may also contribute to poor school performance, especially when children are unable to master control of their active and reactive impulses and behaviors in the classroom and overall school setting.

At home, caregivers and other family members, including siblings, often have challenges and stressors related to a child with ADHD in the family (Deault, 2010; Podolski & Nigg, 2001). Caregivers often say things like, “My child never listens; I have to give instructions 4 or 5 times before anything gets done”, or “My child is constantly on the go; I can’t get anything done when he/she is at home.” Statements like these reflect the challenges that children and their families may experience daily. Chores and homework are especially difficult for families of a child with ADHD to manage (Booster, DuPaul, Eiraldi, Power, 2010; Clarke et al., 2015). Oftentimes, caregivers are conflicted in their management with having to approach their child's ADHD with understanding and recognition of limitations while simultaneously wanting and hoping for their child be successful in school, family relationships, and other areas of childhood. As a result, family stress, caregiver burden, and disruptions in family relationships may occur as a result of managing a child with significant ADHD symptoms (Kendall, Leo, Perrin, & Hatton, 2005; Markel &Wiener, 2014; Reader, Stewart, & Johnson, 2009; Riley et al., 2006).

Furthermore, children with ADHD may experience functional impairments in their peer relationships or their psychological and emotional well-being. This can be especially true for children who are impulsive, reactive, or hyperactive in social situations. Making and keeping friendships may be a challenge for these children as well as developing a repertoire of social skills, which may protect them against teasing, bullying, or social exclusion (Booster, DuPaul, Eiraldi, Power, 2010). Children with ADHD often experience co-morbid anxiety and depressive symptoms (Eiraldi, Power, & Nezu, 1997), which may be related to the social aspects of the condition. Feelings of social inadequacy, low self-esteem, peer rejection, and social isolation may be consequences of untreated or unrecognized ADHD (Karustis, Power, Rescorla, Eiraldi, & Gallagher, 2000; Wehmeier, Schacht, & Barkley, 2010). Furthermore, unrecognized, untreated, or undertreated ADHD increases the risk for children to engage in high-risk behaviors, like substance use (Molina & Pelham, 2003), early sexual activity (Flory, Molina, Pelham, Gnagy, & Smith, 2006), or physical aggression and conduct problems (Harty, Miller, Newcorn, Halperin, 2009). This may be related to poor impulse control or deficits in executive function, which can cause children with ADHD to exhibit poor judgment and decision-making skills.

Because ADHD symptoms are likely to cause functional impairments across multiple domains and settings (e.g., academic, family, peer, emotional), clinicians and researchers attempt to target symptoms of attention, hyperactivity, and impulsivity with evidence-based treatments and interventions. Currently, the standard evidence-based treatment recommendations for ADHD are outlined in the practice parameters set forth by the American Academy of Child and Adolescent Psychiatry (AACAP, 2007) and the American Academy of Pediatrics (APP, 2011). Following specific guidelines on assessment, evaluation, history, and diagnosis, clinicians and providers are advised to consider two mainstays of treatment: 1.) psychopharmacologic intervention (i.e., medications) and 2.) psychosocial interventions. The most common ADHD medications are stimulants, which boost neurotransmission in the areas of the brain responsible for attention, concentration, executive functioning, and integration of complex cognitive processes (Arnsten, 2006). Stimulant medications also decrease physical hyperactivity and behavioral impulsivity by slowing down neural circuits in the areas of the brain responsible for motor movement and inhibition (Greenhill, Pliszka, & Dulcan, 2002).

Psychosocial interventions for ADHD most often include parent management training, behavioral modification, cognitive-behavioral therapy, family therapy, and school-based interventions (Antshel & Barkley, 2008; Fabiano et al., 2009; Watson, Richels, Michalek, & Raymer, 2015). The most utilized non-pharmacologic psychosocial intervention for childhood ADHD is parent management training with behavior modification (Chronis, Chacko, Fabiano, Wymbs, & Pelham, 2004; Pelham & Fabiano, 2000). This therapeutic approach requires active caregiver engagement and ongoing participation by parents and families to modify or change problematic behaviors and counteract the symptoms and functional impairments of ADHD. Behavioral interventions often encourage caregivers of a child with ADHD to:

- Give simple and clear instructions and directives to their child;
- Define rules, expectations, and appropriate limits for their child's behavior;
- Use praise, incentives, and rewards on a regular basis for positive behavior; and
- Consistently follow-thru on appropriate consequences for negative behavior.

(Power, Soffer, Cassano, Tresco, & Mautone, 2011)

Parent management training and behavior modification interventions can be delivered in mental health clinics and non-traditional settings, such as pediatric primary care settings and schools (Fiks, Mayne, DeBartolo, Power, & Guevara, 2013).

Furthermore, these approaches encourage caregivers to develop relationships with school personnel, such as teachers, counselors, and special education services, to maximize the benefits of such interventions by extending behavioral management strategies into a child's daily school life and after-school activities (Mautone, Lefler, & Power, 2011). Strategies to support children with ADHD in the school setting may include: positive reinforcement, the token economy system, a daily report card, self-management and social skills training, organizational skills training, behavioral homework interventions, and computer-assisted instruction (Eiraldi, Mautone, & Power, 2012). When school-based interventions intersect with family involvement, researchers have found a significant positive effect on the quality of family-school relationships, homework performance, and parenting behavior for children with ADHD (Power et al., 2012). In addition, school-based interventions are easy to access by children and are provided in a normalized setting where stigma is minimized, which may enhance the acceptability of ADHD treatment (Owens et al., 2002; Stephan, Weist, Kataoka, Adelsheim, & Mills, 2007).

Disparities in ADHD Care and Treatment

While the benefits of current standard treatment have repeatedly shown significant positive results in childhood ADHD (MTA Cooperative Group, 2004; Murray et al., 2008), social and economic disadvantages may create barriers for diverse caregivers to effectively implement evidence-based treatments into their daily lives. Poverty has shown to lower treatment rates in children with ADHD and is associated with more pervasive barriers to treatment (Bussing, Zima, Gary, & Garvan, 2003). A major barrier for this may be access to the appropriate care and services. Even though ADHD medications are widely available to most children in primary or specialty health care clinics, the availability of high quality behavioral interventions and therapeutic services may be limited for children due to a variety of social, economic, or geographic barriers (Frazier, Bearman, Garland, & Atkins, 2014). Alternatively, even if care is provided, it may be done so with a lower service integrity, which is the degree to which an intervention is implemented as planned (Eiraldi, Mazzuca, Clarke, & Power, 2006). As a result, care may be less likely to decrease problematic symptoms and behaviors, and thus, decrease the effectiveness of treatments designed to positively influence ADHD outcomes.

Furthermore, while evidence-based clinical guidelines are put forth by academic and professional organizations, research suggests there are discrepancies between professional guidelines for treating ADHD and how acceptable they are to caregivers (Bussing & Gary, 2001). In the literature, caregiver accounts oftentimes depict stimulant use, the cornerstone of ADHD treatment in the United States, as a difficult treatment modality to accept (Krain, Kendall, & Power, 2005). Additionally, the feasibility and practical implications of implementing the principles of parent management training and behavior modification into a family's daily life may be more challenging and nuanced than previously realized. In response to this, Eiraldi and colleagues have developed a model for help-seeking, which highlights the multiple barriers and facilitators faced by children and families when selecting and utilizing services for ADHD care (Eiraldi, Mazzuca, Clarke, & Power, 2006). In this model, single-parent status, ethnic minority status, younger parents, low socioeconomic status, households headed by non-biological parents, parental psychopathology, and overly harsh disciplinary practices (2006) are thought to increase risk for poor adherence to parent management and behavior training for the treatment of ADHD.

In addition, Guevara et al (2005) revealed fragmented and disorganized care in health, school, and community services for ADHD youth within the inner city. Kendall, Leo, Perrin, and Hatton (2005) reiterate these findings by acknowledging the unique experiences and barriers faced by racially and ethnically diverse families when navigating the complex systems and services related to mental health care. Caregivers may experience difficulties in coordination and communication with health and school services that prevent access to available resources and maintenance of ADHD treatment (2005). In addition, diverse youth may be more likely to have unmet service needs in school settings, especially in urban areas, due to sparse mental health resources for children with ADHD (Bussing, Zima, Perwien, Belin, & Widawski, 1998). Taken all together, the literature seems to suggest that many caregivers and families experience significant barriers to effectively implement evidence-based ADHD treatments into their children's daily lives, but may disproportionately affect children and youth from diverse communities, due to a multiplicity of inequities regarding access to services, quality of care, and acceptable treatment availability.

Cultural Perspectives of ADHD and its Treatment

While it is evident in the literature that families contribute to the care and outcomes of children with ADHD, caregivers and families from diverse cultural backgrounds may have varying perspectives on ADHD and its treatment (Paidipati, Brawner, Eiraldi, & Deatrick, 2017). Current studies suggest caregivers from racially and ethnically diverse families may have differing views on the etiology of ADHD, including familial, socio-ecological, and spiritual causes, that diverge from traditional biomedical explanations (Carpenter-Song, 2009; Lawton, Gerdes, Haack, & Schneider, 2014; Yeh, Hough, McCabe, Lau, & Garland, 2004). In a qualitative study, Carpenter-Song (2009) found that European-American families tended to link childhood problems, such as

ADHD, to biomedical causes whereas African-American families tended to view childhood behavioral and emotional difficulties as problems originating in, and handled by, the family. Similarly, in another study, Latino-American families more often associated ADHD etiology with imbalances in family life or societal influences (Lawton, Gerdes, Haack, & Schneider, 2014). Yeh and colleagues (2004) found that parents of African-American, Asian or Pacific Islander American, and Latino youths were generally less likely than parents of non-Hispanic whites to attribute children's mental health problems to biopsychosocial beliefs. In this study, other potential causes of childhood mental illness were spiritual or nature disharmony causes, such as spirit possession or disruption of the child's vital energy flow (Yeh, Hough, McCabe, Lau, & Garland, 2004). In other studies, African-American caregivers and communities held persistent beliefs regarding the role of sugar in the etiology of ADHD, the belief that too much sugar in the diet causes ADHD, which may influence how caregivers manage the condition (Bussing et al., 2012; Olaniyan et al., 2007).

Beyond differences in etiological perceptions, major health disparities exist in ADHD symptom recognition, diagnostic rates, treatment acceptability, and service use within culturally, ethnically, and linguistically diverse populations across the United States (Eiraldi, Mazzuca, Clarke, & Power, 2006). According to previous studies, ethnic minority youth are less likely to be identified and/or treated for ADHD than Caucasian youth, despite evidence that symptoms are equally prevalent in these two groups (Morgan, Staff, Hillemeier, Farkas, & Maczuga, 2013; Vierhile, Robb, & Ryan-Krause, 2009). A study of 6,000 children found Latino children (4%) were less likely than

African American (9.1%) and Caucasian children (10.8%) to be diagnosed with ADHD (Rowland et al., 2002). In the same investigation, ethnic minority children (53% of Latinos and 56% of African Americans) were less likely to be on medication for ADHD as compared to 76% of Caucasians (2002). Additionally, DosReis, Mychailyszyn, Myers, and Riley (2007) found that African-Americans parents were hesitant to use stimulant medications to treat childhood ADHD due to fears of addiction, harmful side effects, and negative attitudes by the community or media. In another study, Latino and African-American families also rated counseling and behavioral treatments more positively than Caucasian parents (Pham, Carlson, & Kosciulek, 2010). Krain, Kendall, and Power (2005) echo similar findings by identifying a significant relationship between ethnicity and pursuit of pharmacological treatment in which Caucasian parents were more likely to pursue medications for ADHD than other racial or ethnic groups.

In the help-seeking model previously mentioned, ethnic minority caregivers often move from problem recognition to making-a-decision to seek care for their child's condition (Eiraldi, Mazzuca, Clarke, & Power, 2006). When selecting services for ADHD in the community, caregivers may consider the cultural sensitivity of staff, availability of bilingual clinicians or interpreters, and the perceived support from their social networks, as well as economic factors, such as financial resources, health insurance, and transportation issues (2006). These elements may act as barriers or facilitators for accessing appropriate care and services. Bussing, Zima, Gary, and Garvan (2003) also found significant barriers to help-seeking and service use from caregiver perspectives, including system barriers, negative experiences from past service use, financial barriers, and stigma related to mental health issues (Bussing, Zima, Gary, and Garvan, 2003).

Furthermore, regarding types of services, Kendall, Beckett, Leo, and Hatton (2005) found that African-American families were more likely to request social services, including financial assistance and disability funds, housing, and community-sponsored respite, whereas Hispanic families were more likely to request support services for ADHD, like support groups, parenting classes, social skills classes, and community programs, such as the Boys and Girls Club. This implies that ethnic minority families may have different service needs and priorities for ADHD care and treatment that may go beyond medications and therapy alone. In addition, low mental health service utilization and follow-up found in multiple studies with Hispanic and African-American youth and families have been related to parental concerns about medications, past experiences with service use, and parental perspectives of ADHD (Berger-Jenkins, McKay, Newcorn, Bannon, & Laraque, 2012; Larson, Yoon, Stewart, & DosReis, 2011; Mychailyszyn, Dosreis, & Myers, 2008). This may indicate that further exploration is needed to understand how to better serve ethnic minority families in regard to mental health care and treatment maintenance.

A Family Approach to Promoting Health Equity in ADHD Management

From these differences in etiological perception, diagnostic rates, help-seeking behavior, treatment acceptability, and service use, it is evident from the literature that children and families may experience significant health disparities in the care and treatment of childhood ADHD (some of which reflect problems of health inequity).

Implications of such disparities and issues of health equity have lead advocates of childhood mental health and developmental pediatrics to think innovatively on how to effectively disseminate and implement evidence-based practices for child and adolescent mental health into community settings (Kendall & Beidas, 2014). From a social justice perspective, all youth and families should have fair and equitable opportunities to benefit from high quality, evidence-based treatments available for childhood ADHD, regardless of race, culture, ethnicity, socioeconomic status, or mental health disability (Maddox, 2014). Potential solutions to promote health equities within mental health care and treatment include:

- Delivering evidence-based mental health treatments in school settings;
- Changing policies to increase insurance coverage for mental health care; and
- Providing internet-based programs for parent management and behavior training.

(Boxmeyer et al., 2014; Chamberlain & Saldana, 2014; Elkins & Comer, 2014)

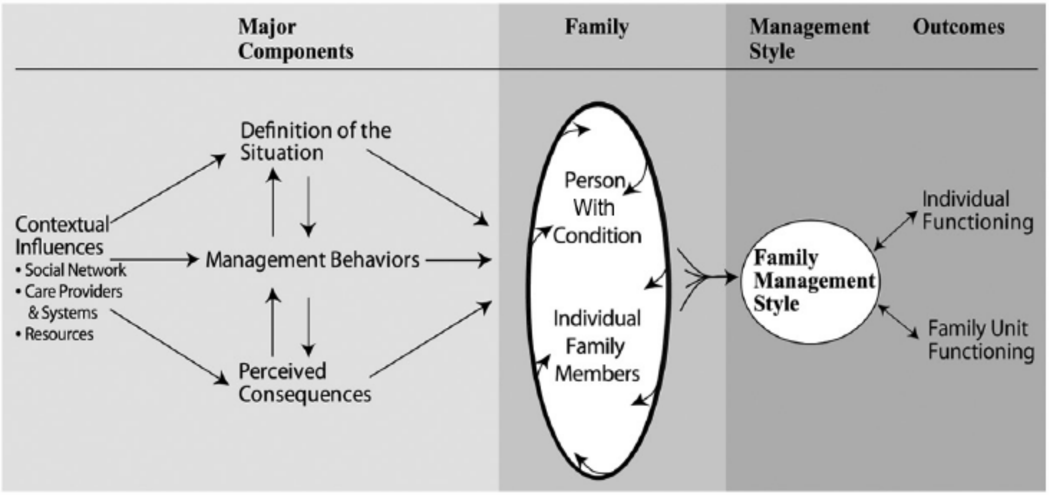
Another possible solution is to design clinical interventions, which focus on the caregivers of children with ADHD and incorporate the strengths and resources of families into the care and management of childhood ADHD. As previously mentioned, families are an integral aspect to the care and management of childhood ADHD (Cunningham, 2007). Typically, children with ADHD rely on their primary caregivers for symptom recognition, seeking healthcare services, decision-making, and treatment implementation (Dishion & Stormshak, 2007). Most often, families are integrated into the treatment planning and implementation of many therapeutic interventions (Bussing & Lall, 2010; Davis, Claudiu, Palinkas, Wong, & Leslie, 2012; DeMarle, Denk, & Ernsthausen, 2003;

Dishion & Stormshak, 2007). Currently, family-based ADHD interventions, such as parent management training or behavior modification, use families and caregivers to initiate and facilitate these interventions with ongoing support and guidance. They do not, however, consider how ADHD is *systematically* integrated into family life (i.e., how specific family processes intersect and influence the daily management of childhood ADHD).

Using the family management theory (Knafl, Deatrick, & Havill, 2012) to better understand how families manage childhood ADHD in their everyday lives may lead to the development of interventions that aim to improve family management strategies for childhood ADHD. As previously defined, Family Management describes key family processes involved in how families and their members incorporate condition management into family life (Knafl & Deatrick, 1990; Knafl, Breitmayer, Gallo, & Zoeller, 1996). The Family Management Styles Framework (FMSF) is a theoretical framework that expands the family management concept into a theoretical model. The FMSF is comprised of three major components: Definition of the Situation, Management Behaviors, and Perceived Consequences (Knafl & Deatrick, 2003). Each component is composed of conceptual dimensions that reflect more specific aspects of the component. The eight dimensions, including Child Identity, Illness View, Management Mindset, Parental Mutuality, Parenting Philosophy, Management Approach, Family Focus, and Future Expectations, are derived from research and the literature on children with chronic illness and their families (Knafl & Deatrick, 1990; 2003; Knafl, Deatrick, & Havill, 2012). See *Figure 2.1* for a diagram of the FMSF.

Figure 2.1

Family Management Styles Framework



The diagram above, *Figure 2.1*, depicts major components of family management (i.e. definition of the situation, management behaviors, perceived consequences) interacting with contextual influences, such as social networks, care providers and systems, and resources, to impact the person or child with the condition and other individual family members. This, in turn, creates a family management style, which impacts both individual functioning as well as overall family functioning (Knafl, Deatrick, & Havill, 2012).

Advancing the science, the FMSF provided a strong base and theoretical framework for the Family Management Measure (FaMM). The FaMM is an instrument developed to measure how families manage caring for a child with a chronic condition/ illness and the extent to which they incorporate condition management into everyday family life (Knafl & Deatrick, 2006; Knafl et al., 2011; Knafl et al., 2015). The FaMM includes summated scales, such as child's daily life, condition management effort, condition management ability and view of condition impact, which reflect dimensions of the FMSF (Knafl & Deatrick, 2006; Knafl et al., 2011; Knafl et al., 2015). Both the FMSF and FaMM have been used to understand how families incorporate the management of a childhood chronic condition or illness into their everyday lives (Knafl, Deatrick, & Havill, 2012; Knafl et al., 2013). Within studies on pediatric chronic illness, family management patterns have emerged in the literature to describe different styles of management for families managing a child with a medical condition (Knafl et al., 2013).

Within the family management framework, qualitative methods also have been used in previous studies to organize ADHD management into different family patterns. For example, qualitative findings have shown different family management styles (e.g., reinvested, surviving, controlled, chaotic) that describe the patterns in which families manage a child with ADHD (Conlon, Strassle, Vinh, & Trout, 2008; Kendall & Shelton, 2003). Unfortunately, these studies did not incorporate contemporary advances in family management theory (Knafl et al., 2013) nor have they incorporated recent advances in measuring family management. Furthermore, these studies were conducted without special consideration to cultural or ethnic perspectives of ADHD.

Gaps and Purpose for this Study

Gaps exist in our understanding of caregivers' perspectives on their child's daily life with ADHD, their own condition management ability and effort, and the impact of ADHD on their child's life and future. Theory-driven research is needed to uncover both perceptions of family management for childhood ADHD (i.e. child's daily life, condition management effort, condition management ability, view of condition impact) and how family management is related to a child's level of functional impairment. These insights will advance the science on the way in which family management factors relate to children's level of functional impairment from their ADHD condition. Ultimately, the knowledge generated can be used in future studies to develop interventions, which aim to strengthen family management, and ultimately, lead to improvements in childhood functioning.

In previous studies, family management factors were related to child behavior or function and family function. For instance, in a non-categorical study, 579 parents of children age 3 to 19 with a chronic condition (349 partnered mothers, 165 partners, 65 single mothers), family factors were significantly correlated to child functional status and behavioral problems and family functioning ($p<.01$) (Knafl et al., 2013; Knafl et al., 2015). Other family management studies, exclusive to children with ADHD, showed similar results with qualitative methods only (Conlon, Strassle, Vinh, & Trout, 2008; Kendall & Shelton, 2003). In these studies, poor family processes and negative family management patterns were associated with poor childhood and poor family functioning. Conversely, positive family processes and family management patterns were associated with better childhood and family functioning. What the literature did not capture, however, was: 1.) how caregivers from diverse families manage childhood ADHD in everyday life, 2.) the barriers and facilitators of ADHD management, and 3.) how family management factors (i.e., child's daily life, condition management effort, condition management ability, view of condition impact) are related to children's level of functional impairment from quantitative methods.

In response to these gaps, this study aimed to investigate the impact of family management on children's level of functional impairment and the challenges and successes experienced by caregivers regarding the management of children with ADHD across a spectrum of childhood functional impairment. In this project, we hoped to understand how ethnically diverse caregivers manage childhood ADHD in their everyday lives and examine how family management factors related to children's level of functional impairment. Caregivers of children with lower and higher levels of functional impairment described their family management. Therefore, this study extended previous research on family management and ADHD in diverse populations and built upon existing knowledge about cultural perspectives of children with neurodevelopmental conditions. The knowledge gained from this study serves as the basis of a larger program of research that aims to develop family-based interventions or adapt existing evidence-based interventions for diverse children with ADHD.

Chapter 3: Methods

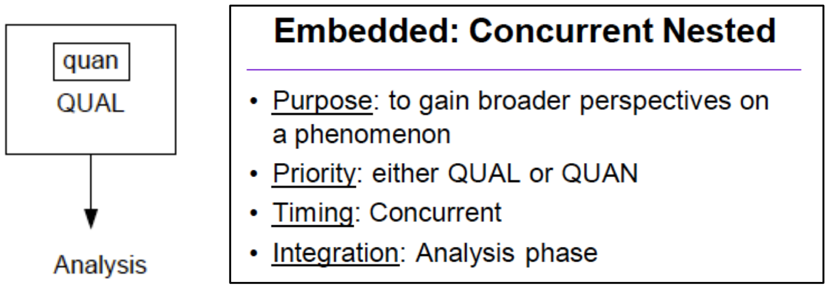
The purpose of this chapter is to describe the methods for this dissertation study. This chapter will explain the design of the study, rationale for chosen approach, and the conceptual model. Participants and sample, recruitment strategies, study procedures, and data collection will be detailed. Next, we will review study measurements, analytic approaches, expected outcomes, and how this study intends to ensure rigor and quality. Finally, we will end the chapter with considerations for human subjects' protection.

Design of the Study

This mixed methods study had a concurrent nested design (QUAL [quan]) (Dickson, 2015). In health disparities research, multiple perspectives of health are critical as they tap into different facets of the phenomenon. The research questions posed in this study require qualitative and quantitative research to achieve the specific aims of the project. The strategies, approaches, and analytic techniques integrated into the study design reflect a theoretical intention to draw conclusions from different ways of knowing (i.e., qualitative, quantitative) and understanding (i.e., subjective, objective). See *Figure 3.1* regarding the mixed methods design (Dickson, 2015) chosen for this study.

Figure 3.1

Mixed Methods Design



Embedded: Concurrent Nested

- Purpose: to gain broader perspectives on a phenomenon
- Priority: either QUAL or QUAN
- Timing: Concurrent
- Integration: Analysis phase

Aligned with the study’s specific aims, this design first examined family management factors via in-person qualitative interviews to better understand the factors, barriers, and facilitators of family management. Next, survey data were analyzed to examine how family management factors were related to children’s level of functional impairment. Lastly, the qualitative and quantitative findings were integrated to explicate overlapping themes and family management factors that related to children’s levels of functional impairment. Cross-sectional data were collected from 50 caregivers of children with ADHD via in-person semi-structured interviews (qualitative) and self-administered survey instruments and questionnaires (quantitative). Caregivers were recruited for this study using a stratified sample to ensure adequate representation from diverse children and families living in the city of Philadelphia.

A semi-structured interview guide was used to direct qualitative data collection to elicit caregiver experiences regarding the chosen family management factors, barriers, and facilitators of ADHD management. Qualitative analyses were conducted first after data collection, followed by quantitative analyses. In the final stage of analysis, data sets were integrated and transformed to answer the final research question. Understanding, both inductively and deductively, how family management was related to children’s level of functional impairment was the first step to building a solid foundation for a future line of research that aims to develop or adapt family-based interventions for diverse children with ADHD and their families.

Rationale for the Proposed Approach

Mixed methods research uses rigorous qualitative and quantitative methods to focus on research questions that call for multi-level perspectives and contextual understandings of cultural influences within a population (Creswell, Klassen, Plano Clark, & Smith, 2011). The research questions posed in this study required both methods to thoroughly answer the specific aims, provide stronger inferences, and understand the phenomenon through deductive and inductive reasoning. This study used a mixed methods approach to seek complementarity of data (Dickson, 2015) to describe themes and facets of the family management in ethnically diverse children with ADHD. That is, using both methods captures important contextual factors and the "voice" of the participants (i.e. qualitative) in terms of how family management may be related (i.e. quantitative; Dickson, 2015) to children's functioning. Thus, by seeking complementarity within data, the mixed methods design strengthens the rigor of the overall study and enhances the validity of its findings.

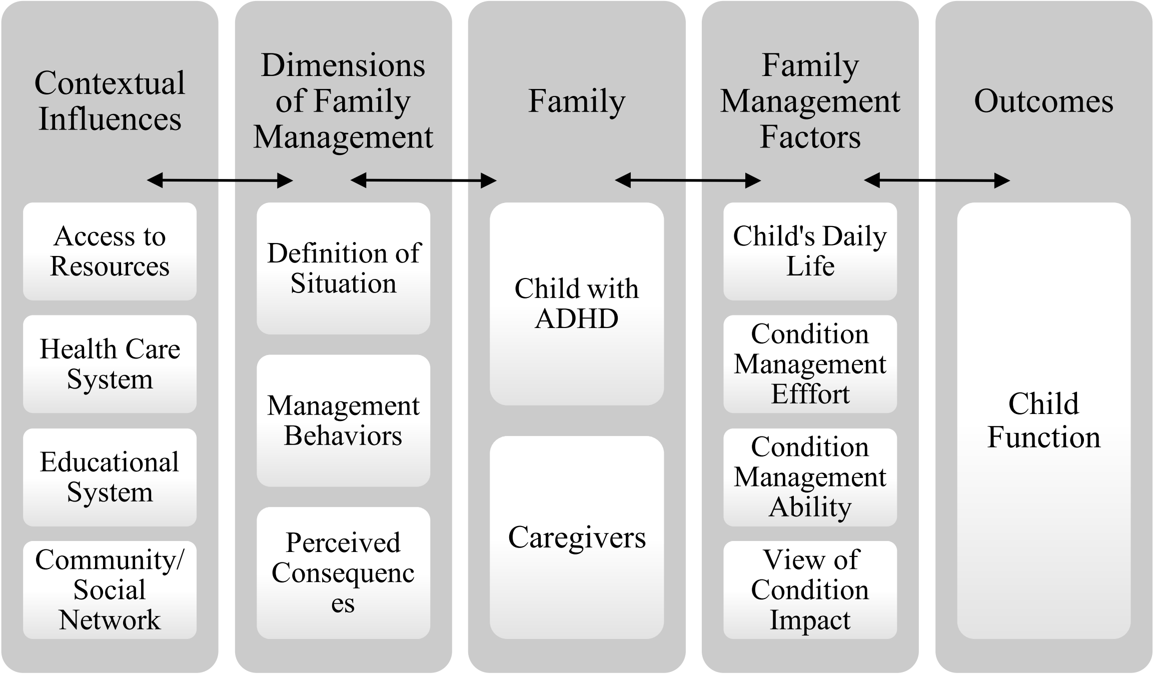
The quantitative aim was embedded within the dominant qualitative aim in the concurrent nested design to gain a contextualized understanding and an integrated perspective on how family management is related to childhood ADHD. In this study, we collected qualitative and quantitative data concurrently and data analyses were conducted sequentially (Creswell & Plano Clark, 2011). Integration of the results was done after independent qualitative and quantitative data analyses were completed. Priority and weighting (Dickson, 2015) were given to the qualitative method as the quantitative data were exploratory in nature and used to better understand the nature of family management of ADHD and the effects of family management factors on the outcome variable.

Study Model

The model for this study was consistent with family management frameworks and social-ecological approaches to care as it considers how family and social systems and structures influence the management of a child's condition (Barakat, 2008). Adapted from the Family Management Styles Framework referenced in *Figure 2.1*, contextual factors (e.g., access to resources, healthcare, educational, community systems) are posed to influence the dimensions of family management in regards to a child's chronic condition. The dimensions of family management describe how the family, including caregivers, incorporate ADHD management into family life. These dimensions include, definition of the situation (e.g., child identity, view of condition, management mindset, parent mutuality), management behaviors (e.g., parenting philosophy, management approach), and perceived consequences (e.g., family focus, future expectations). In this framework, the dimensions are the conceptual underpinnings for the family management factors which are theorized to influence child outcomes. For childhood ADHD, the family management factors hypothesized to impact children's level of functional impairment are *child's daily life, condition management effort, condition management ability,* and *view of condition impact*. See *Figure 3.2* for the adapted family management model for children with ADHD.

Figure 3.2

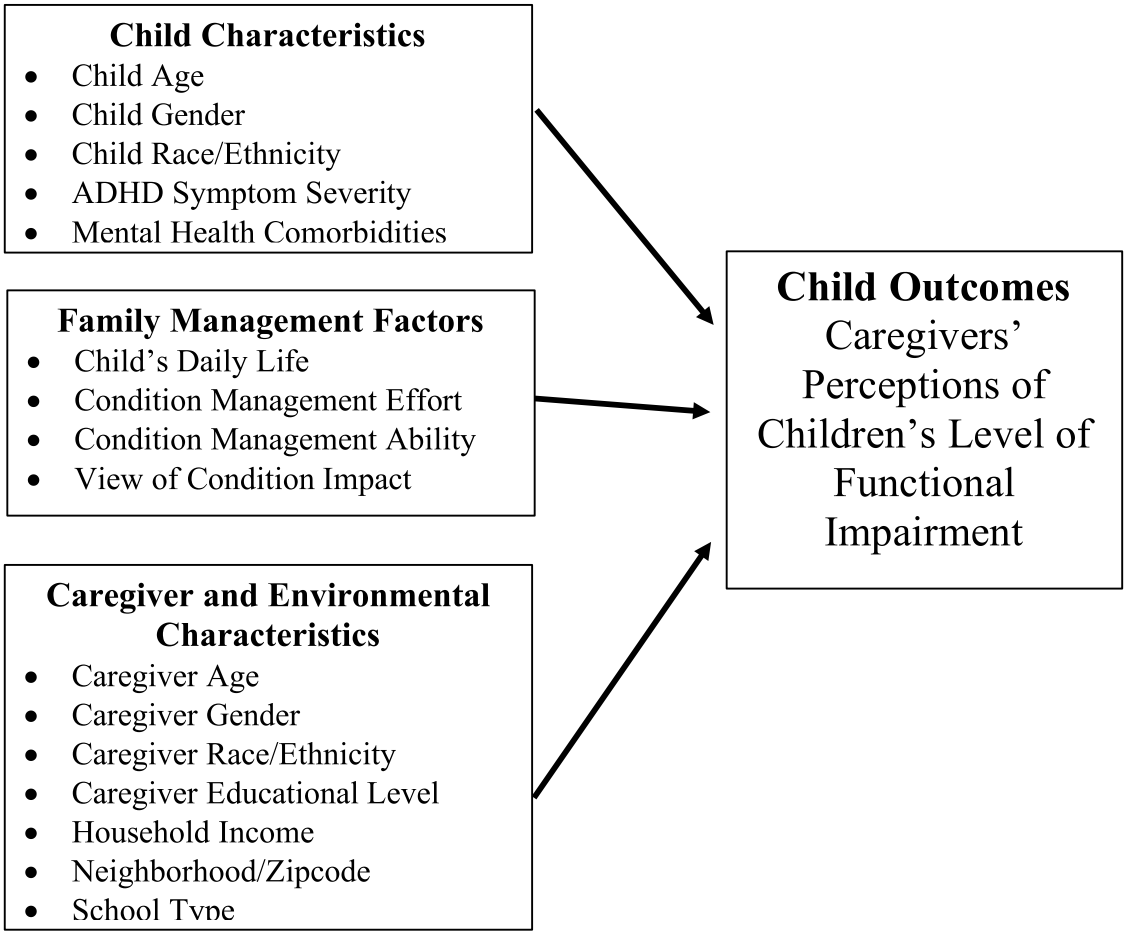
Adapted Family Management Model for Children with ADHD



For this study, we developed a conceptual model that incorporates both family management factors and contextual factors that we believed were important for children with ADHD. Contextual factors include child, caregiver, and environmental characteristics. Child characteristics include: child age, gender, race/ethnicity, ADHD symptom severity, and mental health-comorbidities. Caregiver characteristics include: caregiver age, gender, race/ethnicity, and educational level. Environmental characteristics include: household income, neighborhood/zipcode, and school type. See *Figure 3.3* for a conceptual model for understanding the role of family management in children with ADHD from urban Philadelphia.

Figure 3.3

Conceptual Model for Understanding the Role of Family Management in Children with ADHD



This study extends previous ADHD research with children and families by attempting to explain how family management factors are related to children's functional impairment. This project sought to increase our understanding of how factors such as child's daily life, condition management effort, condition management ability, and view of condition impact are related to functional outcomes for children with ADHD. In addition, this work aimed to further understand the contextual and ecological influences that affect children with ADHD and their caregivers within a large urban city.

Participants

The purpose of this study was to understand the perspectives of diverse caregivers for children with ADHD from an urban northeastern city. As a city with different regions and cultural heritages and a high proportion of children and families who reflect a myriad of culturally, racially, and ethnically diverse backgrounds, this research considered the self-identification of caregiver participants by race and ethnicity as well as their unique cultural backgrounds. Using the 2014 U.S Census data for the City of Philadelphia, a stratified sampling plan was used to ensure adequate representation of caregiver participants from different racial and ethnic backgrounds. See *Table 3.1* for the target and final sample of caregiver participants based on race and ethnicity.

Table 3.1

Target (and Final) Sample of Caregiver Participants by Race and Ethnicity

Caregiver Participants (N=50)	**Target** N=50	**Actual** N=50
Race		
White alone	21 (42%)	16 (32%)
Black or African-American alone	22 (44%)	29 (58%)
American Indian and Alaska Native alone	1 (2%)	0 (0%)
Asian alone	3 (6%)	4 (8%)
Native Hawaiian or other Pacific Islander alone	1 (2%)	0 (0%)
Two or more races	2 (4%)	1 (2%)
Total	**50**	**50**
Ethnicity		
Hispanic or Latino	7 (14%)	3 (6%)
Non-Hispanic or Latino	43 (86%)	47 (94%)
Total	**50**	**50**

It is important to note that this study was not examining the differences *between* racial and ethnic caregiver groups, but rather, we sought a diverse sample of caregivers representative of the racial, ethnic, and cultural diversity within the city of Philadelphia. We believed this would: 1.) bring the voices of historically marginalized families to the forefront of this work, 2.) fill an important gap in knowledge from previous research studies in this area, and 3.) result in study findings that are more reflective of a diverse range of family and caregiver views, not just those of the racial majority. Following this intention, inclusion and exclusion criteria were designed in alignment with the aims and priorities of this study. See *Table 3.2*.

Table 3.2

Inclusion and Exclusion Criteria for Children and Caregiver Participants

Inclusion Criteria	Exclusion Criteria
Children are eligible for this study, if they meet the following criteria: 1. Are between the ages of 5 -12 years 2. Have a diagnosis of ADHD (per caregiver report)	Children are not eligible for this study, if they meet the following criteria: 1. Are younger than 5 years or older than 12 years 2. Have a severe developmental delay or severe cognitive impairment (per caregiver report)
Caregivers are eligible for this study, if they meet the following criteria: 3. Viewing him or herself as assuming major responsibility for the child's care 4. Residing at least 50% of the time in the same household as the child 5. Living in a primary residence within the city of Philadelphia	Caregivers are not eligible for this study, if they meet the following criteria: 3. Are younger than 18 years of age 4. Are non-English-speaking 5. Have a primary residence outside the city of Philadelphia

The age range for child eligibility (5-12 years old) was chosen to investigate the role of family management in school-age children. Adolescents (13 years and older) were excluded from this study, as they may represent a different population of youth with ADHD, who may have different priorities and distinctive barriers and facilitators within family management. A separate, future study focusing on family management and adolescents with ADHD is indicated.

To achieve our goals for participant diversity, recruitment for this study occurred within a large, tertiary care and academic hospital in the northeastern part of the country. As a nurse practitioner within the Department of Child and Adolescent Psychiatry and Behavioral Sciences at the Children's Hospital of Philadelphia, the lead researcher of this study (Cynthia P. Paidipati) was in good standing with key gatekeepers and liaisons within this organization before, during, and after the project was completed. The sponsor for this study (Dr. Ricardo Eiraldi) is also a researcher and clinician in the department and has an excellent reputation for conducting research within the organization and surrounding communities. In addition, partnership with the Recruitment Enhancement Core (REC), a service provided by the Clinical Research Support Office within the institution, made the completion of this study possible. Utilizing REC services, recruitment for this study casted a wide net within the Philadelphia urban environment. The chosen methods maximized the potential for participant diversity in recruitment, which increased the variety of the final sample and enhanced generalizability across the population of children with ADHD (Hulley, Cummings, Browner, Grady, & Newman, 2013; Polit & Beck, 2012).

In regards to sample size, a target number of 50 participants was agreed upon by the consulting statistician (Jesse Chittams) and the dissertation committee. This sample size would allow for relationships in the data to emerge, while also promoting feasibility of the mixed methods concurrent nested design. It does not, however, provide enough power to test the full model proposed in our adapted conceptual framework. Nonetheless, the exploratory analyses may be the first-step in understanding the relationship between family management factors and children's level of functional impairment. In turn, this study may inform future studies on family management in children with ADHD.

Recruitment

Recruitment started once approval to conduct the study was obtained from the Institutional Review Board (IRB) at the Children's Hospital of Philadelphia (CHOP)–the IRB of record—with secondary approval from the University of Pennsylvania (PENN). Recruitment efforts included multiple strategies to maximize outcomes within a limited time frame for this dissertation. Our primary method for recruitment included utilizing a CHOP-based service called the Recruitment Enhancement Core (REC). The REC helped with recruitment plan development and assisted in identifying and contacting potential participants using the CHOP Recruitment Registry (CRU), and internal communication resources. For this research, the REC sent out targeted emails to potential participants (using the inclusion and exclusion criteria for the study). Included in the email was a letter to caregivers of children (see *Appendix 1*) who fit our eligibility criteria. Interested caregivers were instructed to contact the lead investigator of the study via phone or email to learn more about the study. If not interested, an opt-out feature was included in the letter for caregivers stating no further contact regarding the study. If the email method was not successful, a back-up option was created in which the REC would send paper mailings to caregivers of children who fit our eligibility criteria. We did not have to utilize this latter strategy, but was a viable option, if needed. The REC also advertised our study to CHOP employees with a blurb in “This Week @CHOP”. Refer to *Appendix 2* for details on this recruitment advertisement.

Other recruitment strategies included recruitment flyers that were posted at pre-determined CHOP clinics within the city of Philadelphia. These included the Outpatient Behavioral Health Clinic at 3440 Market Street, Developmental and Behavioral Pediatrics Clinic at 3550 Market Street, and the South Philadelphia Primary Care Clinic at 1700 S. Broad Street. The original proposal also included posting flyers at the West Philadelphia (i.e., Karabots) and Chestnut Hill Primary Care locations. We reached our recruitment maximum, however, before flyers could be posted at these sites. Recruitment flyers (see *Appendix 3*) included the purpose, description, basic inclusion criteria, and contact information for the study. An additional Tear-Pad flyer was posted at signage boards at the main hospital. This flyer, featured in *Appendix 4,* was another innovative recruitment strategy provided by the REC.

In the original proposal, we included advertisement on social media sites, specifically Facebook, as a potential recruitment option for this study given that social media was a modern and innovative recruitment method in health-related research (Fenner et al., 2012). In addition, we had an option for snowball sampling as this method offered a way to overcome challenges associated with inviting difficult-to-reach communities to join health care research studies (Sadler, Lee, Lim, & Fullerton, 2010). Lastly, in the original proposal, as an active recruitment strategy, we included direct on-site recruitment at designated primary and specialty care clinics (Yancey, Ortega, & Kumanyika, 2006). Months prior to the study start, the lead investigator met with the medical directors of the sites to gather information and recruitment recommendations. We did not have to utilize these recruitment strategies (e.g., social media, snowball sampling, direct recruitment) given the tremendous interest in the study using the recruitment enhancement core. See *Figure 3.4* for a flow chart of the recruitment process and outcomes for the family management ADHD study.

Figure 3.4

Recruitment Flow Chart for Family Management ADHD Study

November/December 2016:
Flyers Posted at Clinics and Employee Advertisement within “This Week @CHOP”

↓

January 3, 27, and March 8, 2017:
REC Mass Emails Sent (500 caregivers per mailing)

↓

March 2017:
Tear-Pad Flyer posted at CHOP Main Signage Board

↓

N=60 Screened, Eligible, and Scheduled
(N=1 no longer able to participate, N=9 no call/no show and/or unreachable to reschedule)

↓

Within 12-weeks of Active Recruitment (Jan 1-March 31, 2017),
N=50 Caregivers Enrolled and Completed

Study Procedures and Data Collection

Once interested caregivers contacted the lead investigator by any means above, procedures for screening participants for eligibility occurred either over the phone (98%) or in-person (2%). For all potential participants, the lead investigator: 1.) introduced the study, 2.) obtained informed consent for screening (verbal or written), 3.) asked eligibility screening questions, and 4.) if eligible and interested, scheduled in-person appointment with the caregiver. See *Appendix 5* for the consent to screen form with HIPAA authorization. The eligibility screen and appointment set-up form is included in *Appendix 6.* Prior to ending the phone call, the lead investigator asked the caregiver if there were any further questions and concerns and obtained the preferred contact information (e.g., phone numbers, email addresses). The lead investigator requested permission to call, text, or email with an appointment reminder the day before the visit. Most caregivers preferred the text message option with a few caregivers requesting an email confirmation with appointment information in addition to the text reminder. Within email and text messages, information included: date, time, location, time requirement, contact information, and instructions for the visit.

During the recruitment process, the lead investigator and study intern tracked activities via an Excel spreadsheet saved on a designated research drive for the study at the University of Pennsylvania School of Nursing. Caregivers were assigned a unique ID number (starting at 001 and progressing consecutively). Essential information on each participant was entered into the secure spreadsheet for recruitment and tracking purposes only. This included: participant id#, caregiver race/ethnicity, recruitment type, screening date and type (over-the-phone or in-person), eligible (yes/no- if no, reason why), enrolled (yes/no- if no, reason why), appointment scheduled (yes/no), appointment date, day of the week, time, and location, duration of appointment (min), interview length (min/sec), visa gift card (yes/no), and completed C-2 form to track subject payments (yes/no).

In regards to caregiver appointments, all participant visits were conducted in-person with the lead researcher at CHOP's Outpatient Behavioral Health Clinic at 3440 Market Street in Philadelphia. A small, private meeting room was typically booked for the caregiver appointments. Occasionally, a larger conference room, also private, was booked for larger family visits and/or when the smaller room was occupied. Caregivers reported the 3440 Market location was easily accessible via public transportation or driving with convenient and free parking available at the clinic. Following are the procedures for these in-person caregiver appointments: 1.) obtaining written informed consent; 2.) completing questionnaires/surveys; 3.) conducting a semi-structured qualitative interview; 4.) debriefing from the interview and answering any additional questions from the caregiver; 5.) providing a hand-written thank you card, gift card compensation, and ADHD Resource Binder; and 6.) completing the University of Pennsylvania C-2 human subject voucher form.

To start, introductions were made at the beginning of the visit between the lead researcher, caregiver(s), any siblings or child participants who attended the appointment, and the study intern (Jamil Lane), if present for the visit. While child participants were not required to attend, if child participants and/or their siblings attended the visit, they were offered coloring books, crayons, and a CHOP-approved tablet with child-friendly games and educational apps to keep them busy during the visit; the study intern monitored the children during the interview. Approximately 20% of caregiver participants (N=11) had the child participant and/or their sibling(s) attend the appointment. In addition, 10% of caregiver participants (N=5) had a second caregiver (i.e., child's father, caregiver's spouse/boyfriend) attend the visit. The lead researcher welcomed the second caregiver to the visit and explained that the consent form, questionnaires, and surveys were to be completed by the primary caregiver, who first contacted the research team about the study. During the qualitative interview, however, secondary caregivers were asked to contribute, as they felt comfortable, to the discussion with the primary caregivers. Overwhelmingly, they agreed and enjoyed doing so.

From here, the written informed consent document was reviewed at length between the lead researcher and the caregiver participant with adequate time for the caregiver to ask any questions or express concerns, if any. All primary caregivers provided written informed consent to participate in the study (See *Appendix 7* for the informed consent form with HIPAA authorization). The lead researcher also signed the consent form, made a copy for the study records, and gave the original form to the caregiver participant. Once the informed consent process was completed, the lead researcher reviewed the instructions for each of the four study questionnaires/surveys. Further details about the study instruments are included in the measurement section of this chapter. Caregivers were given as much time as they needed to complete the questionnaires, and if caregivers had any questions or concerns, the lead researcher was present the entire time. On average, it took caregivers 20 minutes to complete the questionnaires. After caregivers completed the questionnaires, the lead investigator double-checked the study instruments to ensure adequate completion of the measures. For any blank spaces or unanswered items or responses, the researcher would give the caregiver the option to complete (if accidentally missed) or leave blank (if preferred not to answer). The lead researcher also briefly reviewed the demographic questionnaire for basic information about the child and family prior to the start of the qualitative interview.

Before the interviews began, the lead researcher repeated the purpose for the interview and the rationale for audio-taping. Caregivers were also asked to create a pseudonym for their child with ADHD as well as additional pseudonyms for themselves and other family members, as needed. A semi-structured guide was used to direct and facilitate the interview (further details in the measurement section of this chapter). The lead researcher also took field notes, as needed, to keep track of important details or pertinent areas of interest during interviews. See *Appendix 8* for the Field Notes form. As mentioned above, if a secondary caregiver was present, interview questions were predominantly aimed at the primary caregiver, but with additional contributions from the secondary caregiver. Some caregiver participants became teary-eyed and emotional during the interview and required a tissue or a brief break before continuing. While reassured by the lead researcher that they could stop the interview at any time, all caregivers wanted to continue and complete the interview. After the qualitative interview was complete, the lead researcher stopped the audio-recorder and continued to the next step of the visit.

After the interview, the lead researcher offered caregivers time to debrief from the interview and ask additional questions or share concerns (see *Appendix 9*). Typically, caregivers had questions that could be answered by reviewing the ADHD Resource Binder, which was designed for this study and included information and resources as well as provided contact information for CHOP's Center of the Management of ADHD. The ADHD Resource Binder included CHOP-approved handouts regarding childhood ADHD, treatment options, management strategies, articles, website links, and additional information regarding services and resources. In addition, our study intern (Jamil Lane) created a handout including ADHD support organizations, activities, and learning apps. See *Appendix 10* for the Table of Contents for the ADHD Resource Binder. Following, caregivers were given a hand-written thank you card and $40 Visa Gift Card for participating in the study. Caregivers were asked to complete the University of Pennsylvania C-2 Human Subject Voucher Form *(Appendix 11)*, which is a university requirement for human subject's research when they receive a subject payment. At this point, the lead researcher concluded the appointment and graciously thanked the caregivers for their participation in the study. Total appointment time from start to finish ranged 40 to 120 minutes with an average of approximately 75 minutes for session completion.

Measurements

For qualitative data collection, a semi-structured guide was used to facilitate and direct the caregiver interviews. The primary researcher conducted interviews with each caregiver participant. Qualitative interviews were between 14 minutes and 52 minutes in length across the sample of caregivers. Interviews focused on how families manage childhood ADHD using the four family management factors as a guide. Caregivers were also asked about the barriers/challenges and facilitators of ADHD management for their child and family. In addition, caregivers were asked to share any strengths about themselves, their families, and their child with ADHD. Finally, before the interviews concluded, caregivers were asked if they would like to share anything else that would be helpful for other parents of children with ADHD. See *Table 3.3* for a sample of interview guide questions. The full interview guide is available in *Appendix 12.*

Table 3.3

Sample Questions from Qualitative Semi-Structured Interview Guide

Family Management Factor	Interview Question related to Family Management Theory
Child's Daily Life	Tell me more about how your child is different or similar from other children his/her age, because of the ADHD.
Condition Management Effort	Tell me about the time and work involved in your (son or daughter's) daily ADHD care? What do you specifically have to organize?
Condition Management Ability	How have you (or haven't you) developed a routine for taking care of your child's ADHD?
View of Condition Impact	Tell me more about how you worry (or don't worry) about your child's future in relation to the ADHD condition.
Barriers/ Challenges	What are the major barriers or challenges faced by you or your family when it comes to your child's ADHD?
Facilitators/ Strengths	What are the major strengths of you and your family when it comes to managing your child's ADHD?

In this study, the main variable of interest was Caregivers' Perceptions of Children's Level of Functional Impairment and the associated variables were Family Management Factors, including *Child's Daily Life, Condition Management Effort, Condition Management Ability, and View of Condition Impact*. The Impairment Rating Scale (IRS) was used to measure caregiver perceptions of child's functional impairment. The IRS is an 8-item multidimensional scale that measures children's functional impairment across different domains, including peers, sibling, parent, academics, self-esteem, family, and global (Pelham, Fabiano, & Massetti, 2005). Each item asks the caregiver to respond on a 7-point Likert-scale ranging from "No problem" to "Extreme problem". The IRS takes about 10 minutes to complete. The IRS has shown good psychometric properties (i.e., internal consistency reliability, content and construct validity) and has empirically derived cutoff points for children ages 4 through 12. See *Table 3.4* for more information on the IRS. *Appendix 13* includes the IRS study instrument.

The Family Management Measure (FaMM) was used to measure the four family management factors hypothesized to be related to children's level of functional impairment in this study. The complete instrument has 53 items scored on a Likert-scale from 1(strongly disagree) to 5 (strongly agree). Six independent scales measure different dimensions of family management, including child's daily life, condition management effort, condition management ability, family life difficulty, view of condition impact, and parent mutuality (Knafl et al., 2011). In accordance with the study aims and hypotheses, only the scales that corresponded with the family management factors conceptualized to be most related to functioning for children with ADHD would be included in this study (i.e, child's daily life, condition management effort, condition management ability, view of condition impact). Furthermore, the FaMM does not have an overall summary score. Instead, it has a series of separate and distinct scales that each measure a different dimension of family management, which are described below.

The Child's Daily Life scale is a 5-item measure that addresses caregiver perceptions of their child and his or her everyday life. Higher scores on this scale indicate a life that is seen as more normal or usual by parents despite the condition. The Condition Management Effort scale is a 4-item measure that addresses caregiver perceptions about the time and work needed to manage the condition. Higher scores on this scale suggest that more effort is expended in managing the child's illness. The Condition Management Ability scale is a 12-item measure that addresses caregivers' perceptions of the overall manageability of the child's condition, including knowing what needs to be done to take care of the condition and a caregivers' ability to competently carry out the management of their child's condition. Higher scores on this scale suggest that the condition is viewed as more readily manageable. The View of Condition Impact scale is a 10-item measure that addresses caregivers' perceptions of the seriousness of the condition and its implications for the child's and family's future. It incorporates the degree to which caregivers worry about their child's condition. Higher scores on this scale indicate that there is greater concern about the seriousness of the condition. See *Table 3.4* for more information on the FaMM scales. *Appendix 14* includes the FaMM study instrument.

The Vanderbilt ADHD Assessment Follow-Up Scale was used to measure caregiver-reported ADHD symptom severity. ADHD symptom severity is an important child characteristic and a potential cofounding variable in the relationship between family management factors and caregivers' perception of children's level of functional impairment. The Vanderbilt scale is an 18-item Likert-measure that addresses caregivers' perceptions about key areas of inattention and hyperactivity/ impulsivity for a child with ADHD. The Vanderbilt has shown good psychometric properties (i.e., excellent internal reliability, content/construct validity) with norms based on age and gender. See *Table 3.4* for more information on the Vanderbilt scale. *Appendix 15* includes the Vanderbilt study instrument.

A Demographic Questionnaire was completed by caregiver participants in the study. Child information included: child birthdate, gender, race and ethnicity, cultural or national associations, treatment for ADHD (e.g., medications, therapy), mental health comorbidities, school type (e.g., public, private, charter), grade level, and residence type (e.g., one or two parent home). Caregiver information includes: relationship to the child, caregiver birthdate, gender, race and ethnicity, cultural or national associations, neighborhood and zip code of residence, highest level of education, and annual income. Other information included: participant ID, date, and recruitment site/type. See *Table 3.4* for more information on the Demographic Questionnaire. *Appendix 16* includes the demographic questionnaire.

See *Table 3.4* for the study measurements, their properties, variable measured, level of measurement, and data on reliability and validity.

Table 3.4

Study Instruments

Measurement	**Properties**	**Variable**	**Reliability & Validity**
Impairment Rating Scale (IRS) – Parent APPENDIX 13	This 8-item multidimensional Likert-scale measures children's functional impairment across different domains, including peers, sibling, parent, academics, self-esteem, family, and global. Each item asks the parent/guardian to respond on a 7-point scale ranging from "No problem" to "Extreme problem". The IRS-parent takes about 10 minutes to complete. For children ages 4 through 12, the IRS has shown good psychometric properties and has empirically derived cutoff points.	Caregivers' Perceptions of Children's Level of Functional Impairment *Measurement Level: Ratio*	The IRS exhibits concurrent, discriminant, and convergent validity, and acceptable levels of temporal stability. (Pelham, Fabiano, & Massetti, 2005).
Child's Daily Life (Scale of the FaMM) APPENDIX 14	This 5-item Likert-scale addresses caregiver perceptions of their child and his/her everyday life. Two items are positively scored; three are reverse coded. Higher values indicate a more normal life for the child despite the condition.	Child's Daily Life *Measurement Level: Interval*	Internal consistency .76 to .79. Test-retest reliability .83. Construct validity -.21 and .39 (Knafl et al., 2015).
Condition Management Effort (Scale of the FaMM) APPENDIX 14	This 4-item Likert-scale addresses caregiver perceptions about the time and work needed to manage the condition. Three items are positively scored; one item is reverse coded. Higher values mean more effort is expended in managing the illness.	Condition Management Effort *Measurement Level: Interval*	Internal consistency .74 to .78. Test-retest reliability .81. Construct validity 16 and -.33 (Knafl et al., 2015).
Condition Management Ability (Scale of the FaMM) APPENDIX 14	This 12-item Likert-scale addresses caregivers' perceptions of the overall manageability of the child's condition, including knowing what needs to be done to take care of the condition and their ability to competently carry out the management of their child's condition. Eight items are positively scored; four are reverse coded. Higher values mean the condition is viewed as more readily manageable.	Condition Management Ability *Measurement Level: Interval*	Internal consistency .72 to .73. Test-retest reliability .79. Construct validity -.35 and .32 (Knafl et al., 2015).

Measurement	Properties	Variable	Reliability & Validity
View of Condition Impact (Scale of the FaMM) APPENDIX 14	This 10-item Likert-scale addresses caregivers' perceptions of the seriousness of the condition and its implications for the child's and family's future. It incorporates the degree to which caregivers worry about their child's condition. Six items are positively scored; four items are reverse coded. Higher scores indicate greater concern in managing the condition.	View of Condition Impact *Measurement Level: Interval*	Internal consistency .73 to .77. Test-retest reliability .87. Construct validity .22 and -.32 (Knafl et al., 2015).
Vanderbilt ADHD Assessment Follow-Up Scale (Parent) APPENDIX 15	This 18-item Likert-scale addresses caregivers' perceptions about key areas of inattention and hyperactivity/ impulsivity for children potentially with ADHD, plus 8 additional items that evaluate learning and relationships.	Caregiver-Reported ADHD Symptom Severity *Measurement Level: Ratio*	Internal consistency .90 to .9527. Concurrent validity .7927 (Wolraich, 2003).
Demographic Questionnaire APPENDIX 16	This 2-page questionnaire has child and caregiver information, including birthdate, gender, race/ethnicity, and cultural/national associations. For child information, we asked caregivers to report on ADHD treatment type, mental health comorbidities, school grade and type, and primary residence. For caregiver information, we asked caregivers to report on relationship to child, neighborhood/zip code, educational level, and household income. Other information included participant ID#, date of appointment, and recruitment site/type.	Child Characteristics (age, gender, race/ethnicity, and mental mental co-morbidities) Caregiver Characteristics (age, gender, race/ethnicity, educational level) Environmental Characteristics (household income, neighborhood/ zipcode, school type) *Measurement Level: Mixed*	N/A

Analysis

Qualitative Analysis

To achieve the primary aim of the study, directed content analysis using the qualitative descriptive methodology (Streubert & Carpenter, 2011) was used to analyze the 50 caregiver interviews. Interviews were audiotaped by the lead researcher, and then, uploaded to a secured-server and sent to a transcription service (details about privacy and confidentiality are included in protection of human subjects section). Field notes and memos taken during or after interviews were not transcribed, but used as a reference during analysis as needed. After the interviews were transcribed, the lead researcher listened to half of the total sample of audio files (N=25) and double-checked the transcripts for accuracy. Aside from a few minor typos and errors in spelling (e.g., medication names, care provider abbreviations, such as BCS- behavior care specialist), transcripts were accurate with no major discrepancies from the audio recordings.

Once transcripts were checked for accuracy, they were uploaded into the Atlas.ti data management system via a secured-server at UPenn SON. Transcripts were coded using directed content analysis techniques (Hsieh & Shannon, 2005). While this type of content analysis starts with predetermined categories based on a theory or framework, new categories emerge as data are analyzed. Within this technique, a codebook, which was sensitized by the study framework, was created prior to coding interviews and was modified throughout the analysis based on the emerging subcategories, categories, and finally the themes. Major coding headings were the four family management factors (i.e., child's daily life, condition management effort, condition management ability, view of condition impact), and the barriers/challenges and facilitators of ADHD management. Further categories (i.e., parent mutuality, child strengths, caregiver strengths, advice/recommendations) were inductively derived as they were areas that emerged within the interviews. Then, these categories were expanded to include subcategories. When subcategories overlapped they were collapsed; when other subthemes identified they were added (Graneheim & Lundman, 2004). The senior qualitative advisor (Janet A. Deatrick) and study intern (Jamil Lane) provided input and feedback throughout this process. After multiple reiterations, the categories were collapsed into themes.

Participant transcripts were coded using the codebook prepared for this study. Coding for this study consisted of highlighting quotations taken directly from the transcript and labeling with one of the categories or sub-categories which was either existing or created based on the data. After approximately one-fourth of the transcripts were coded (N=12), the senior qualitative expert (Janet A. Deatrick) reviewed the coded transcripts directly in Atlas (using the copy/send bundle feature) and provided initial feedback to the lead researcher regarding coding patterns. Any discrepancies, errors in judgement, or systematic biases were addressed. After the first round, the lead researcher continued coding transcripts using constructive feedback from the senior qualitative expert for the reminder of the interviews. Once the entire sample of transcripts (N=50) were coded, the data output from Atlas was saved and printed per participant (i.e., the list of codes, marked quotations) to support the lead researcher in the next steps of the qualitative process. On average, it took 45 minutes to code each participant transcript (i.e., with shorter interviews taking less time, longer interviews requiring more time to complete).

At this point, qualitative case summary matrices were created to summarize the codes for each participant. An Excel spreadsheet consisted of 50 rows (one for each participant, or case) and 31 columns (representing each code, or subcategory). After approximately one-third were complete, the senior qualitative expert reviewed the spreadsheet for content and the lead researcher’s understanding of the process. Feedback and further instruction was provided by the senior advisor. In addition, emerging biases and blind spots were discussed between the lead researcher and the qualitative advisor. Approximately 40-hours later (an average of 45-50 minutes per participant), the final spreadsheet with all 50 qualitative case summaries was complete.

Next, a table was created with the broader, more abstract study themes. The senior qualitative advisor guided the lead researcher in this process and in setting up the table. In the left column, each of the categories were listed (e.g., child’s daily life, condition management effort). The other columns included the definition, a thematic description, and exemplar quotations. Creating themes was also a reiterative process with the senior qualitative advisor providing additional direction and guidance for completing the table. Themes were robust and rich in detail to provide the readers with a vivid description of family management factors, barriers, and facilitators associated with ADHD management. Within the quotations section, the lead researcher intentionally included quotations from a variety of sources to provide thoughtful insight and reflection on the lives of caregivers and children with ADHD. Definitions, thematic descriptions, and quotations are presented in the results section of this paper.

Quantitative Analysis

To achieve the secondary quantitative aim, descriptive statistics (Allison, 1999) and inferential statistics (Moore, McCabe, & Craig, 2009) were used to analyze the quantitative data. To our knowledge, no previous studies have used the family management measure to quantitatively understand the impact of family management on functional impairment in a sample of children with ADHD. Being so, the goals of this research were to describe the sample of child and caregiver participants and to provide basic information about family management and the relationships between the four family management factors and the main variable of interest (i.e., childhood functional impairment). In addition, the study team could compare these descriptive statistics to other studies using the family management measure in other populations (e.g., pediatric brain tumor survivors, general childhood chronic illness).

Data collected from quantitative measures were entered into the REDCAP system. The study was created in REDCAP by the lead researcher with assistance provided by the BECCA lab at the University of Pennsylvania. Within REDCAP, all fields were created and checked by J. Rhodes, including the scoring equations for the FaMM scales. The final project was approved and launched by statistician, Jesse Chittams. Data were entered by the lead researcher throughout data collection. Any problems or concerns that arose with data entry were brought to the attention of the statistical support team and resolved promptly. Data entries were double-checked by the study intern (Jamil Lane) and the lead researcher (Cynthia P. Paidipati) throughout data collection. Discrepancies in the data entry system were changed immediately. In addition to this, a few participants (N=3, or 6%) completed the questionnaires with multiple or double responses. In cases, such as these, the lead researcher consulted with the statistical team and made decisions together on how to address these issues. For each incident, a memo was created detailing this process and saved as a study file on the secured-research drive.

After all the data were entered and double-checked in REDCAP, the data were exported from REDCAP to the statistical software chosen for this study (Stata13). The data set was also saved as an Excel file. In the data cleaning and preparation processes, two issues had to be resolved. First, caregiver and child birthdates were used to calculate participants' ages. Second, the Impairment Rating Scale (IRS) contained a question regarding siblings and for children who did not have siblings (N=9), the item was left blank, which created missing data in the final dataset. As a proposed solution, the consulting statistician (J. Chittams) and lead researcher made the decision to code these missing values with a "0" value as we made the assumption that no impairment could occur if the sibling relationship did not exist. This decision would not affect the total IRS score (which was the outcome variable), but the values are potentially lower.

Descriptive statistics were used to describe the demographic variables and the data from the study instruments within the sample. Measures of central tendency (i.e, means, standard deviations, and ranges) were reported for continuous variables and frequencies and percentages for categorical variables. For the Vanderbilt instrument, total

ADHD symptom severity scores were reported. In addition, total Vanderbilt scores were separated into 3 different categories (i.e., mild, moderate, severe) to represent different levels of ADHD symptom severity. Total ADHD symptom scores were calculated as the following: 0-18 (mild symptom severity); scores of 19-36 (moderate symptom severity); and scores of 37-54 (severe symptom severity). Frequencies and percentages were reported for each symptom severity category. For the FaMM scales, measures of central tendency were reported for each separate scale. For the IRS, means, standard errors, ranges, and confidence intervals were computed for each of the 7 Likert-items, and frequencies were computed for dichotomous (yes/no) question on the IRS (e.g., does the child have a best friend). Total IRS summary scores (the main variable for this study) were also calculated along with measures of central tendency. Cronbach's α is also reported for the instruments used in this study to substantiate reliability of the measures in the study sample.

Inferential statistics were used to analyze the relationships between the four family management factors and the main variable of interest (i.e., functional impairment) as measured by the total summary score on the IRS. Bivariate correlations between ADHD symptom severity and functional impairment scores were examined as well as the correlations between the four family management factors (i.e., child's daily life, condition management effort, condition management ability, and view of condition impact) and caregivers' perceptions of children's level of functional impairment. To answer the secondary aim of this study, we hypothesized: 1.) Higher scores for child's daily life (higher scores more positive) and condition management ability (higher scores more positive) would be correlated with lower levels of children's functional impairment, and 2.) Higher scores for condition management effort (higher scores more negative) and view of condition impact (higher scores more negative) would be correlated with higher levels of children's functional impairment.

It is important to note that correlation does not equal causation. Because our sample size was too small to create predictor models with adequate power, the consulting statistician and lead researcher agreed upon correlational analyses to obtain preliminary information on the impact of each family management factor on the main variable of interest. These correlations may be used by future researchers to calculate effect size estimates, which in turn, may be used to power a larger study on family management for children with ADHD. We also examined the mean score values for the FaMM to see if our results were similar to other studies that have used the family management measure to understand child outcomes in samples of young people with chronic medical illness (Deatrick et al., 2014; Knafl et al., 2015; Knafl et al., 2013).

Mixed Methods Analysis

After each data set was independently analyzed, qualitative and quantitative data were integrated and transformed into qualitative definitions and themes. Using an analytic matrix to explicate definitions and themes as well as exemplar quotations, each family management factor was expanded further to capture children and families at higher and lower levels of functional impairment. For the quantitative data, IRS summary scores were split into two categories (by the median of the total distribution of scores) with the bottom half of the scores 4-20 (indicating lower functional impairment, or high function), and the top half of the scores 21-36 (indicating higher functional impairment, or low function). Participants were placed into higher and lower categories based on these scores and placed into an analytic matrix using participant ID numbers. Case summaries that were prepared for each case (family) on a spread sheet not only facilitated recognition of themes in qualitative analyses but were also used in this mixed methods analysis to identify themes for children at high and low function. The senior mixed methods expert (Janet A. Deatrick) guided and advised the data integration process for this study. See *Figure 3.5* for the data integration template for each of the family management factors at higher and lower levels of functional impairment for children with ADHD.

Figure 3.5

Mixed Methods Analytic Grid for Family Management ADHD Study

	Child's Daily Life	Condition Management Effort	Condition Management Ability	View of Condition Impact
Higher Function (n=x)	Description	Description	Description	Description
Lower Function (n=x)	Description	Description	Description	Description

Using a mixed methods approach enhanced the validity of the findings from both methodological approaches (QUAL and quan) and provided explanatory data that were used in the interpretation of quantitative results and to increase the trustworthiness and scientific adequacy within the study (Creswell & Plano Clark, 2011). By integrating and transforming the data from each method, we could qualitatively assess and examine the families that fell quantitatively within categories of higher and lower levels of functional impairment. This data transformation was not only informative, but also complementary. Relationships in the quantitative data could be explained with the qualitative data by evaluating the thematic descriptions on the matrix. Both expected and unexpected outcomes between the family management factors and impairment rating scores (from the quantitative analyses) could be illustrated and explained also by examining the thematic descriptions within the mixed methods analytic matrices.

Expected Outcomes

The qualitative findings of this study were expected to add richness, complexity, and depth to family management factors within the context of childhood ADHD and highlight key barriers and facilitators associated with family management in a diverse sample from the city of Philadelphia. Based on previous studies and the theoretical underpinnings of this study (Knafl et al., 2013; Knafl et al., 2011; Deatrick et al., 2014), hypotheses for the quantitative aim were set-forth a priori and used to guide the data analysis. Mixed method findings were expected to produce a detailed matrix of how caregivers of children at higher and lower levels of functional impairment perceive their child's daily life, condition management ability, condition management effort, and view of condition impact in respect to ADHD.

Ensuring Quality and Rigor

The overall study was designed to ensure the trustworthiness and scientific adequacy of the data and reflect the rigor of a mixed methods approach. This study used conceptual frameworks from previous caregiver studies of childhood chronic illness to advance the science and guide the conduct of the study (Knafl et al., 2011; Knafl, Deatrick, & Havill, 2012; Knafl et al., 2013; Barakat, 2008; Deatrick et al., 2014). By using both qualitative and quantitative data, the final data set provided a comprehensive picture of family management for ethnically diverse children with ADHD. Data integration at the level of analysis also expanded the depth and breadth of these findings.

In the naturalistic or qualitative paradigm, establishing and evaluating trustworthiness of a research study entails four components: credibility, transferability, dependability, and confirmability (Guba, 1981). In this study, credibility was enhanced by the comprehensive and systematic data analysis under the mentorship of a qualitative expert. Developing robust themes using detailed quotations from participant interviews added to the transferability of the study results. Dependability was established by leaving an audit trail of interview transcriptions, field notes, and memos, reflecting the analytical process of the researcher along the way. Confirmability was created as the primary investigator engaged in an ongoing dialogue and communication with the senior mentors of the project by identifying biases, challenging assumptions, and discerning flaws in the data collection and analytic process. Critical interpretation of the raw data, methodology, and study design was pursued by the lead researcher and primary mentors throughout the research process to increase the rigor of the study (Whittemore, Chase, & Mandle, 2001).

Protection of Human Subjects

Risks to Human Subjects and Adequacy of Protection Against Risks

Caregivers of children with ADHD, especially those from diverse families, are considered an at-risk population due to social, political, and economic influences that may intersect with their role as parents and caregivers for their child with ADHD. Caregivers recruited for this study may have had previous negative experiences with health-related research or awareness of current or past abuses in medical research within diverse populations. Being so, it was very important to the lead researcher to protect the rights, welfare, and autonomy of caregivers and children, who were interested and/or participated in this study. In response, the research team applied principals of risk/benefit, informed consent, safety, and privacy/confidentiality rigorously throughout the study to protect participants from undue harm or exploitation from medical research.

Caregiver participants were informed about the potential inconveniences or risks of the study, including (a) time taken away from work or home to participate in the study; (b) emotional or psychological stress related to the research topic; and (c) unintended messages that caregivers and families are to blame for their child's condition or behavioral problems. Caregivers were also informed that any suspected child abuse or neglect would be reported to the authorities, in accordance with state law. In addition, caregivers were informed that any concerns for safety (i.e., suicidality, family violence) would be addressed by the research team (see below).

Measures taken to decrease these risks or disadvantages included, (a) reasonable, but non-coercive, compensation for their time away from work and/or family to participate in the research study; (b) time after the interview to debrief with the researcher with additional information and resources given to families about ADHD; and (c) the lead investigator clearly communicated to caregiver participants their children and families are valued by the research team, and we are conducting this study from a strengths-based perspective regarding families.

In addition, caregivers of children with ADHD, especially from diverse families, were assumed to experience structural, geographic, and socio-economic barriers that impede their ability to access and utilize appropriate and adequate care and treatment for their child. This study brought to light these inequities in health and health care and enhanced the individual and collective consciousness in the room regarding these systemic and structural inequities. In response to this, the lead researcher validated and supported caregiver experiences during the interviews. In addition, the lead researcher spent time after the interviews briefing and answering any additional questions or concerns from the caregivers. Furthermore, the ADHD Resource Binder with information, resources, and important contact information was provided to all caregiver participants as a potential bridge to narrow these gaps in information, communication, and services regarding care and treatment for childhood ADHD. Throughout the study, caregivers stated this resource binder was incredibly valuable to them and greatly appreciated. Some caregivers (from high to low income and educational levels) explicitly pointed out that the binder was more cherished than the $40 gift cards.

Undue influence, especially with diverse populations, was a concern when recruiting participants for health-related research. Offering financial incentives may have been viewed as an undue influence, however our research team aimed to strike a balance between recruiting diverse caregivers and incentivizing participation in this study. We decided $40 was a reasonable amount to compensate participants for their involvement in the study, as it would potentially cover transportation and the time away from work or home to complete study questionnaires and interviews. Also, the lead investigator received feedback from the recruitment sites that a Visa Gift Card is the best option for compensation for caregivers as the gift cards are practical, convenient, and can be used anywhere, which was presumed to be very helpful and appreciated by families of children with ADHD. Throughout the study, caregivers readily accepted the gift cards and expressed appreciation for them.

Another way to address possible undue influence was to provide ample time and opportunity for participant decision-making. All participants were involved in the informed consent process with the lead researcher from the first contact. Recruitment emails sent to potential participants included an opt-out option, which allowed families to opt-out of the research from the start, if they chose to do so. For the caregivers who were interested, they could call or email the lead researcher to obtain more information about the study prior to engaging in the eligibility screen. During the eligibility screen, the lead researcher allowed another opportunity for caregivers to opt-in or opt-out of the study. If caregivers were still interested, then an in-person appointment was arranged. From the date of eligibly screen to the interview date, caregivers were also given the opportunity to call or email the lead researcher with any further questions or concerns about the study. At the beginning of the in-person visit, caregivers were informed of the study purpose, description, risks, benefits, compensation, and opt-out option (using the informed consent form as a structured guide). Caregivers were notified of the voluntary nature of the study and that they could withdraw from the study at any time without negative consequences to their child's care. After the informed consent document was thoroughly reviewed, caregivers could ask additional questions or express concerns. Once the lead researcher sufficiently answered these questions or concerns, then both parties signed the informed consent form. At this moment, caregivers were considered enrolled in the study. Because the length from initial contact (i.e., the recruitment email or seeing a flyer) to the point of study enrollment (i.e., the in-person appointment) was often days to weeks or even months, caregivers were given ample time and multiple opportunities to opt-in or opt-out of the study, therefore, reducing the risk of coercion. In addition, there was more interest in the study than predicted, which also reduced the risk for coercion as the research team did not feel immense pressure to recruit participants who were not completely interested or invested in the study.

Informed Consent and HIPAA Authorization

Written consent and HIPAA authorization was obtained from subjects screened in person. A waiver of documentation of consent and an alteration of HIPAA to obtain verbal consent and HIPAA authorization was requested for subjects screened over the phone. CHOP IRB approved this as it would be impracticable to conduct the research obtaining verbal HIPAA authorization for the phone questionnaire (i.e., as the research team would not meet with participants until the in-person interview). A waiver of assent was approved for child subjects as they were not available during the screening phone call. For the main study procedures, written consent and HIPAA authorization was obtained from all participants. A waiver of assent was approved for child subjects as their participation was not required for the research (parents answer questions about their child). All subjects received a copy of the informed consent document for their records. The lead investigator maintained copies of all study informed consent documents on file.

Safety Considerations

Safety for the caregiver and child were considered throughout the duration of the study. Since the study procedures were not greater than minimal risk, serious adverse events were not expected. However, if any unanticipated problems related to the research involving risks to participants or others happened during the study, these would have been reported to the IRB in accordance with CHOP IRB SOP 408: Unanticipated Problems Involving Risks to Subjects. We do not have any clinical adverse events or serious adverse events to report from this study.

For medical or psychiatric emergencies, plans or procedures for handling medical or psychiatric emergencies that might occur during the research study were detailed in the IRB protocol for this study. None of the study instruments directly ask caregivers about thoughts of self-harm or suicide for themselves or their child. However, if at any time during the research, the caregiver expressed suicidal thinking or behavior regarding themselves or their child, action would be taken immediately by the lead investigator. For suspected suicidal ideation, behavior, attempt, or any other concerns for self-harm for the caregiver or their child, the lead investigator would complete a suicide risk assessment using the C-SSRS (Columbia Suicide Severity Rating Scale). See *Appendix 18* for the C-SSRS suicide risk assessment form. The lead investigator is a clinically-trained psychiatric-mental health nurse practitioner with experience in managing suicide risk in children and adults. The lead investigator would follow the C-SSRS form to gather additional information about suicidal ideation, intent, method, plan, and/or previous or current attempts. After the suicide risk assessment is completed, the lead investigator would contact the Principal Investigator of the study, Ricardo Eiraldi, CHOP Clinical Psychologist and Researcher, to develop a safety plan for the caregiver or the child. Included in this safety plan would be the Contact Information for the National Suicide Hotline # 1-215-686-4420, CHOP Psychiatry On-Call Service #215-590-1000 (for the child), and HUP Emergency Room # 215-662-4000 (for the caregiver). For a child with suicide risk, the lead investigator would also contact the child's primary care or mental health provider to discuss the suicide safety plan and recommendations.

For high risk of self-harm, such as suicidal ideation with method/plan and intent, the lead investigator would contact 911 and send the caregiver to the Hospital of the University of Pennsylvania (HUP) emergency department or the nearest emergency room for evaluation. For minors under the age of 18, the lead investigator would call 911 and send the child to CHOP's emergency department or nearest emergency room for evaluation. Within 24 hours of the incident, the lead investigator would document the suicide risk assessment and the safety plan and review the process with the Principal Investigator (i.e., Ricardo Eiraldi). We have no incidents of caregiver or child current suicidal ideation or behaviors to report for this study.

For suspected child abuse or neglect, the lead investigator was mandated to report the abuse to the Pennsylvania Department of Human Services at 1-800-932-0313. In this instance, the lead investigator would consult with CHOP Social Work to report the abuse according to CHOP's policy on Suspected Child Abuse or Neglect for Patients seen in

Pennsylvania and procedure on How to Report Suspected Child Abuse or Neglect for Patients seen in Pennsylvania. If the child was injured or in immediate danger, the lead investigator would call 911 and instruct the caregiver/family to take the child to the CHOP emergency room or the nearest emergency room. For suspected family violence without specific concern for child abuse or neglect, the lead investigator would encourage the caregiver or family member to call the Philadelphia Domestic Violence Hotline at 1-866-SAFE-014. If the caregiver or other family member was injured or in immediate danger, the lead investigator would call 911, and instruct the caregiver/family member to go to the nearest emergency department for assessment, evaluation, and treatment, if indicated. We have no incidents of child abuse or neglect or family violence to report for this study.

Confidentiality, Privacy, and Data Security

To begin, confidentiality and privacy was prioritized during recruitment as the CHOP Recruitment Enhancement Core (REC) was the responsible entity for initially sending out emails to parents and caregivers of children with ADHD who fit our eligibility criteria. For confidentiality and privacy purposes, the study team did not have access to email addresses unless caregivers reached out to the lead researcher via CHOP-secured email after the initial contact by the REC. Privacy and confidentiality were also maintained during telephone encounters by speaking in private spaces and not repeating information aloud when others were around. Information from telephone encounters was recorded on the eligibility screen form and stored in a locked file cabinet within the lead researcher’s office at UPenn SON, which was locked when not in use. Email addresses were stored on the CHOP-secured email server, which is password protected. Phone numbers were recorded on the eligibility screen form, which was stored in a locked file cabinet within a locked office at UPenn SON, as mentioned above. During in-person visits, confidentiality and privacy were maintained by conducting survey/questionnaire completion and interviews with caregivers and families in a private space at 3440 Market Street, Suite 410. Doors were always closed during these visits to secure participant privacy and caregiver confidentiality.

As interested caregivers contacted the study team, completed the eligibility screen, and agreed to set-up appointment, the lead researcher assigned a unique identification number (ID #) to each potential participant. This unique ID # replaced names to protect the confidentiality and privacy of families and was included as the key identifier within a master list of participants. This list, encrypted and password protected, was maintained and stored on the secured research drive at UPenn SON. The ID # was used to code all study instruments, documents, and forms. Paper files for each participant were stored in an envelope with this unique participant ID # written on the outside in black and bold ink. When data were transferred to the REDCAP system, this ID # was used as the primary identifier during data entry. This ID # was also used to track audio files and transcripts from qualitative interviews. For an extra layer of protection, caregivers were asked to create pseudonyms for their child and other family members to be used during interviews to protect their identities.

As mentioned above, paper files of the study instruments, consent forms, documents, and field notes were kept in marked participant envelopes within a locked file cabinet in a locked office at the UPenn SON. Qualitative interviews were recorded and stored on an audio recorder and transferred to a secured server at UPenn SON. The UPenn SON secured server (i.e., the research drive) met the CHOP IT standards for encryption and password protection, which was a CHOP IRB requirement. For this study, data breaches were most susceptible to risk during transport from the primary data collection site to the lead researcher's office at UPenn SON. To reduce this risk, the audio recorder and envelopes (containing study documents and participant information) were placed in a locked box/bag under the direct and constant supervision of the lead researcher during transport. No breaches of data security were reported for this study.

Audio files and transcriptions from interviews were sent back and forth to and from a transcription service frequently used by UPenn SON (Transcribing4You by Charlene J. Sullivan) using a secure file transfer site. A business associate agreement was in place between the lead researcher of the study and the transcription service to cover services rendered. Final transcripts of the interviews did not contain names of children, caregivers, or families. Identifying information that may have been included on audio files (e.g., specific names of health or education providers) were also eliminated from typed transcripts. Audio files will be deleted after the study is complete and the final dissertation is successfully deposited with the University.

Finally, all data and records generated during the study were kept confidential in accordance with CHOP and UPenn Institutional policies and HIPAA on subject privacy. The study team also did not use such data and records for any purposes other than conducting the study.

In addition, no identifiable data will be used for future study without first obtaining IRB approval.

Potential Benefits of the Proposed Research to Human Subjects and Others

At the outset of the study, participants were not likely to obtain a direct benefit from this research. However, medical directors at the recruitment sites recommended providing caregivers with a binder of information and resources as part of the study procedures. This was presumed to provide an added benefit to caregivers and families who are managing a child with ADHD and who took the time and energy to participate in this study. On the other hand, participation in this study would also provide an opportunity for caregivers to reflect on their family and child's story and their experiences with caring for a child with ADHD. This reflection would potentially deepen caregivers' level of insight and understanding into their own experiences and family's life, which could be considered an intellectual or emotional benefit for participating in this study. While some caregivers found participation in the study or responding to specific interview or questionnaire questions emotional at times, the degree of stress was minimal. Even caregivers who expressed emotion during the interview process stated their appreciation and happiness to participate in the study. Some caregivers found the overall experience a mental and emotional release in a safe and secure place. This is consistent with researchers doing similar work who have reported that participants are more likely to find their involvement in research meaningful and express gratitude for the opportunity to share their views and stories in a research study that includes their child and family's experiences.

This study also offers benefit to others. In this research, we gained a more complete understanding of the array of issues that shape caregiver experiences for families of children with ADHD. This project elicited themes surrounding caregiver experiences, including the barriers and facilitators for ADHD management within the family, and how these relate to children's level of functional impairment. Previous studies have explored family management within the context of general childhood chronic illness or primarily with a single method of research (i.e. qualitative, quantitative) in the ADHD literature. This study developed a deeper understanding of family management for children with ADHD living in the city Philadelphia using both methods. In addition, family management has been a concept theoretically applied to caregivers of children with chronic illness, but not necessarily in the context of children with ADHD and from a diversity perspective. Generating this knowledge about the unique experiences of diverse caregivers helps to better understand the intersection between childhood ADHD, family management, and health care diversity. For future researchers and clinicians, who hope to develop or adapt family-based interventions for diverse populations, the findings from this study may benefit communities of children with ADHD and their families.

Risk Benefit Assessment

The anticipated risks of the study were minimal and did not outweigh the potential benefits for participants and future children with ADHD and their families. It was, therefore, held the risks to participants was reasonable in relation to the anticipated benefits of the study.

Payment to Participants

Each caregiver participant who completed the study received a $40 Visa Gift Card for their time, effort, and investment in this study. We understood that caregivers of children with ADHD have competing responsibilities, including work, family, and other obligations, and may travel a considerable distance within the city to reach the interview site. The research team offered this compensation as a token of our appreciation, gratitude, and thankfulness for the caregivers of children with ADHD living in the city of Philadelphia. A thank you card for participating in the study and a binder of information and resources for ADHD was also given to caregiver participants at the time of study completion.

Inclusion of Women and Minorities

One goal of this study was to include caregivers of children with ADHD from diverse cultural, socioeconomic, and geographic backgrounds within the city of Philadelphia. By study definition, caregivers assumed a profile of: (a) residing at least 50% of the time in the same household as the child and (b) viewing him or herself as assuming major responsibility for the child's care. Self-identified women continue to play a major role in childrearing and bear a large share of caregiving responsibilities for children with ADHD. Even in multiple-partner households, female caregivers often lead management efforts for chronic conditions, such as ADHD. As expected, a high proportion of women (98%) participated in this study as the primary caregiver for their child. Male primary caregivers (2%) were not excluded, however, as the perspectives of both genders were equally important for a study about families and caregiving.

Secondary caregivers were a mix of females (e.g., grandmothers) and males (e.g., fathers) and were welcomed to participate in the qualitative interview portion of the study.

Another goal was to recruit caregivers and children who reflect a diversity of families in Philadelphia with regards to age, gender, race and ethnicity, cultural associations, relationship to child, income, caregiver educational level, child's school type, and neighborhood/zip-code. Our hope was to gain a deeper understanding and cultural perspective from different families living all over the city. This included caregivers and children from minority populations. Minorities were defined by the National Institutes of Health (2001) as any person who self-identifies with an ethnic background including: Hispanic or Latino and/or a racial background including: American Indian or Alaska Native, Asian, Black or African American, or Native Hawaiian or other Pacific Islander. Non-minorities were also included in this study as the research team led with a principle of inclusion verses exclusion. These included any person who self-identified with an ethnic background of Non-Hispanic or Non-Latino and/or a racial background of White. See *Appendix 19* for NIH-definitions for race and ethnicity. In addition to racial and ethnic self-identification, caregivers were also able to select additional cultural or national associations (e.g., Italian, Jewish, Puerto-Rican) on the demographic questionnaire, which allowed further exploratory insight into cultural perspectives. By intentionally recruiting caregivers from diverse racial and ethnic backgrounds, this study provided a rich and inclusive understanding of how caregivers approach ADHD management for their children and families.

To summarize, this mixed methods study aimed to explore family management from a diverse sample of caregivers and children with ADHD from a large urban northwestern city. We used a conceptual model, including child, caregiver, and environmental influences, derived from the family management styles theoretical framework (Knafl, Deatrick, & Havill, 2012) to understand the relationship between family management and child functioning. Valid and reliable instruments were used to measure children's level of functional impairment (i.e., main variable of interest) and family management factors (i.e., child's daily life, condition management effort, condition management ability, view of condition impact). Participants were recruited from a large academic medical institution in the northwest using innovative strategies. Rigorous qualitative, quantitative, and mixed methods were used to analyze the data. The study was approved by Institutional Review Boards with adequate considerations and protections for human subjects' research with children, caregivers, and families.

Chapter 4: Results

The purpose of this chapter is to report the results of this dissertation study. We begin with the demographics of the sample, followed by qualitative results, then, quantitative results, and mixed methods results concluding with a summarizing paragraph.

Sample Demographics

For this research, we intended to describe the sample of child and caregiver participants as well as environmental influences included in our conceptual model. See *Table 4.1* for the sample demographics.

Table 4.1

Sample Demographics for the Family Management ADHD Study

Variable	**Caregiver (N=50)**	**Child (N=50)**
Age		
Mean	37.54 (SD=1.18)	8.96 (SD=.33)
Range	24-61 years	5-12 years
Gender		
Female	49 (98%)	12 (24%)
Male	1 (2%)	38 (76%)
Race		
African-American/Black	29 (58%)	28 (56%)
White	16 (32%)	13 (26%)
Asian	4 (8%)	1 (2%)
Multi-Racial	1 (2%)	8 (16%)
Ethnicity		
Latino/Hispanic	3 (6%)	4 (8%)
Non-Latino/Hispanic	47 (94%)	46 (92%)

Variable	Caregiver (N=50)	Child (N=50)
Cultural or National Associations		
Chinese	3 (6%)	3 (6%)
Indian	2 (4%)	1 (2%)
Irish	7 (14%)	6 (12%)
Italian	6 (12%)	4 (8%)
Jewish	2 (4%)	2 (4%)
Polish	2 (4%)	2 (4%)
Puerto Rican	2 (4%)	2 (4%)
Other	4 (8%)	3 (6%)
ADHD Symptom Severity		
Mild		9 (18%)
Moderate		26 (52%)
Severe		15 (30%)
ADHD Treatment Type*		
Medications		36 (72%)
Therapy		24 (48%)
Mental Health Co-morbidities*		
Depression		5 (10%)
Anxiety		8 (16%)
ODD (Oppositional Defiant Disorder)		12 (24%)
Conduct		3 (6%)
ASD (Autism Spectrum Disorder)		6 (12%)
Other		4 (8%)
School Grade		
Pre-K		1 (2%)
Kindergarten		7 (14%)
1st grade		4 (8%)
2nd grade		8 (16%)
3rd grade		5 (10%)
4th grade		4 (8%)
5th grade		9 (18%)
6th grade		7 (14%)
7th grade		5 (10%)
School Type		
Public		22 (44%)
Private		6 (12%)
Charter		19 (38%)
Other		3 (6%)

*Note: Caregivers were able to select more than one option for these items.

Variable	**Caregiver (N=50)**	**Child (N=50)**
Relationship to Child*		
Biological Mother	43 (86%)	
Adoptive Mother	2 (4%)	
Grandmother	2 (4%)	
Biological Father	1 (2%)	
Legal Guardian	3 (6%)	
Other	1 (2%)	
Residence Type*		
Single Parent	24 (48%)	
Two Parent	24 (48%)	
Other	3 (6%)	
Highest Educational Level*		
High School	13 (26%)	
Technical/Vocational School	3 (6%)	
College	14 (28%)	
Graduate	17 (34%)	
Other	6 (12%)	
Annual Household Income		
Up to $10,000	5 (10%)	
$10,001- $20,000	5 (10%)	
$20,001- $30,000	2 (4%)	
$30,001- $40,000	9 (18%)	
$40,001- $50,000	6 (12%)	
$50,001- $60,000	2 (4%)	
$60,001- $70,000	2 (4%)	
$70,001- $80,000	3 (6%)	
$80,001- $90,000	5 (10%)	
$90,001- $100,000	3 (6%)	
$100,001 and over	8 (16%)	

*Note: Caregivers were able to select more than one option for these items.

Variable	Caregiver (N=50)	Child (N=50)
Neighborhood		
Bella Vista	2 (4%)	
Bridesburg	1 (2%)	
East Falls	2 (4%)	
East Oak Lane	1 (2%)	
Eastwick Section	1 (2%)	
Germantown	3 (6%)	
Germantown/Mt Airy Border	1 (2%)	
Lawncrest	2 (4%)	
Mayfair	1 (2%)	
Mount Airy	3 (6%)	
North Philadelphia	1 (2%)	
Northeast/Franklin Mills area	1 (2%)	
Northwood	1 (2%)	
Pennsport/South Philly	1 (2%)	
Pennypack/Northeast	1 (2%)	
Queen’s Village	1 (2%)	
Roxborough	4 (8%)	
South Philadelphia	12 (24%)	
Southwest Philadelphia	2 (4%)	
Southwest/Eastwick	1 (2%)	
Washington Square West	1 (2%)	
West Philadelphia	7 (14%)	
Zipcode		
19119	3 (6%)	
19120	2 (4%)	
19121	1 (2%)	
19124	1 (2%)	
19126	1 (2%)	
19128	4 (8%)	
19129	1 (2%)	
19131	1 (2%)	
19136	1 (2%)	
19137	1 (2%)	
19139	3 (6%)	
19140	1 (2%)	
19143	5 (10%)	
19144	4 (8%)	
19145	3 (6%)	
19146	5 (10%)	

Variable	**Caregiver (N=50)**	**Child (N=50)**
Zipcode (continued)		
19147	5 (10%)	
19148	4 (8%)	
19152	1 (2%)	
19153	2 (4%)	
19154	1 (2%)	
Recruitment Type		
Recruitment Enhancement Core	46 (92%)	
Flyers	4 (8%)	

Within this dissertation study, children were between the ages of 5 and 12 years with a mean age of 8.96 (SD = .33). Seventy six percent (N=36) of the children were identified by their caregivers as male and 24% (N=12) were female which is was consistent with population studies that show boys are two to three times more likely than girls to be diagnosed with ADHD (Coles, Slavec, Bernstein, & Baroni, 2012). In regards to race and ethnicity, 56% (N=28) of the children were identified by their caregivers as African-American or Black, 26% (N=13) as White, 2% (N=1) Asian, 16% (N=8) as Multi-Racial, and 8% (N=4) as Latino/Hispanic. When asked about their child's cultural or national associations, caregivers checked off the boxes for Chinese (6%), Indian (2%), Irish (12%), Italian (8%), Jewish (4%), Polish (4%), Puerto Rican (4%), and Other (6%; i.e., Ecuadorian, Greek, Peruvian).

In this sample, 18% (N=9) of the children had mild ADHD symptom severity (scores of 0-18), 52% (N=26) had moderate symptom severity (scores of 19-36), and 30% (N=15) had severe ADHD symptom severity (scores of 37-54) as rated on the Vanderbilt ADHD scale. In regards to treatment for ADHD, caregivers could select more than one treatment option (e.g., medications, therapy). In this study, 72% (N=36) of the children were taking medications whereas only 48% (N=24) were in therapy. In addition, over 75% of caregivers reported a mental health comorbidity for their child. Caregivers reported that children had many issues of concern, including depression (10%), anxiety (16%), oppositional defiant disorder (ODD; 24%), autism spectrum disorder (ASD; 12%) and other (8%; e.g., PTSD, phonics reading disorder, medical trauma). Additionally, children attended school grades Pre-Kindergarten through 7th grade. The spread was evenly distributed with 50% of the sample between Pre-K and 3rd grade and 50% between 4th and 7th grades. Children were enrolled in a variety of school types, including public 44% (N=22), private 12% (N=6), charter 38% (N=19), or other 6% (N=3; i.e., Catholic, developmental, behavioral schools).

The age of caregivers in this study ranged between 24 and 61 years with a mean age of 37.54 (SD =1.18). Primary caregivers were predominantly female 98% (N=49) and only 2% (N=1) self-identified as male. In terms of race and ethnicity, caregivers self-identified as African-American or Black 58% (N=29), White 32% (N=16), Asian 8% (N=4), Multi-Racial 2% (N=1), and/or Latino/Hispanic 6% (N=3). When asked about cultural or national associations, caregivers identified as Chinese (6%), Indian (4%), Irish (14%), Italian (12%), Jewish (4%), Polish (4%), Puerto Rican (4%), and Other (8%; i.e., German, Greek, Peruvian).

Caregivers endorsed diverse family structures when asked how they were related to the child with ADHD, including the child’s biological mother 86% (N=43), adoptive mother 4% (N=2), grandmother 4% (N=2), biological father 2% (N=1), legal guardian

6% (N=3), or step-mother 2% (N=1). Caregivers who reported their child's primary residence type included: 48% (N=24) as single-parent homes; 48% (N=24) as two-parent home; and, 6% as other (N=3; i.e., living with grandmother, significant other, child's visiting father). In regards to highest education level, caregivers reported 26% (N=13) high school; 6% (N=3) technical or vocational school; 34% (N=17) college degree; 28% (N=14) graduate education, and 12% other (N=6; i.e., college, a bachelor of fine arts, business school, a nursing diploma). Total annual household income ranged between 0-$10,000 to over $100,000 for the caregivers and families within this sample. The mean income was $60,000, and over half of the sample (54%) had annual income levels less than $50,000.

In regards to geographic location, caregivers and children resided in 21 different zipcodes and approximately 22 neighborhoods within the city of Philadelphia. When comparing these to a map of city zipcodes (*Appendix 20),* children and families in this sample primarily lived in South Philadelphia, followed by West Philadelphia, and then, North Philadelphia. Finally, within this study, the majority of participants 92% (N=46) were recruited by the Recruitment Enhancement Core (REC) and only 8% (N=4) were recruited by flyers.

Qualitative Results

Specific Aim 1 was to qualitatively examine via in-person interviews (using family management as a guide) how ethnically diverse caregivers manage ADHD in their everyday lives and to understand the barriers and facilitators of family management for their child's ADHD. As detailed in the methods chapter, we used qualitative case summaries to identify themes and patterns within the data for the 50 caregiver participants. We created a table that illustrated each of the major headings, including the child's daily life, condition management effort, condition management ability, view of condition impact, parent mutuality, barriers/challenges, facilitators, child and caregiver strengths, and advice or recommendations. Within this table, the definition, thematic description, and exemplar quotations were completed for each heading. Family management definitions were derived from the chronic conditions literature (Knafl et al., 2011; Knafl, Deatrick, & Havill, 2012; Knafl et al., 2015). Themes were described to provide the readers with a vivid description of the challenges and strengths faced by the caregivers and families within this study by including robust and rich details. Quotations were intentionally chosen to represent different areas within the theme and provided thoughtful insights and reflections on the lives of caregivers and children with ADHD. *Appendix 21* includes an expanded list of quotations from qualitative interviews for reference. See *Table 4.2* for the definitions from the literature on chronic conditions and the thematic descriptions and exemplar quotations derived from the qualitative data.

Table 4.2

Qualitative Themes within Family Management for Children with ADHD

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD- Qualitative Data	Exemplar Quotations
Child's Daily Life Caregivers' perceptions of their child's everyday life; Explores child identity and how parents view their child with ADHD and the extent to which those views focus on	Caregivers see differences in their child due to ADHD and other mental-health comorbidities yet view their child as overall very similar to other children their age in ways that are important to them. Caregivers recognize and accept ADHD as a real phenomenon, but still hold their	*"He's different in a lot of ways, but to me, I'm looking at this normal kid."* *"I don't make excuses for him because he has a*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD-Qualitative Data	Exemplar Quotations
ADHD and vulnerabilities or normalcy and capabilities. More positive views indicate that a child has a more normal life despite the ADHD.	children responsible and accountable for their actions and behaviors. At times, it can be challenging to distinguish which behaviors are from their child's ADHD and which are typical childhood behavior. Caregivers, however, tend to normalize ADHD within the context of their everyday lives and focus on their children's strengths and capabilities.	*condition. But I still recognize that he has one."* *"Like you're trying to figure out what is six-year old behavior and what's the ADHD."* *"He's still a kid at the end of the day."*
Condition Management Effort Caregivers' perceptions about the work, demand, and time needed to manage their child's ADHD. More negative views of the ease or difficulty indicate more effort is expended in managing their child's ADHD.	Caregivers are forthright about the work, demand, and time involved in managing their child's ADHD. Physical effort often involves constantly repeating self; giving frequent reminders, prompts, directives, and instructions; getting ready for school in the morning; medication administration; frequent in-person or over-the-phone contacts and conversations with the school and teachers; labored homework time; afternoon and evening tasks; taking to healthcare appointments; and managing prescriptions and medication pick-up. Caregivers express the emotional demand in terms of feeling frustrated, exhausted, and tired. Psychologically, caregivers explain that it can be difficult, challenging, a struggle, stressful, tough at times, and hard.	*"He needs extra, extra, extra. I have to constantly repeat myself."* *"It's everyday life. Redirecting every single second. Every single day."* *"It's hard work. You'll be exhausted some days."* *"It can be really frustrating at times."* *"I will admit, sometimes it's hard. Some days he would bring me to tears over something."*
Condition Management Ability Caregivers' perceptions of the overall manageability of their child's ADHD, including knowing what needs to be	Caregivers describe their ability to manage their child's ADHD in terms of specific management strategies (which are closely tied to the emotional demand/effort of implementing them), such as routines, structure, and consistency;	*"Everyone knows the routine in the house. You have to stay on task. Consistency is key."* *"It's all about*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD-Qualitative Data	Exemplar Quotations
done to take care of the condition and their ability to competently carry out the management of their child's ADHD now and into the future. More positive views indicate their child's ADHD is viewed as more readily manageable.	daily goals and point systems or behavior charts/boards; post-it note reminders; giving single-point instructions; setting clear expectations; rewards and incentives for positive behaviors and consequences for negative behaviors; positive praise; daily school-home reports; keeping active and busy with different activities; trial and error approaches; and daily medications. Caregivers express knowing what needs to be done to take care of their child's condition, but also acknowledge the difficulty of maintaining this on daily basis. Despite the effort, caregivers hold a strong value in persisting and persevering; a firm belief that children can continue to grow and learn; and hold a resolved mindset that management is an ongoing process that ebbs and flows over time and circumstance. Caregivers tend to be open, flexible, and negotiate the daily routine as indicated. They continue to build upon their own learning capacities, expand their repertoire of skills, and exude a willingness to change.	*routine and schedule."* *"You have to look at it like you're the one that's got to do the work first. You have to change before you can help your child learn to manage what they have."* *"We have routines, but I don't make it so rigid that it can't change."*
View of Condition Impact Caregivers' perceptions of the seriousness of their child's ADHD and its implications for the child's and family's future. More negative views indicate greater concern in managing their child's ADHD.	Caregivers recognize ADHD as a condition that requires attention and intervention, but believe other conditions can be much worse. Caregivers strongly believe that ADHD should not be used as an excuse or crutch for their children not to reach their full potentials and capacities in life. Caregivers see a bright future overall for their children, including moving onto high school, going to college,	*"ADHD is not easy, but it's not the worst."* *"There's no excuse not to succeed. He has ADHD, but I'm gonna hold him up to his responsibilities."* *"We're just tryin' to make it through the year. I'm just worried. Anything*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD- Qualitative Data	Exemplar Quotations
	living independently, pursuing career interests, and having a family. However, significant concerns, worries, and questions plague these families, such as requiring higher doses and long-term effects of medications; questions regarding possible outgrowth of the condition; social skills in both personal and professional spaces; and the safety of their children, especially in neighborhoods and settings that may target these youth. Caregivers see their role as instrumental in their child's future success and recognize the need for ongoing support either professionally or within the family and community.	*could happen."* *"I see a very bright future ahead of him. It's just guiding, harnessing, nurturing, and helping him..."*
Parent Mutuality Caregivers' perceptions of the support, shared views, and satisfaction with how partners work together to manage their child's ADHD, including parents' beliefs about the extent to which they have shared or discrepant views of their child, ADHD, parenting philosophy, or approach ADHD management. More positive views indicate mostly a shared response and greater satisfaction with how the partners work together to manage their child's ADHD.	Partnered caregivers tend to vary with their partners' views and acceptance of the ADHD diagnosis, the preferred treatment, condition management strategies, and general parenting philosophies. Primary caregivers (usually mothers or other female caregivers) stated that they are accepting and understanding of the ADHD diagnosis; willing to trial medications despite their own hesitations and reservations; have knowledge and awareness of the specific management strategies and techniques; take charge of medications, appointments, and school communication; and utilize collaborative parenting styles with their children. Secondary caregivers (either fathers, other male caregivers, or grandparents) were perceived by primary caregivers as struggling more with understanding and accepting the ADHD diagnosis;	*"Dad is in the picture but dad does not believe ADHD. Nothing is wrong with his son."* *"That was kind of our conflict. He [child's father] does not like him on the medicine."* *"We do things differently at certain times. We have disagreements on how to deal with it."* *"We really try to approach it as a team."* *"We see eye to eye. Not on every single thing but we have the same set of values."*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD-Qualitative Data	Exemplar Quotations
	having strong views against using medications as a treatment option; relying on their partners for knowledge and leadership on management strategies; and having more authoritative parenting styles with their children.	
Barriers/Challenges Caregivers' perceptions of the barriers or challenges of ADHD management for their child, including immediate and extended family, stigma, educational, healthcare, financial/insurance/policy challenges or barriers.	Caregivers express individual challenges within their immediate families, but more burdensome challenges within their extended families in terms of understanding and managing their child's ADHD. Stigma plays a major role for families regarding mental illness in general; the validity of ADHD as a medical condition vs. a disciplinary or parenting issue; use of medications to treat the condition; ADHD medications themselves; and the negative labels placed on children diagnosed with ADHD and their families. Within the educational sphere, the major barriers for families are: lack of awareness, understanding, and training for ADHD/ management for teachers and school personnel; disciplinary systems within schools that emphasize punishment vs. positive reinforcement; different levels and qualities of parent-teacher communication; inconsistent standards between schools in regards to special services and accommodations; minimal guidance and navigation to obtain services and resources; lack of professionalism from behavioral health workers; and transportation issues. Within the healthcare sphere, the	*"We don't live in the best of neighborhood[s]."* *"My health's not too good."* *"A few family members… They don't understand. That's our hardest issue."* *"As far as family-wise, I had to cut some relationships off."* *"People look at ADHD and meds like a dirty topic."* *"Especially being Black… there's a lot of stigma with ADHD."* *"I think the education system is a big barrier."* *"When they don't follow the IEP, it causes issues."* *"For mental health, it's just hard to find services."* *"We were on a wait*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD-Qualitative Data	Exemplar Quotations
	major barriers for families are: having access and insurance to services that will help their child; long wait times for specialty care providers; minimal guidance and navigation to obtain services and resources; constant turnover of therapists and other behavioral health workers; inconsistency across providers within a practice; lack of professionalism from behavioral health workers; and transportation issues. The financial, policy, and insurance barriers, include the challenges of: obtaining services that are only available with Medical Assistance (MA) for which some families are not eligible due to income level; applying for MA through the Supplemental Security Insurance (SSI) route which can take months to years to approve; and interfacing with providers and practices who only accept certain types of insurances and deny others.	*list for almost a year, actually."* *"I can't imagine that constant turn-over."* *"Then our insurance changed, so we had to go somewhere else."* *"I almost lost my job because FMLA wouldn't cover it without a diagnosis [for child's ADHD]."* *"I've been like trying to work on the process [getting MA/SSI and Services] for like years, and it's difficult."*
Facilitators Caregivers' perceptions of the facilitators of ADHD management for their child, including family, community, educational, and healthcare facilitators.	Caregivers highlight the strong, supportive families and friends, who connect them with information, resources, and guidance, and community groups, such as online support groups and church. Caregivers also reflect on the counselors, teachers, and behavioral workers within schools who are heavily invested in their child's academic success; have strategies on how to manage ADHD in the classroom; actively partner and communicate with parents/caregivers; and provide families with guidance and support	*"They say it takes a village to raise a child. My village has stepped up for me."* *"One of our strengths is we are a tight family."* *"I joined this Facebook mom group, and it's for ADHD… The support groups really help."* *"The school was a big help with getting us in touch with the*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD-Qualitative Data	Exemplar Quotations
	for additional services and resources.	*right people."*
	Healthcare providers facilitated positive ADHD management when providing families with accurate information; help and anticipatory guidance when navigating complex services and systems; available in-home or at-school behavioral services; being flexible with appointment times; and willing to listen to caregiver concerns or questions.	*"The biggest part that helped us was forming the relationship with the school teacher."* *"We have access to good doctors."* *"She [health care provider] seems to be really open and listens to us."*
Child Strengths: Caregivers' perceptions of their child's strengths, including personality traits, hobbies/activities, academic strengths, tasks, and likes/interests.	Caregivers overwhelmingly portray children with ADHD as artistic and creative; curious, inquisitive, and intelligent; caring, sweet, and loving; active with sports, music, dance, and art; academically strong in math and science; helpful with different individual or family tasks; and likes or interests similar to other children their age.	*"He's smart as a whip."* *"Definitely creative."* *"Very nurturing, caring, affectionate."* *"Very good at ballet."* *"He's a great helper…"*
Caregiver Strengths Caregivers' perceptions of their strengths, including personal qualities, individual attributes, actions, and behaviors.	Caregivers consistently portray their major strengths as love, patience, and communication; being calm, supportive, and encouraging; proactive, present, and highly involved in their children's lives; and persistent advocates for their children.	*"I am very patient."* *"…being a good communicator."* *"I'm a very involved parent. I am very goal oriented, positive. I'm very strong."* *"Well, I think, number one, just being his biggest advocate."*

Family Management Definitions- Chronic Conditions Literature	Thematic Descriptions within Family Management ADHD-Qualitative Data	Exemplar Quotations
Advice/Recommendations Caregivers' advice or recommendations for other parents/caregivers of children with ADHD, the community, and providers or entities within the educational and healthcare systems.	Caregivers strongly encourage other parents or families of children with ADHD to be persistent; don't give up; seek information, guidance, and support; don't be afraid to ask for help; consider medications; and be open to therapy and additional strategies. Caregivers recommend more support from the community, schools, and healthcare systems regarding practical guidance, support groups, and advocacy events or activities.	*"Read about it. Get as much information as possible."* *"Don't be afraid to ask for help."* *"Just be persistent, be proactive."* *"Just know that it'll get better…"* *"Don't give up. Keep fighting until something works."* *"Take time out for yourself."*

In the following section, family management definitions and thematic descriptions will be discussed using quotations to illustrate meaning and further understanding for the child and caregiver participants in this study.

Child's daily life. For the child's daily life, we defined this as the caregivers' perceptions of their child's identity and everyday life, including how parents view their child with ADHD and the extent to which those views focus on ADHD and vulnerabilities or normalcy and capabilities. More positive views indicated that a child has a more normal life despite ADHD. In our study, caregivers saw differences in their child due to the ADHD and other mental-health comorbidities yet viewed their child overall as very similar to other children their age, specifically in ways that were important to them. In regards to differences, one caregiver expressed, *"Because of the ADHD, I think that she's a little bit different than other children her age. Kids say 'why are you so hype all the time, or why are you so extra?'."* Another caregiver stated, *"He's different because he definitely struggles with school and sitting still and paying attention; whereas, some other kids can easily do that."* On the other hand, caregivers described how their children were like other children their age. For example, one caregiver said, *"I think he's pretty similar. I mean obviously, the ADHD makes it a little different in certain aspects, but for the most part, I think he's similar."* Another caregiver stated, *"He's different in a lot of ways, but to me, I'm looking at this normal kid."*

Caregivers also recognized and accepted ADHD as a real phenomenon, but still held their children responsible and accountable for their actions and behaviors. One caregiver stated, *"He has ADHD, but I'm gonna hold him up to his responsibilities"* whereas another remarked, *"I don't make excuses for him because he has a condition, but I still recognize that he has one."* Furthermore, it was challenging for caregivers to distinguish which behaviors were from the ADHD and which were typical childhood behavior. For example, one caregiver said, *"You're trying to figure out what is six-year old behavior and what's the ADHD."* Another caregiver observed, *"Is it the ADHD or is it him just being a boy?"* Despite these challenges, caregivers tended to normalize ADHD within the context of their everyday lives and focused on their children's strengths and capabilities. One caregiver stated, *"He's still a kid at the end of the day."* Another caregiver explained, *"I think sometimes it takes her a little bit of time to pick up things. But we don't really make her feel like she has a condition."* Finally, caregivers believed

ADHD did not define their child. As one caregiver commented, *"It's just a piece of him… it's not who he is."*

Condition management effort. Within the family management framework, condition management effort was defined as caregivers' perceptions about the work, demand, and time needed to manage their child's ADHD. More negative views of the ease or difficulty indicated more effort was expended in managing their child's ADHD. For our participants, caregivers were forthright about the work, demand, and time involved in managing their child's ADHD. This effort and work could be physical, emotional, or psychological. Physical effort often involved daily caregiving activities including constantly repeating self; giving frequent reminders, prompts, directives, and instructions; getting ready for school in the morning; medication administration; frequent in-person or over-the-phone contacts and conversations with the school and teachers; labored homework time; afternoon and evening tasks; taking to healthcare appointments; and managing prescriptions and medication pick-up. One caregiver described, "*It's just constant repeating over and over and over."* Another caregiver explained, *"It's everyday life… redirecting every single second… every single day… every single moment-redirecting."* Caregivers also recognized their vital role with daily management activities, which was evident in this statement: *"Yeah, I have to stay on top of him… I am a constant reminder for him… even with the schedule and reminders in his phone."* These management activities required significant time and effort, however, as this caregiver stated, "*Some people, they'll say to me, you gotta keep him busy at all times, but you must understand, keeping him busy means keeping me busy."*

In addition, caregivers expressed emotional demands in terms of feeling frustrated, exhausted, and tired. During the interviews, caregivers expressed, *"It's hard work… you'll be exhausted some days. Like some days are rough and you are overwhelmed."* Another caregiver reported, *"It's really exhausting, sometimes just the day in and day out…it's tiresome."* In some cases, caregivers shared, *"Some days he would bring me to tears over something."* Psychologically, caregivers specified that it can be stressful, challenging, and hard. One caregiver explained, *"I act as her executive function, and it's very taxing."* Another stated, *"He stresses me out."* Other times, it was tough, difficult, and a struggle. As one caregiver expressed, *"It can be really frustrating at times… sometimes it's like chaos, and it's difficult… that's our struggle."*

Condition management ability. Condition management ability, on the other hand, was defined as caregivers' perceptions of the overall manageability of their child's ADHD, including knowing what needs to be done to take care of the condition and their ability to competently carry out the management of their child's ADHD. More positive views indicated their child's ADHD was viewed as more readily manageable. In this way, caregivers described their ability to manage their child's ADHD in terms of specific management strategies (which were closely tied to the emotional demand or effort of implementing them), such as routines, structure, and consistency; daily goals and point systems or behavior charts/boards; post-it note reminders; giving single-point instructions; setting clear expectations; rewards and incentives for positive behaviors and consequences for negative behaviors; positive praise; daily school-home reports; keeping active and busy with different activities; trial and error approaches; and daily medications. In regards to routines, one caregiver stated, *"Everyone knows the routine in the house… we have to stay on task… consistency is key."* Other caregivers stressed consistency as one caregiver remarked, "*You have to be very consistent and keep the goals very small."* Some caregivers used positive behavioral management strategies, as this caregiver explained, *"Positive reward works better, especially with ADHD… it really does".*

For many caregivers, they expressed knowing what needs to be done to take care of their child's condition, but also acknowledged the difficulty of maintaining this on a daily basis. One caregiver stated, *"That's the best I can do, because at the end of the day, I want to feel good that I tried my best"* whereas another explained *"I'd like to be more consistent, but there are things that prevent that in the real world… It's like, I'm not sitting down and saying let's work on the [behavior] chart".* Caregivers also varied in regards to their daily management routine and flow. Some caregivers noticed, *"Like the routine is not a routine. Everything is different, new adventure every day. We just go with the flow."* Similarly, another caregiver observed, *"It's different day by day with him. You have to kind of press whatever button and you know just try things until they work with him".* Other families, however, required more consistency in their daily routines as stated here: *"He has to have a detailed routine. I can't switch up- it has to be the same thing every day. Everything has to be planned."* A second caregiver explained, *"We try to have a routine. We know our morning routine, we know our afternoon routine, so I try to keep things in order."*

Despite the differences, caregivers held a strong value in persisting and persevering; a firm belief that children can continue to grow and learn; and held a resolved mindset that management was an ongoing process that ebbed and flowed over time and circumstance. One caregiver expressed her dedication towards management when she stated, "*I don't care what it takes… We're gonna learn this condition that he has, and I'm willing to give whatever I got to help him.*" Another caregiver explained, *"He really doesn't want to be on the medication, so I'm like okay, then you gotta learn to control your behavior."* Caregivers were persistent in their efforts as this mother claimed, "*Tomorrow is the next day, and it's a brand new day, and we're gonna try harder tomorrow than we did today.*" Caregivers tended to be open, flexible, and negotiate the daily routine as indicated. One caregiver explained, *"We really have to try and just be open and flexible and try new things. Like, okay, that's not working, keep on moving."* Another caregiver claimed, *"We have routines, but I don't make it so rigid that it can't change."* Other caregivers observed, *"It's learning to adjust… and work through solutions."* Caregivers also continued to build upon their own learning capacities, expand their repertoire of skills, and exude a willingness to change. As one caregiver so eloquently remarked, *"You have to look at it like you're the one that's got to do the work first. You have to change before you can help your child learn to manage what they have"*. Another observed, *"Yeah, I had to think kind of, like, out of the box on what we could do. There's so much information out there, you just got to find it. The more you know, the better you can manage."*

View of condition impact. For view of condition impact, our definition highlighted caregivers' perceptions of the seriousness of their child's ADHD and its implications for the child's and family's future. More negative views indicated a greater concern in managing their child's ADHD because of its perceived seriousness. In this study, caregivers recognized ADHD as a condition that required attention and intervention, but also believed other conditions could be much worse. One caregiver said, *"ADHD is not easy, but it's not the worst."* Another noticed, *"For us, it's like a walk in the park compared to other parents with children who have worse conditions."* For these caregivers, *"in the grand scheme of things, it's [ADHD] not horrible."* In a similar way, caregivers strongly believed that ADHD should not be used an excuse or crutch for children not to reach their full potentials and capacities in life. One caregiver explained, "*Yes, you have this disability, but it's not going to allow her to use it as a handicap that prevents her from doing what she wants to do in life."* Another caregiver claimed, *"He has ADHD, but I'm gonna hold him up to his responsibilities… There's no excuse not to succeed."*

Overall, caregivers saw a bright future for their children, including moving onto high school, going to college, living independently, pursuing career interests, and having a family. During the interviews, caregivers claimed, "*We always tell her that the sky's the limit. Whatever you want is what you'll achieve. There's no limitations to what you can and cannot do."* Another caregiver explained, *"I always tell him that he can be whatever he wants to be."* Furthermore, many caregivers believed, *"I have no question that he is going to be a success in life",* and others said, *"He's going to do something great. Really* *make a positive impact and make a difference in whatever he loves to do… God has a great purpose for him."*

On the other hand, caregivers also harbored significant concerns, worries, and questions regarding their child with ADHD, such as requiring higher doses and long-term effects of medications; questions regarding possible outgrowth of the condition; social skills in both personal and professional spaces; and the safety of their children, especially in neighborhoods and settings that may target these youth. One caregiver expressed her uncertainty when she stated, *"Like, is he going to be okay? Is he going to grow out of it? Or, are we going to be down this road with mental stuff as he gets older?".* Another caregiver commented, *"It's scary to think about the medication piece. Do we keep upping the medication, then what happens?".* For other caregivers, real world dangers and worries lingered in their minds. One caregiver expressed, *"I'm like terrified. I have so much fear that he's gonna get hurt somehow… It's just other people around him and surrounding him around the neighborhood and stuff that I don't trust."* Another caregiver stated, *"I try to explain to him all the time… these are small consequences, in the real world there are bigger consequences that I cannot save you from."* Despite their concerns and apprehensions for the future, caregivers viewed their role as instrumental to their child's future success and recognized the need for ongoing support professionally or within the family and community. One caregiver proclaimed, *"I definitely believe that he can be whatever he desires to be, and I have every intention on aiding him, down that path"* whereas another caregiver commented, *"I see a very bright future ahead of him. It's just guiding, harnessing, nurturing, and helping him along the way."*

Parent mutuality. For caregivers with an active partner in the home, we defined parent mutuality as caregivers' perceptions of the support, shared views, and satisfaction with how partners work together to manage their child's ADHD, including parents' beliefs about the extent to which they have shared or discrepant views of their child, ADHD, parenting philosophy, or approach ADHD management. More positive views indicated mostly a shared response and greater satisfaction with how the partners work together to manage their child's ADHD. Within our analysis, partnered caregivers tended to vary in regard to their partners' views and acceptance of the ADHD diagnosis, the preferred treatment, condition management strategies, and general parenting philosophies. Primary caregivers (usually mothers or other female caregivers) stated that they were accepting and understanding of the ADHD diagnosis; willing to trial medications despite their own hesitations and reservations; have knowledge and awareness of the specific management strategies and techniques; take charge of medications, appointments, and school communication; and utilize collaborative parenting styles with their children. In regards to information and knowledge, one primary caregiver stated, *"I am more informed than him [child's father] … so he's getting a lot of knowledge of it now."* Another primary caregiver discussed how she and her partner viewed medications when she remarked, *"We [the child's parents] disagreed with giving the kids medicine, but I'm with them more, so I'm gonna give her the medicine."* Furthermore, primary caregivers described their lead role in family management, as one mother stated, *"I'm the one that does all the phone calls and the emails and the scheduling and the getting everything ready."*

Secondary caregivers (either fathers, other male caregivers, or grandparents) were perceived by primary caregivers as struggling more with understanding and accepting the ADHD diagnosis; having strong views against using medications as a treatment option; relying on their partners for knowledge and leadership on management strategies; and having more authoritarian parenting styles with their children. One primary caregiver explained the views of her child's father when saying, *"Dad is in the picture but dad does not believe in ADHD. Nothing is wrong with his son."* In regards to medication management, one caregiver remarked, *"His dad was real against medication… he's just not a believer in medicating."* When negotiating management duties with their partners, caregivers in this study stated, *"My husband, he tends to lean on me and allows me to kind of take over and do everything."* Furthermore, caregivers explained differences in parenting styles with their partners. As one caregiver stated, *"He's [child's father] more of a disciplinary type."* While some caregivers had different opinions or even conflicts with their partners, other caregivers responded with reflections of concordance and partnership. In this regard, caregivers stated, *"Well, I think we definitely try and approach it together."* Another caregiver echoed this support from her partner stating, *"Yeah, we co-bossing it together."* Caregivers also explained the strength of partnership, including, *"I think our strengths together is that when one breaks down, the other one picks up where the other one broke down. So, I think we're good that way."* Another caregiver expressed the shared management approach with her partner, when she said, *"We [the child's parents] really try to approach it as a team."*

Barriers and challenges of family management. In this study, we explored caregivers' perceptions of the barriers or challenges of family management for their child's ADHD, including challenges within their immediate or extended families, mental health stigma, or barriers within educational, healthcare, or financial/insurance/policy systems. Caregivers expressed individual challenges within their immediate families, and more burdensome challenges within their extended families in terms of understanding and managing their child's ADHD. Within immediate families, caregivers acknowledged limitations in their own health with, *"I got diagnosed with MS [Multiple Sclerosis], that didn't help",* mental health struggles within the family, like, *"She's [biological mother] got bipolar disorder",* and losses in the family such as, *"Their father died."* Within extended families, caregivers reported significant challenges. As one caregiver said, *"It's hard for them to understand his condition. So, that has been a huge challenge."* Similarly, another stated, *"The only thing is, like, how other family members deal with it. It's hard with other family members trying to figure how to manage it. That can be hard."* In some cases, caregivers even said, "*As far as family-wise, I had to cut some relationships off. I don't think that's a healthy situation for my son to be in."*

Beyond and within families, stigma played a major role for children with ADHD. Stigma surrounding mental illness, in general, and specifically for ADHD, was prominent in caregiver interviews. Caregivers observed how frequently others viewed ADHD as a disciplinary or parenting issue verses a valid medical condition. As one caregiver stated, *"People are judging you, and they're like, you're not disciplining him enough."* Additionally, caregivers noted an extra layer of stigma for those children and families in racial or ethnic minority groups. As this caregiver stated, *"Especially being Black… there's a lot of stigma with ADHD."* Children with ADHD were also negatively labeled by others as one caregiver explained, *"He [my child] said, 'the teacher said I was bad today… or good today'. So, I said, kids aren't good or bad. They don't listen or they did listen. But they are not bad kids."* Finally, the use of medications to treat ADHD was extremely controversial, as one caregiver commented, *"People look at ADHD and meds for it as like a dirty topic."* Other caregivers expressed their fears or concerns about the medications, describing what some perceived to be a "zombie" effect: *"A lot of people be like… I don't want my child taking meds, or meds slow them down and they be like zombies. Like a lot of people told me that before I gave him medication. They was like, you don't want to give him medication 'cause he's gonna be a total different person. He's gonna be sluggish, a zombie. He's not like that. He's just calmer. Like he's not like a zombie. Like he's not like sluggish. He's just calmer. Like he still likes to do stuff."*

In this study, the major barriers or challenges of family management for children with ADHD were captured in seven different categories within the educational system. These categories included: 1.) lack of awareness, understanding, and training for ADHD/ management for teachers and school personnel; 2.) disciplinary systems within schools that emphasized punishment versus positive reinforcement; 3.) different levels and qualities of parent-teacher communication; 4.) inconsistent standards between schools in regards to special services and accommodations; 5.) minimal guidance and navigation to obtain services and resources; 6.) lack of professionalism from behavioral health workers; and 7.) transportation issues. During interviews, caregivers noted the lack of knowledge and awareness of appropriate management approaches. As one caregiver observed, *"The teachers at his school that he goes to now… they don't understand."* Another said, *"I think that a lot of times the teachers are not really equipped to deal with it."* Caregivers also pointed to the inconsistencies within the educational system, such as, "*Every year it's a different challenge, every single grade… like up and down,"* or as one caregiver explained, "*Two of the schools that he was at didn't provide the support he needed due to his ADHD."* For other caregivers, these inconsistencies would create problems for their child, as this caregiver stated, *"When they don't follow the IEP [Individualized Education Plan], it causes issues."* Caregivers in this study were also very astute saying things like, *"I think the education system is a big barrier,"* or another caregiver remarked, *"One of the struggles… especially in the city… is the lack of support from the school systems."* Finally, caregivers expressed their frustrations and challenges with the system when claiming, *"She really needs supports in school right now, but it takes so long to get a worker",* or as another caregiver said, *"You really have to push to get what you need."*

In this study, the major barriers or challenges of family management for children with ADHD were captured in seven different categories within the healthcare system. These included: 1.) having access and insurance to services that would help their child; 2.) long wait times for specialty care providers; 3.) minimal guidance and navigation to obtain services and resources; 4.) constant turnover of therapists and other behavioral health workers; 5.) inconsistency across providers within a practice; 6.) lack of professionalism from behavioral health workers; and 7.) transportation issues.

During interviews, caregivers illustrated several barriers to access mental health care, like, *"For mental health… it's just hard to find services or it's hard to find services that you can afford and really get the help that you need."* For another caregiver, *"We were on a wait list for almost a year, actually."* Other caregivers discussed the barriers to attend healthcare appointments, such as, *"It was a little bit hard for me to get there all the time. They didn't really have transportation."* Additional challenges presented once children and families had access to care, such as, *"The biggest issue - on the healthcare side- in the provider's office… It's like multiple hands in the pot. There's no consistency from who you're talking to and who's prescribing this medicine."* Another caregiver remarked on inconsistent practices within mental health care when she said, *"Every therapist has their own tactic. It really just depends on the therapist."* Other healthcare barriers and challenges included those with medications and provider turnover. One caregiver explained, *"Honestly, sometimes the pharmacy doesn't have the medication."* For another caregiver, the constant turnover of therapists was a barrier for her child's care and treatment, as evidenced by, *"She's literally on her third therapist. Not because she didn't like them or whatever, but the therapist just moved on."*

In this study, the major barriers or challenges of family management for children with ADHD were captured in three different categories within financial, insurance, and policy systems. These included: 1.) obtaining services that were only available with Medical Assistance (MA) for which some families are not eligible due to their income level; 2.) applying for MA through the SSI (Supplemental Security Income) which could take months to years to approve; and 3.) interfacing with providers and practices who only accept certain types of insurances and deny others. In general, it was a barrier for caregivers to access care due to insurance limitations. One caregiver stated, *“They had behavior and development [services] at the school but my insurance didn’t cover it.”* Another carefully detailed, *“Most of the providers that, you know, specialize in her conditions only take MA. A lot of children’s childcare treatment centers, they only take MA. They don’t take private insurance. She had CHIP [Children's Health Insurance Program]. But still nobody wanted it.”* For some, there was a tension between access to services and what families could afford. As one caregiver explained, *“I’ve always wanted to get him in there… they offer so many resources, but he doesn’t take insurance, so you’ve got to pay out of pocket and who has got the money to pay for that?”.*

In addition, many caregivers within this study also faced significant challenges regarding obtaining medical assistance, which was required to access certain in-home or school-based services for ADHD. As one caregiver described, *“We live in a two-parent household, and they say we make too much money and some of the benefits, we were overqualified for, which doesn’t make sense to me, because I’m not asking for money. We can take care of our kids our self. Like I’m not asking for money. I need the services.”* Furthermore, caregivers often had to apply for Medical Assistance multiple times before getting approved. This was a considerable struggle as one caregiver stated, “*You have to literally fight a very long fight. So, my fight to get health insurance for her through the state took a year, and it involved going to court, appeals and stuff, like that.”* This fight often included pursuing Supplemental Security Income (SSI), which opened doors to Medical Assistance for families who did not meet the traditional low income requirement. These children were eligible for SSI, because ADHD is considered a disability within the policy. As one caregiver remarked, *"Even though we're over income, because he's disabled, they give the Medicaid. He's going to have that insurance forever. So, that's good."*

Facilitators of family management. In this study, we also explored caregivers' perceptions of the facilitators of family management for their child's ADHD, including those within family, community, educational, and healthcare systems. Generally speaking, caregivers believed support was essential for their child and family, as evidenced by, *"One of the key things that I believe holds it all together is the support."* During interviews, caregivers emphasized strong, supportive families and friends, who connected them to pertinent information, resources, and guidance for their child's condition. As one caregiver stated, *"One of our strengths is we are a tight family. We're a small family, but we're a tight family."* Another said, *"They say it takes a village to raise a child… My village has stepped up for me -- everybody, like, friends, family, everybody."* Caregivers explained that family, friends, and community networks provided a link to services or resources. As one caregiver stated, *"My best friend had similar stuff with her son. So, she kind of like paved the way for me."* Another said, *"I have had to rely on friends and informal communications with people I know to try to get tapped into some of these things."* Other community-based supports, such as church and online support groups, were also helpful and important to caregivers in this study.

In this study, major facilitators of family management for children with ADHD were captured in four different categories within the educational system. These included the counselors, teachers, and behavioral workers within schools who were: 1.) heavily invested in their child’s academic success, 2.) had strategies on how to manage ADHD in the classroom, 3.) actively partnered and communicated with parents/caregivers, and 4.) provided families with guidance and support for additional services and resources. Despite their frustrations with the educational system as a whole, many caregivers positively remarked about their child’s teacher, counselor, or school. One caregiver stated, *“The teachers are really great... They’re very willing to help,”* whereas another said, *“They have a new counselor at the school. She understands what’s going on.”* In regards to support, one caregiver explained, *“He has a lot of support at school with the teachers and the special education teacher that works directly with me to make sure everything is going as smoothly as can be”.* Strong communication and partnerships between families and school providers surfaced as an important aspect for caregivers in this study. As one caregiver observed, *“I think the biggest part that helped us was forming the relationship with the teacher… that partnership with the school.”* For another caregiver, this communication and coordination was evidenced by, “*Overall, we have really good communication. They're really helping me. Everybody is on board.”*

In this study, major facilitators of family management for children with ADHD were captured in five different categories within the healthcare system. These included healthcare providers who were: 1.) providing families with accurate information and resources, 2.) helpful and offering anticipatory guidance when navigating complex services and systems, 3.) connecting families to resources for in-home or at-school behavioral services, 4.) flexible with appointment times, and 5.) willing to listen to caregiver concerns or questions. Despite the challenges observed, caregivers reported on many positive experiences within the healthcare system, including their providers. As one caregiver stated, "*We have access to good doctors.*" Another caregiver commented, *"She's had the same therapist for three years. If there's a problem I can call the therapist, and her doctor now that prescribes her medication- he's very flexible."* Caregivers also valued open, honest, and consistent communication with their healthcare providers. One caregiver explained, "*We try and work with one [provider] specifically because she seems to be really open and listens to what we feel and will work with us.*" Another caregiver described, *"The pediatrician… she's so good. She was like, do you trust me? And I was like, yes."* In this study, caregivers relied on healthcare providers for support and guidance in regards to their child's ADHD management, as evidenced by, *"I'm in constant contact, because I can't do all of this without them helping me."*

Child strengths. During the interviews, we recognized the importance of highlighting child strengths, which we defined as the caregivers' perceptions of their child's strengths, including personality traits, hobbies/activities, academic strengths, tasks, and likes/interests, to equalize the discussion surrounding ADHD and its challenges. Within our analysis, caregivers overwhelmingly portrayed children with ADHD as artistic and creative. Other caregivers remarked on their child's curious, inquisitive, or intelligent nature, as one caregiver stated, "*He's super intelligent… very smart… a budding leader.*" Another caregiver said, "*She's really a critical thinker.*" Caregivers also described their children as caring, sweet, and loving. One mother stated, *"He's sweet… he will make you feel like you are the only person in the world."* In this sample, children with ADHD were very active in different hobbies and activities, such as sports, music, dance, and art. One caregiver said, *"She likes to dance, sing. Now she's into sewing and art. She's a mime at church, and on the choir,"* whereas another caregiver said, *"He's very involved in sports. He plays baseball and ice hockey."* Caregivers also observed their children's academic strengths, specifically in math and science. One caregiver said, *"She gets straight As on her report card for math,"* whereas another caregiver shared, *"He has a fascination with science."* At home, caregivers reflected on their child's ability to help with tasks such as, *"Actually, he wants to have chores at home."* Another caregiver stated, *"Yeah, he's actually pretty good with his medicine; he'll come to me and say, oh, mom, is it time to take my medicine, and I'm like, sure is."* Finally, caregivers shared about their child's interests and enjoyments, which mirrored other children their age with things like. One caregiver said, "*He loves building and doing volcanoes,"* whereas another caregiver commented, *"He loves dogs and animals."* Based on these findings, caregivers looked beyond the symptoms of ADHD and viewed children as individuals with considerable strengths in both quality and action.

Caregiver strengths. Within this study, we also hoped to illuminate caregiver strengths. These were defined as caregivers' perceptions of their strengths, including personal qualities, individual attributes, actions, and behaviors. During the interviews, caregivers often initiated discussions about their child's strengths and abilities, but the lead researcher had to deliberately inquire and sometimes probe on how caregivers' viewed their own strengths and abilities. They consistently portrayed their major strengths as love, patience, and communication. As one caregiver stated, *"I am very* *patient"* whereas another caregiver conveyed her strength as, *"Being a good communicator."* In this study, caregivers were highly involved in their children's lives and described themselves as calm, supportive, and encouraging. As one caregiver explained, *"I support him, listen to him, and understand him."* Another caregiver said, *"I'm a very involved parent. I am very goal oriented, positive. I'm very strong."* Caregivers also displayed strength by being present, proactive, and persistent. They were strong advocates for their children, as one mother said, *"Well, I think, number one, just being his biggest advocate."* Another caregiver exclaimed, *"I think my strength is that I don't give up. I don't care what it takes. I'm willing to give whatever I got to help him."*

Advice and recommendations. Spontaneously throughout interviews (unprompted) and at the conclusion, caregivers provided advice and recommendations for other parents or caregivers of children with ADHD, the community, and providers or entities within the educational and healthcare systems. Within our study, caregivers strongly encouraged other parents or families of children with ADHD to be persistent; not to give up; seek information, guidance, and support; not be afraid to ask for help; consider medications; and be open to therapy and additional strategies. Caregivers also recommended more support from the community, schools, and healthcare systems regarding practical guidance, support groups, and advocacy events or activities. For health care providers, caregivers recommended, *"If you had a little bit more guidance or support in terms of setting things up for school and at home, that would be helpful."* For educational providers, caregivers recommended, *"One of the things that's not focused on enough is the fact that the private schools need to be held to the same standard as the* *public school as far as IEPs and the standard of care."* For community providers, caregivers recommended, *"I think more support groups, even if it's just like a monthly newsletter or something like that."* Other caregivers said, *"If there were options or opportunities to connect with other parents who live in the area, that would be huge."* Furthermore, caregivers suggested improving community involvement as reflected in this statement: *"I wonder why they don't do ADHD walks… It's definitely something I would participate in."*

Summary of qualitative findings. Taken as a whole, these robust and detailed qualitative findings helped to better understand how families manage caring for a child with ADHD on a daily basis. Exploring family management factors, such as child's daily life and view of condition impact, provided insight into the world of caregivers as they perceive children with ADHD and their present and future lives. Probing deeper into condition management effort and condition management ability offered caregivers an opportunity to express the hard work associated with ADHD management and discuss the management strategies and philosophies that have worked for their child and family. For caregivers with a partner, the concordance and discordance about management for their child with ADHD and how this affects caregivers and families was highlighted. Furthermore, this study provided ample evidence of the barriers, challenges, facilitators, and strengths that caregivers and families experience in regards to ADHD management. This contextually-derived exploration provides a comprehensive awareness and understanding of the issues important to families in this study. In the discussion section, we will provide additional interpretation regarding the themes explored in the narratives above and discuss the implications of such findings, including the advice and recommendations from caregivers themselves.

Quantitative Results

Specific Aim 2 was to quantitatively describe child, caregiver, and environmental characteristics and examine how family management factors (i.e., child's daily life, condition management effort, condition management ability, view of condition impact) were related to children's level of functional impairment within this sample.

As discussed in the methods chapter, we used descriptive and inferential statistics to analyze the quantitative data in this study. For this research, we intended to describe the results from the study instruments (i.e., Vanderbilt, Family Management Measure, Impairment Rating Scale). Next, we aimed to answer the second aim of this study by testing the relationships between family management factors and the main variable of interest (i.e., childhood functional impairment). In addition, we examined the relationship between ADHD symptom severity and children's level of functional impairment. Finally, the mean scores on the FaMM were compared to other family management studies (e.g., pediatric brain tumor survivors, childhood chronic illness) to see how our results compared to other pediatric samples. In this section, we present descriptive findings first, then, inferential results, and lastly, mean comparisons across samples. A summary of the quantitative results will conclude the section.

Table 4.3 contains the descriptive statistics for the key instruments in this study, including the Vanderbilt ADHD rating scale, FaMM scales, and the Impairment Rating Scale.

Table 4.3

Mean, Standard Deviation, Range, and Cronbach Alpha for the Vanderbilt ADHD Scale, Family Management Measure (FaMM) and Impairment Rating Scale (IRS)

Variable/ Scale	**N**	**M**	**SD**	**95% CI**	**Possible Range**	**Actual Range**	**Cronbach's α**
Vanderbilt ADHD Scale	50	29.32	11.36	[26.09, 32.54]	0-54	5-52	.93
Child's Daily Life	50	17.58	4.32	[16.35, 18.80]	5-25	5-25	.65
Condition Management Effort	50	13.62	3.48	[12.63, 14.60]	4-20	4-20	.55
Condition Management Ability	50	44.94	7.11	[42.91, 46.96]	12-60	30-60	.74
View of Condition Impact	50	26.12	5.65	[24.51, 27.72]	12-50	14-38	.68
IRS Summary Scores	50	21.06	9.01	[18.49, 23.62]	0-42	4-36	.86
IRS Item 1 Peer	50	2.7	0.23*	[2.22, 3.17]	0-6	0-6	
IRS Item 1a Best Friend	50	.64	0.06*	[0.50, 0.77]	0-1 (0=No, 1 =Yes)	0-1	
IRS Item 2 Sibling	50	2.34	0.28*	[1.78, 2.89]	0-6	0-6	
IRS Item 3 Parent	50	2.96	0.25*	[2.45, 3.46]	0-6	0-6	
IRS Item 4 Academic	50	3.4	0.27*	[2.85, 3.94]	0-6	0-6	
IRS Item 5 Self-Esteem	50	2.68	0.25*	[2.16, 3.19]	0-6	0-6	
IRS Item 6 Family Functioning	50	3.05	0.23*	[2.59, 3.52]	0-6	0-6	
IRS Item 7 Global	50	3.92	0.21*	[3.49, 4.34]	0-6	0-6	

Note: *represent Standard Errors for each item score.

Findings from the Vanderbilt ADHD scale. For the Vanderbilt ADHD scale, caregivers reported total ADHD symptom summary scores that ranged between 5 and 52 (possible score range 0-54) with a mean of 29.32 (SD = 11.36). As previously stated, these total scores are typically divided into 3 distinct categories (e.g., mild, moderate, severe) to represent children who had the lowest total scores, highest total scores, and moderate total scores. Within this sample, over 80% of the children had moderate or severe ADHD. The Cronbach's α for the Vanderbilt ADHD scale in this dissertation sample was high (.93) with excellent internal consistency.

Findings from the FaMM scales. The Child's Daily Life scale had total scores ranging from 5 to 25 (possible score range 5-25) with a mean of 17.58 (SD = 4.32). Higher scores on this scale indicated a more normal life for the child despite the condition. The Cronbach's α for the child's daily life scale in this dissertation sample was moderate (.65), with an acceptable internal consistency. The Condition Management Effort scale ranged between 4 and 20 (with possible scores from 4-20) and a mean of 13.62 (SD = 3.48). Higher scores on this scale indicated more effort was expended in managing the illness. The Cronbach's α for the condition management effort scale in the dissertation sample was borderline acceptable (.55), with weaker internal consistency. The Condition Management Ability scale had scores ranging between 30 and 60 (possible score range 12-60) with a mean of 44.94 (SD = 7.11). Higher scores on this scale indicated the condition was viewed as more readily manageable. The Cronbach's α for this scale was moderate-high (.74), with good inter-item reliability. The scores on the View of Condition Impact scale ranged from 14 to 38 (possible score range 12-50) with a mean of 26.12 (SD = 5.65). Higher scores on this scale indicated a greater concern in managing the condition. The Cronbach's α was moderate (.68) for internal consistency, but acceptable.

Findings from the Impairment Ratings Scale (IRS). The main variable of interest for the quantitative analysis in this study (IRS) included 8 items on each of 6 domains or subscales of functioning within childhood plus a total IRS summary score. Scores on this scale were measured by a 7-point Likert scale ranging from 0 to 6 for each item; one item is dichotomously measured. The summary score for the IRS in this study ranged between 4 and 36 (possible score range 0-42) with a mean of 21.06 (SD= 9.01). The Cronbach's α for the IRS scale was excellent (.86) with good inter-item reliability.

Bivariate correlations. For this dissertation study, the bivariate relationship between ADHD symptom severity scores and IRS summary scores was tested first. Then, bivariate relationships between family management factors (i.e., child's daily life, condition management effort, condition management ability, view of condition impact) and IRS summary scores were tested. Study hypotheses included: 1.) Higher scores for child's daily life (higher scores more positive) and condition management ability (higher scores more positive) would be correlated with lower levels of children's functional impairment, and 2.) Higher scores for condition management effort (higher scores more negative) and view of condition impact (higher scores more negative) would be correlated with higher levels of children's functional impairment. These hypotheses were supported by study results with bivariate correlations at or below <.05 significance levels.

See *Table 4.4* for bivariate correlations, which indicate both strength and direction of the relationships between study variables.

Table 4.4

Bivariate Correlations between Family Management Factors and Functional Impairment

	Total IRS Score	
Variable	Correlation	p Value
ADHD Symptom Severity	.41	.0025*
Child's Daily Life	-.56	< .001
Condition Management Effort	.46	.0007**
Condition Management Ability	-.56	< .001
View of Condition Impact	.33	.0164*

Note: Correlations are based on Pearson's correlation; * indicates p < .05, ** p < .01

Based on the results, all study hypotheses were supported with bivariate correlations significant at or below the <.05 level. Before analyzing our study hypotheses, we tested the bivariate correlation between ADHD symptom severity and functional impairment, which was moderate in strength, and the relationship was significant (r = .41, $p < .05$). Next, the bivariate correlation between child's daily life scale and total IRS score was stronger, but still moderate, and the relationship was significant in a negative direction (r = -.56, $p < .001$). Likewise, condition management ability was negatively correlated with total IRS scores, and the relationship was significant (r = -.56, $p < .001$). The bivariate correlation between condition management effort and total IRS scores was weaker in a positive direction (r = .46, $p < .01$), but the relationship was still significant. Finally, view of condition impact was positively and significantly correlated with total IRS scores (r = .33, $p < .05$).

Means across pediatric samples. For this study, we also evaluated how the FaMM mean scores were similar to other studies using the family management measure to understand outcomes for children with other chronic illnesses (Deatrick et al., 2014; Knafl et al., 2015; Knafl et al., 2013). These comparison samples include: pediatric chronic illness (N=412), pediatric brain tumor survivors (N=183), and childhood ADHD (N=50). See *Table 4.5* for the means and standard deviations for each FaMM scale.

Table 4.5

Means across Samples using Family Management Measure

FaMM Mean Scores	Pediatric Chronic Illness (N=412)	Pediatric Brain Tumor Survivors (N=183)	Childhood ADHD (N=50)
Child's Daily Life	17.92 (SD* 4.95)	15.21 (SD 5.92)	17.58 (SD 4.32)
Condition Management Effort	13.72 (SD 4.7)	9.75 (SD 4.12)	13.62 (SD 3.48)
Condition Management Ability	48.99 (SD 6.28)	47.81 (SD 6.80)	44.94 (SD 7.11)
View of Condition Impact	27.09 (SD 6.78)	26.01 (SD 7.13)	26.12 (SD 5.65)

*Note: SD = Standard Deviation

Based on these results, the means and standard deviations on family management scales were overall similar for children with ADHD as compared to other studies of children with chronic illness. Further commentary on these results are included in the discussion chapter.

Summary of quantitative results. To summarize, part two of the second aim was to examine how family management factors (e.g., child's daily life, condition management ability, condition management effort, view of condition impact) were related to children's level of functional impairment. Our study findings were consistent with the stated hypotheses. When examining these bivariate relationships, child's daily life and condition management ability had the strongest correlations and were significant at the .001 level. In addition, condition management effort was moderately correlated with functional impairment with significance at the .01 level. View of condition impact and functional impairment were weakly correlated, but still significant at the .05 level.

Overall, the instruments within this study showed acceptable reliability except for condition management effort, which may indicate a difference in how work is defined when managing a child with a mental health condition as opposed to a chronic medical condition. Means for each measure trended towards the middle except for Vanderbilt scale, which reflected slightly higher mean scores for ADHD symptom severity. We also examined mean scores for the Family Management Measure across different pediatric samples. In this study, we found that children with ADHD were overall very similar to other pediatric samples suggesting this measure could be used for children with ADHD or other chronic mental health or neurodevelopmental conditions.

Mixed Methods Results

Specific Aim 3 was to use a mixed methods approach to integrate the qualitative and quantitative findings explicating overlapping complementary themes and family management factors that influence children with ADHD at higher and lower levels of children's functional impairment.

Based on functional impairment summary scores, children in this study were in the higher function group (n=24) with lower levels of functional impairment (scores 4-20) or the lower function group (n=26) with higher levels of functional impairment (scores 21-36). As discussed in the methods chapter, each family management factor (i.e., child's daily life, condition management effort, condition management ability, view of condition impact) was further expanded using qualitative data from caregiver interviews to thematically describe children at higher and lower levels of functional impairment. See *Table 4.6* for the completed mixed methods data integration matrix for this study.

Table 4.6

Mixed Methods Data Integration for Family Management ADHD Study

	Child's Daily Life	Condition Management Effort	Condition Management Ability	View of Condition Impact
Higher Function (n=24)	Caregivers view their children as overall similar to other children their age despite the ADHD. They stressed the importance of treating their child the same as other children to protect them from stigma or feeling different than their peers.	Caregivers are forthright about the of physical, emotional, and psychological demand that is required to manage a condition, like ADHD. While ADHD management is burdensome at times, caregivers feel a sense of duty to care for their child as best as they can.	Caregivers boldly assert the management strategies that work for their child and family. They explained a period of trial and error, but overall have achieved a steady state in their routines and ADHD management with only the occasional bumps in the road.	Caregivers envision a bright future filled with hope, promise, and excitement for their child. Caregivers admit to having some fears and worries regarding their child's future, but overall, they are confident their child will succeed with the right supports and services in place.
Lower Function (n=26)	Caregivers recognize and acknowledge the differences in their child with	Caregivers are equally as forthright about the physical, emotional, and	Caregivers have some clear ideas and management strategies for their child with	Caregivers express more concerns, worries, and uncertainties

	ADHD. However, even when the condition is severe, caregivers strive to maintain as much normalcy as possible for their child and family's life and believe strongly in holding their child accountable for their actions.	psychological demand that is required the manage their child's condition. The tone, however, changes from one of duty and strong resolve to improve their child's condition to one of exhaustion and just-getting-by. Caregivers are tired of the grind, but don't feel like there's any alternative to relieve the stress and burden.	ADHD, but struggle with finding consistency and balance. Caregivers are still in the trial and error phase and feel unsure on how to manage the condition sometimes. They describe life as more chaotic with more up and down days than smooth days.	regarding their child's condition and future. They are still hoping for the best, but are more realistic in their outlook. Caregivers foresee negative consequence in their child's future if they do not stay on top of the condition and prepare their child for the future.

For each family management factor, we identified distinguishing features between children at higher and lower levels of functional impairment from caregiver perspectives. Below, themes for children in higher and lower function categories will be described and explained using quotations from the qualitative interviews to support our findings.

Child's daily life. For child's daily life, caregivers of children in the higher child function category (i.e. those with less impairment) viewed their children as overall similar to other children their age despite their symptoms and behaviors of ADHD. As noted in the qualitative results, caregivers understood that a condition, like ADHD, may present differences for their child, but despite these differences, caregivers saw their child overall as a normal kid with a relatively normal life. One parent said during the interview, *"She's an average kid with a normal life and not that much different from other kids."* In addition, caregivers stressed the importance of treating their children the same as other children to protect them from stigma or feeling different than their peers. One caregiver stated, "*He's his own person – unique. So, different in that sense. But, I don't stigmatize his condition… Everyone has problems, and for him, it's ADHD".* For these caregivers, ADHD is a real condition with real differences, but it does not prevent their child or family from living a normal life similar to other children their age. This trend focused on normalcy complemented our quantitative findings, as the negative correlation between scores on the child's daily life and impairment rating scale was modest and significant ($r = -.56, p < .001$).

Caregivers of children in the lower child function (i.e. those with more impairment) category recognized and acknowledged differences in their child with ADHD. Even when the condition was recognized by the parent as severe, however, caregivers strived to maintain as much normalcy as possible for their child and family's life and believed strongly in holding their child accountable for their actions. For these caregivers, the differences were clear (e.g., *"she is way different"),* but at the same time, caregivers didn't want to *"make excuse[s] for their child's behavior."* Furthermore, one caregiver stated, *"He is different - the ADHD he has is severe. It's a part of him; that's who he is."* For this caregiver, ADHD cannot be separated from who the child is- it's part of the child and child's life. On the other hand, despite the child having a condition that cannot be separated from his daily life, this caregiver said *"…doesn't think he's less of a child and still expect[s] the same expectations from him as any other child his age."*

Condition management effort. For condition management effort, caregivers who have children in the higher child functioning category were forthright about the physical, emotional, and psychological demand that was required to manage the condition. As reported in the qualitative results, caregivers consistently report that ADHD management is *"a lot of time and work and effort."* For caregivers, it can be *"hard and difficult and frustrating."* While ADHD management was burdensome at times, caregivers felt a sense of duty to care for their child as best as they could. One caregiver stated, *"I take care of her. It's a lot of work… I get tired sometimes and I'll snap at her… But, this is what I have to do. And, I just do it. It can be a burden at times, but I love her, and I want the best for her. Because if I don't, who else will do it?".* These caregivers put forth a considerable amount of the effort and energy to manage their child's ADHD, but did so with a sense of duty for their children's health and well-being.

Caregivers who have children in the lower child function category were equally as forthright about the physical, emotional, and psychological demand that was required to manage their child's condition. The tone, however, changed from one of duty and strong resolve to improve their child's condition to one of exhaustion and getting-by. Caregivers voiced *"…it's a fight and a struggle."* For another caregiver, *"…it's very frustrating to balance helping out my child at the school and at home and own responsibilities. I can't focus and do my work because of this".* For these families, caregivers were tired of the grind, but didn't feel like there was any alternative to relieve the stress and burden. As one caregiver stated, *"It's a lot to deal with as a single mother with other children to care for… Can be irritating and frustrating… Wish I wouldn't have to do as much, but it's* *required for my child's treatment and progress."* It should not be surprising, then, that the positive correlation for condition management effort and functional impairment was relatively modest (r = .46, p < .01), suggesting the difficulty in discerning higher or lower functioning children based on caregivers' perceived management effort scores alone.

Condition management ability. For condition management ability, caregivers whose children are the higher child function category boldly asserted the ADHD management strategies worked for their child and family. One caregiver was honest and said, *"It's easy, because I know how to navigate the situation. It's all about routine, routine, routine and schedule, schedule, schedule. Consistency is very important."* Caregivers also explained a period of trial and error in the past, but have achieved an overall steady state with their ADHD routines and management strategies. As one caregiver expressed, *"There's been a lot of trial and error, [but] for the most part, we are pretty well adjusted. We have moments and spurts, but for the most part… [We have] routines with small bumps."* These caregivers have developed a sense of confidence and competence when managing their child's ADHD. While occasional bumps in the road may have occurred, as evidenced by, *"of course, we have bumps in the road,"* caregivers in this category perceived a strong sense of ability to manage their child's condition and continued to work hard towards improving their management of the condition. As one mother articulated, *"Tomorrow is the next day. It's a brand new day, and we are going to try harder tomorrow than we did today. Keep persisting and persevering until there's a good flow."*

Caregivers whose children are in the lower child function category also had some clear ideas and management strategies for their child with ADHD, but struggled with finding consistency and balance. As one mother said, *“I'd like to be more consistent, but there are a lot of things going on that prevent that in the real world.”* Caregivers remained in the trial and error phase and felt unsure on how to manage the condition. One caregiver explained, she *“sometimes feel unsure how to manage. Like every step of the way is guessing.”* Furthermore, caregivers described life as more chaotic with more up and down days than smooth days. As one mother described, *“Sometimes my house can be chaotic. Things can be up and down. But, we get it back together.”* Another family said, *“We really just manage it - get by the best we can”* which revealed how families were still trying to find their stride. For children in this lower function category, caregivers struggled in their ability to manage the condition and help improve their child’s functioning. This was also seen in the quantitative findings with a strong and statistically significant negative correlation between functional impairment and condition management ability ($r = -.56$, $p < .001$), which suggests caregivers’ perceived ability may play a considerable role in ADHD management and child function.

View of condition impact. For view of condition impact, caregivers of children in the higher child function category envisioned a bright future filled with hope, promise, and excitement for their child. One caregiver earnestly stated, *“The sky's the limit. There are no limitations to what you can and cannot do. You may have to work harder and focus more than other kids, but that doesn't mean it can't be done.”* Caregivers did admit to having some fears and worries regarding their child’s future. As one caregiver said, *"Yes, I worry about the ADHD and the impact on school and college opportunities, but I think he'll do great."* Despite some concerns about the future, caregivers were confident that their child would succeed with the right supports and services in place. One mother firmly believed the future was going to go well for her child, because she was going to make sure that it went well. She was going to hold him up to his expectations and hold the adults in his life accountable as well. She said he had no excuse not to succeed given everything the family was putting in place and further explains that colleges and workplaces have accommodations for youth now. She completed her thought by saying, *"…He's going to be successful. That's just the way it is".* For another mother, it was as simple, *"When you think positive, you become positive".*

Caregivers of children in the lower child function category expressed more concerns, worries, and uncertainties regarding their child's condition and future. These caregivers were troubled about real-world consequences- ones they might not be able to protect their children from. As one mother stated, "*I try to explain to him all the time… these are small consequences, in the real world there are bigger consequences that I cannot save you from."* Furthermore, caregivers anticipated negative outlooks, if they did not stay on top of the condition and prepare their child for the future. To this point, one mother explained, *"Right now, it's like… If I don't get him the help right now, I think it won't be as bright as it could be. If he gets the help and the structure now, then, I think he'll be okay. Hopefully, it will all come together".* Another caregiver elucidated*, "I put more into him, because I am afraid. Scared that if I am not here, who's going to step in. So, I'm trying to install things in him now to prepare for the future."* This tenuous relationship with the future may be one reason for the weak positive correlation between caregivers' views of condition impact and children's functional impairment (r = .33, $p < .05$). The relationship was significant, however, as supported by the qualitative findings. For these families, the future was questionable, but hope was not lost, as evidenced by, *"As a parent, I just hope for the best. I don't know what's going to happen. I can only try for improvement and hope it does improve."* Another caregiver expressed her thoughts by saying, *"I just try to go day by day… but with support, we will get through".* Despite their doubts and worries, caregivers clearly had strong beliefs for a hopeful future.

Summary of mixed methods results. For our tertiary aim, we examined each family management factor and identified distinguishing features between children at higher and lower levels of functional impairment from the perspectives of caregivers. In this study, 24 children fell within the higher functioning group and 26 children in the lower functioning group. The profiles between the two groups were similar with some distinguishing characteristics. For instance, in condition management ability, caregivers of higher functioning children reported a steady state in their management routines and strategies with only occasional bumps in the road. Whereas, caregivers of lower functioning children remained in the trial and error phases and struggled to find balance and consistency. Overall, these results revealed distinguishing characteristics between the two groups, but also considerable variability, for each family management factor within higher and lower levels of children's functional impairment.

Chapter 5: Discussion

The purpose of this chapter is to discuss the results of the study with emphasis on the qualitative, quantitative, and mixed methods findings as well as implications for research, practice, and policy. Limitations and methodological considerations are also discussed before concluding with final remarks.

Discussion of Qualitative Results

The primary aim of this study was to qualitatively examine via in-person interviews (using the family management factors as a guide) how ethnically diverse caregivers manage ADHD in their everyday lives and to understand the barriers and facilitators of family management for their child's ADHD. In the following section, family management factors, the barriers and facilitators of family management, child and caregiver strengths, and advice from caregivers are discussed using qualitative findings.

The normality of ADHD. Caregivers tended to normalize their child's daily life (i.e., FaMM child's daily life) while still recognizing and acknowledging certain behaviors or challenges related to their child's ADHD condition. Within the narratives, it became increasingly clear that caregivers viewed ADHD in a contextualized manner. Children in this study were perceived to be very similar to other children their age, but in certain places, contexts, or situations, their ADHD symptoms and behaviors became more apparent and problematic for these children compared to "normal" children. In these instances, caregivers distinguished differences in their child in ways that were important to them. This finding was consistent with prior research that suggested diverse caregivers may normalize some symptoms of ADHD, including hyperactivity and impulsivity, as these symptoms were not perceived by caregivers as worrisome or impairing as the symptoms of inattention (Hogue, Dauber, Lichvar, and Spiewak, 2014; Paidipati, Brawner, Eiraldi, & Deatrick, 2017). Within the current study, we also found that caregivers were concerned about symptoms of inattention, especially how these symptoms might impair their children's school functioning or academic performance. On the other hand, this process of identifying which symptoms to normalize and which ones to acknowledge as "different" was a very personalized experience for each caregiver (i.e., caregivers defined for themselves which ADHD symptoms to normalize and which to distinguish as different for their child). This finding contributes to the literature on how caregivers perceive children with ADHD and how caregivers want to see beyond their child's ADHD symptoms and conceptualize their child's daily life in the context of the whole person.

Managing daily life. Reflected in accounts of the effort (i.e. FaMM Management Effort) it took to manage the condition, caregivers were forthright about the work and demand required to manage their child's ADHD. Even the small details regarding everyday life (e.g., getting ready in the morning, completing homework, bedtime routines) can be work and require significant demand from caregivers. As the narratives revealed, this effort may not be easily recognized by others, or even by caregivers themselves, without adequate reflection on what it takes to manage the condition. In some cases, weekly or monthly management duties (e.g., taking to healthcare appointments, refilling prescriptions) also took a significant amount of time and effort to coordinate and complete, but went mostly unrecognized as work by others. This invisible or unspoken work on the behalf of caregivers is important to acknowledge and speaks to the high level of effort and energy required to effectively manage a child with ADHD. The intensity of the families' daily effort and the consistent pattern of work and demand connoted in their stories further contributes to our understanding about the experiences of caregivers of children with chronic illness (Knafl, Deatrick, & Havill, 2012; Knafl et al., 2013). This study also extends previous research on family management and ADHD (Conlon, Strassle, Vinh, & Trout, 2008; Kendall & Shelton, 2003) by addressing gaps in the literature on cultural and ethnic perspectives of ADHD.

The ability of caregivers. In terms of perceived ability, (i.e., FaMM Management Ability), caregivers in this study varied in their management strategies as well as their perceived confidence and competence for managing the condition. During the interviews, caregivers rarely used explicit words to share whether they perceived themselves as unable or lacking the skills to manage their child's condition (Deatrick personal communication). Instead, caregivers closely tied accounts of their management ability to the demand or effort required to implement management strategies. Given the majority of caregivers in the sample were women and women of color, this may have been related to a cultural pressure on behalf of caregivers to outwardly show strength rather than weakness or vulnerability to the researcher (Woods-Giscombé, 2010). The gendered expectation for mothers or other female caregivers to be relentless in their efforts to care and provide for their children, or the racial or ethnic expectation to be a "strong Black mother" or "fierce Italian mother" may have contributed to how caregivers expressed their confidence about being able to manage the condition (Woods-Giscombé, Lobel, Zimmer, Wiley Cené, & Corbie-Smith, 2015). With an emphasis on strength rather than deficit, caregivers in this study wanted to share with the researcher the numerous techniques, strategies, and abilities acquired and practiced in regards to their ADHD management. This tied closely with how caregivers' perceived their management ability– as an ongoing and continual process to build their skills and competence levels when managing their child's condition.

To this point, caregivers within this study showed a tenacious spirit in which they persisted and persevered in their management ability, wanted to learn new information and new skills to manage their child's ADHD, and exuded willingness to change for the sake of their child and family. Even though caregivers were already contributing a significant part of their lives towards managing their child's condition, they verbalized investment in continuing to improve themselves and their family members. One caregiver spoke about how she was working on her ability to be more patient with her child with ADHD, which is a testament to how caregivers in this study continually strived to enhance their management ability and skills. Many caregivers also stated they were interested in participating in research to learn more about ADHD and how to better understand or manage the condition. This attraction and affiliation to gain knowledge represents a shift from previous research in which studies reported that ethnic minority caregivers were less likely to seek information from healthcare or educational providers and more likely to rely on informal networks and communication (Bussing, Gary, Mills, & Garvan, 2007). Findings from this study, however, suggested that caregivers from both minority and non-minority backgrounds are very interested in seeking information and resources from healthcare providers and research settings. During interviews, caregivers expressed relying on informal sources of information and support, because they were not receiving adequate knowledge and resources from their healthcare and educational providers. This finding is a potential avenue for intervention for research and practice.

Bright futures, dark shadows. When asked about their child's condition and future, (i.e. FaMM Condition Impact), caregivers were generally optimistic about the future, but also expressed varying levels of fear and worry depending on their child and environmental influences. Caregivers often expressed specific safety concerns, which spoke to the pervasive threat of violence for some families and communities within a large urban environment. Due to multiple present and historical layers of race, discrimination, and injustice within our society, being a racial minority, especially a Black or African-American youth, may increase caregivers' worries or fears about the safety of their children (Olaniyan et al., 2007). For children with ADHD, this risk increases as youth with ADHD may have difficulty with impulsivity, risk-taking behaviors, or hyperactive-traits that are highly vulnerable to police scrutiny or the gaze from other authority figures. Recognizing safety concerns and validating caregivers' experiences regarding their fears and worries about their child's life and future contributes to the body of knowledge surrounding racial experiences, specifically for children with ADHD.

Caregivers' strong belief that having ADHD is not going to hold their child back from achieving their hopes and dreams was a prevalent expression. In this study, caregivers' belief in their child's ability to succeed (despite the challenges) was closely aligned with caregivers' commitment and value for holding children accountable for their actions and behaviors despite their condition. These two values and beliefs may have cultural nuances that can be explored further. Namely, a norm of resilience may exist which encourages caregivers to recognize the areas of struggle for their child or family, but at the same time, encourages them to endure and proceed with their lives in such a way that maximizes their child's potential and minimizes their limitations (Zolkoski & Bullock, 2012). Furthermore, caregivers and families, who have been oppressed by race, class, and/or gender, (Elias & Haynes, 2008; Cauce, Cruz, Corona, & Conger, 2011), could be engaging in perspective-taking that holds ADHD as a condition to intervene and treat, but not one that is going to define their child's life or future. Overall, study findings highlight the complex relationship between ADHD, race/ethnicity, and caregiver perspectives of their child's future and extends previous research on parent perspectives on ADHD within ethnic minority populations (Bussing, Gary, Mills, & Garvan, 2007; Bussing et al., 2012).

Parent mutuality concerns. While parent mutuality was not a primary family management factor for this study, caregivers with an active partner in the home verbalized differences regarding their perspectives on their child's ADHD, how to best intervene and treat the condition, and their approaches to management and overall parenting. These findings were aligned with previous research that suggests a gendered difference in how female or male caregivers perceive and manage a child with chronic illness (Barnard-Brak, Schmidt, & Sulak, 2013). In our study, female caregivers often described their perceptions of what the other caregiver thought or believed about ADHD and its management and the potential conflict this may have created in their relationship, parenting dynamics, or family life. On the other hand, some caregivers said they weren't sure how their partner viewed ADHD or the shared responsibility of managing the condition. Within clinical practice, providers often have only one caregiver present for appointments or treatment. When this occurs, clinicians naturally focus on the engaged caregiver, but it's also important for clinicians to be family-focused and inquire about secondary caregivers and what their perspectives are on the condition and care management. This investment with multiple caregivers underscores the foundation of family-focused or family-centered care and emphasizes the philosophy behind holistic nursing practice (Smith, Swallow, & Coyne, 2015).

Barriers to ADHD Management. In this study, we explored caregivers' perceptions of the barriers or challenges associated with family management for children with ADHD. Barriers and challenges were identified by caregivers in six major areas, including those within: 1.) the immediate family, 2.) extended families, 3.) stigma regarding mental health, 4.) educational systems, 5.) healthcare systems, and 6.) financial, insurance, or policy systems. The qualitative findings accentuated the relative influences of individual family members and dynamic family processes within the management of ADHD. During the interviews, some caregivers identified their own chronic illnesses or injuries that created more challenges and burdens when managing their child's ADHD. For other caregivers, extended family members, who often had limited understanding of ADHD, less tolerance for ADHD symptoms, and minimal guidance on how to manage ADHD behaviors, were the major challenge. This is consistent with family management theory that supports the role of family processes regarding disease or condition management and its influence on caregiver, family, and child outcomes (Knafl, Deatrick, & Havill, 2012). This underlines the importance of integrating family theory into the research of children with ADHD.

Furthermore, stigma played a significant role for these families regarding mental illness, parenting, stimulant medications, and negative labels placed upon children and families who are managing ADHD. Previous research suggests that stigma is a major barrier to seeking care and services for mental health, especially for ethnic minorities (Gary, 2005). Within this study, however, children and families still faced stigma after seeking services and care and while managing the condition at home, at school, and in the community. Stigma interfaced onto the lives of these children and families in different ways. Many caregivers reported that stigma prevented them for trialing medicine for their child's ADHD, including significant concerns and misconceptions that stimulants would turn their children into "zombies" or change their personalities. This is consistent with previous research that suggests parents and caregivers, especially those from racial and ethnic minority backgrounds, have significant fears, worries, and concerns about the use of stimulant medications to treat ADHD (DosReis, Mychailyszyn, Myers, &, 2007; Krain, Kendall, & Power, 2005). In addition, many caregivers reported that family members, educational providers, and the community were judgmental and labeled caregivers negatively who have a child with ADHD. In the interviews, caregivers often spoke about the resistance they felt from their parents on diagnosing and treating their child's ADHD, and the challenges associated with staying the course despite the strong feelings and opinions of others, including family members. Black and African-American caregivers in this study reported this was especially burdensome and difficult, which is supported by prior literature on African-American experiences with childhood ADHD (Bussing et al., 2012; Olaniyan et al., 2007).

In regards to barriers within the educational system, caregivers described major challenges experienced when managing their child's ADHD within the educational system. Caregivers' perceived that teachers and school personnel had varying levels of understanding and awareness about ADHD and how to manage the condition. In addition, there were inconsistent discipline and policy standards between schools and different levels of communication, guidance, and support between schools and caregivers. These findings were consistent with previous research that showed children and families within inner city schools have significant difficulties in communication and coordination with school providers (Guevara et al., 2005; Morgan, Staff, Hillemeier, Farkas, & Maczuga, 2013). Current and past research initiatives are addressing some of these barriers and challenges by targeting school culture and climate change (Eiraldi et al., 2012) and enhancing family-school partnerships (Power et at., 2012). More widely disseminating and implementing school-based interventions for children with ADHD may provide an opportunity to reduce the barriers and challenges for caregivers and families engaging in educational systems and services.

Within the healthcare system, the major barriers for families in this study were related to access and clinical issues (i.e., obtaining access to services, long wait times, multiple providers and frequent provider turnover, lack of appropriate guidance and support and clinical experiences in the mental health field). Caregivers in this study also experienced significant challenges and barriers to accessing services that were primarily covered by medical assistance. In fact, the process of applying for additional insurance or income was an extremely tedious and lengthy process for caregivers within this study. This finding contributes to the literature on ADHD-related services within the context of a large urban environment in which essential mental health services are linked to having medical assistance as a primary or secondary form of insurance coverage.

Caregivers also discussed the facilitators for ADHD management that contributed to their child and family's success, including support from the community, their families, educational, and health care environments. The dissertation findings that caregivers rely on strong supportive families, friends, and communities that connect them with information, resources, and guidance, was consistent with the literature on informal support networks for children with ADHD (Bussing et al., 2003). In addition, when caregivers discussed the strong partnership and collaboration between schools and teachers, this was also reflected in previous literature, which suggests that family-school partnership leads to better outcomes for children with ADHD (Power et al., 2010). Caregivers who reported that providers gave them anticipatory guidance, were flexible with appointment times, and actively listened to parental concerns, had more positive experiences.

Children with ADHD are children first. Perceptions from caregivers about the strengths of their children emerged in this research as secondary findings that contributed to our understanding of how caregivers view their child with ADHD and reflect an emphasis in the resiliency literature (Dvorsky &, Langberg, 2016; Lee, Sibley, & Epstein, 2016). Caregivers portrayed children with ADHD in regards to their personality traits, hobbies, academic strengths, task-related activities, and interests. These descriptions included terms such as artistic and creative; curious, inquisitive, and intelligent; caring, sweet, and loving; active with sports, music, dance, and art; academically strong in math and science; helpful with different individual or family tasks; and likes or interests similar to other children their age. These findings indicated a defining moment in the research process in which these children were not just children with ADHD, they were children with their own individual interests, identities, and abilities. During the interviews, caregivers unearthed the humanity of their children and the importance of including caregivers and children with ADHD in healthcare and medical research. Children in this study were not defined exclusively by their symptoms of ADHD and were more than just research subjects (Goffman, 2009). These children were real people with real identities and real lives. In this study, caregivers created a cohesive and clear narrative in which children with ADHD were more than just children with a chronic illness. These children had personalities and lives beyond the context of this research, and caregivers dreamed about the possibilities of their children becoming artists, dancers, engineers, veterinarians, politicians, or cruise entertainers.

Caregivers as strong advocates. In regards to their own strengths, caregivers required extra time to contemplate on their own strengths and abilities. This is consistent with other caregiver literature which demonstrates that caregivers typically prioritize others' needs and attributes above their own (Murphy, Christian, Caplin, & Young, 2007). When necessary, the lead researcher would provide reflections on the strengths identified during interviews to prompt caregivers to recognize their strengths. This may have introduced some bias by doing so, but findings across the sample of caregivers consistently revealed that caregivers were strong advocates for their child and encouraged efforts to promote their child's health, well-being, and success. By providing consistent love, patience, devotion, and commitment, caregivers showed how much they supported and cared for their children.

Fighting for others. Caregivers also provided advice and recommendations for providers and other parents of children with ADHD. They were outspoken in their attempts to help other families of children with ADHD and made powerful statements and declarations as parents and caregivers of children with ADHD. They communicated that they were caregivers who have fought the "good fight" and who will continue to fight for their child and family. They wanted to share their experiences and wisdom with other parents and families of children with ADHD on the importance of perseverance, providing preliminary evidence for the need of a support group or online support venue for parents and caregivers of children with ADHD. This adds to the literature regarding the importance and value of informal support networks and community-based services for caregivers of children with ADHD, (Bussing et al., 2003; Kendall, Beckett, Leo, & Hatton, 2005), especially those from racial and ethnic minority families.

Discussion of Quantitative Results

The second aim of this study was to quantitatively describe child, caregiver, and environmental characteristics and examine how family management factors were related to children's level of functional impairment. Hypotheses regarding family management factors were: 1.) Higher scores for child's daily life and condition management ability would be correlated with lower levels of children's functional impairment, and 2.) Higher scores for condition management effort and view of condition impact would be correlated with higher levels of children's functional impairment. In the following section, sample demographics, correlations between major study variables, use of the family management measure compared to other pediatric studies, and use of the impairment rating scale for ethnically diverse children with ADHD will be discussed using quantitative findings.

Sample demographics. Our sample of children was diverse on multiple demographic variables, such as age, gender, race/ethnicity, ADHD symptom severity, ADHD treatment type, and mental health comorbidities. With 74% racial and ethnic minorities, this study included both male and female children from a large urban environment. These numbers exceeded our expectations for racial and ethnic diversity in the sample. In addition, we gathered information on national or cultural associations for both children and caregivers. With 11 different cultural groups represented in this study, these findings speak to the diversity within NIH-defined categories for race and ethnicity and breaks down the monolithic view of race and ethnicity as single entities. Rather, broad categories of race and ethnicity are multi-faceted phenomena with many national or cultural groups represented within each racial or ethnic category. Overall, the diversity within this study contributed to the body of literature on children with ADHD from ethnic minority populations, which had been previously identified as a significant gap in the literature (Paidipati, Brawner, Eiraldi, & Deatrick, 2017).

Over 80% of the children in the study had moderate or severe ADHD based on the Vanderbilt scale scores, which suggests caregivers in this study were managing children with significant symptoms or behaviors. These scores, however, only reflected primary caregivers' perceived ratings of ADHD. Clinician and teacher ratings would be instructive in future research. In regards to treatment, psychopharmacologic intervention is often warranted for moderate to severe cases of ADHD (AACAP, 2007). This may explain the high proportion of children on ADHD medications in this study (72%). On the other hand, these results are somewhat unexpected as the number of racial and ethnic minorities outnumbered non-minority children in this sample. Previous research suggests that racial and ethnic minority caregivers are less likely to pursue pharmacologic intervention for children with ADHD (Krain, Kendall, and Power, 2005). Based on previous literature, we would expect the proportion of children on ADHD medications to be lower considering the racial and ethnic diversity of caregivers in our sample. Our qualitative findings, however, suggested that even though racial and ethnic minority caregivers continued to approach medication treatment for ADHD with hesitation and worry, they often decided to treat their child with medications to improve their functioning and well-being. Less than half the sample (48%) reported therapy as their current treatment option. Here, caregivers may not consider school interventions or home-based services as traditional therapy. Future research should examine this issue.

In addition, almost one-fourth of children in the sample (24%) were diagnosed with Oppositional Defiant Disorder (ODD) per caregiver's report. Previous studies have shown that managing a child with ADHD and disruptive behavior disorder, like ODD, can increase caregiver strain and stress within the family (Hinojosa et al., 2012). The prevalence of ODD within this sample may have increased the amount of work and effort required by caregivers to manage their child’s condition as well as added significant challenges faced by caregivers within educational settings and their families’ lives.

Caregivers were also diverse in terms of age, race/ethnicity, and relationship to the child. Caregivers in this sample were biological and adoptive parents, grandparents, or legal guardians which highlighted the importance of including all types of caregivers to better understand the issues related to ADHD. Based on previous research, we were anticipating challenges recruiting caregivers from racial and ethnic minority families (Yancey, Ortega, & Kumanyika, 2006). In this study, we recruited fewer Latino and Hispanic caregivers than expected, possibly due to the English-speaking requirement. On the other hand, the majority of the sample included Black and African-American women (58%). Throughout the research process, caregivers stated they would participate in research or any activity that increased their knowledge about ADHD, management strategies, and resources or supports available. These women also clearly expressed wanting to help other families of children with ADHD by participating in research. This study provides counter-evidence that racial minority populations are less interested or less willing to participate in medical or health-related research, or at least, research in pediatric mental health (Kurt et at., 2016; Zamora, Williams, Higareda, Wheeler, & Levitt, 2016). While historical accounts and previous abuses against minorities in research are important to understand and contextualize in the modern day, they should not limit or preclude researchers from welcoming and including minority populations in their studies. This study contributes to the body of knowledge regarding research with minority populations and the importance of including institutional and structural supports for researchers to increase recruitment efforts for diverse populations. For example, the academic institution in which this research took place included recruitment enhancement services which provided the institutional support to recruit caregivers from a wide network and facilitated the diversity within the final sample of this study.

Our final study sample also represented significant diversity within residence type, socioeconomic status—marked by caregiver education and household income, and geographic location. The number of single and two-parent homes were equal in this study (48%). This was consistent with reports from the US Department of Health and Human Services, which stated 59% of children in Philadelphia county live in single-parent households (Blackwell, 2010). Based on these data, it may be important for pediatric and family researchers to develop and anticipate studies to include caregivers from both single and dual caregiver homes and to further explore differences in perspectives of ADHD by single verses dual caregiver homes. Also, researchers may want to reexamine previous research regarding single-parent households. Even though prior research suggests children from single-parent households have increased risk for poor adherence to parent management and behavior training for the treatment of ADHD in the research (Eiraldi, Mazzuca, Clarke, & Power, 2006), the findings from this study did not reflect this. In fact, single parent households were very similar to dual parent households in previously published family management research, only differing in their expressed management effort or demand (Knafl et al., 2011).

This study showed a marked difference in socioeconomic status, particularly related to caregiver educational and household income levels. The range for caregiver educational level varied with almost three-quarters of the sample (74%) having a college degree or higher. Hence, caregivers in this study were highly educated. The income range was quite variable, however, from less than $10,000 to over $100,000, with over half of the sample (54%) with annual income levels below $50,000. Furthermore, twenty percent of the sample were below the federal poverty level for families of four (<$24,000/year) and ten percent of those lived in deep poverty (<$12,500/year) (Cauthen & Fass, 2008). This suggests that many families in this study were living in poverty or with very low incomes despite the high levels of caregiver education. During this study, lower income levels (e.g., less than $50,000) were noted on demographic questionnaires for caregivers with higher educational levels (e.g., a college or graduate degree), especially for African-American women. These findings may suggest an education-to-wage gap for caregivers in this study (Mandel & Semyonov, 2014; Richard, 2014) and should be explored further. Finally, children and families in this study represented over 20 different neighborhoods and zipcodes, which highlights the geographic diversity of the sample and increases the generalizability of these findings to other major cities and large urban environments.

Correlations with main study variables. In this study, there was a positive correlation between ADHD symptom severity and children's level of functional impairment. The correlation of this relationship was medium strength ($r = .41$, $p < .05$) recognizing its importance, but other variables could have contributed to children's functional impairment besides ADHD symptom severity in this sample. Future research should examine the relationships between functional impairment and additional child, caregiver, or environmental factors, such as those in the conceptual model on *Figure 3.3*.

The main purpose for this study, however, was to examine the relationships between family management factors and children's level of functional impairment. We aimed to understand this area of the conceptual model to enhance the science on family management and test our hypotheses related to family management and functional impairment. All the hypotheses theorized for this dissertation study were supported by quantitative findings and will be discussed further below. The child's daily life scale (i.e., higher scores more positive) was negatively correlated with the total IRS score (r = -.56, $p < .001$). As caregivers perceived their child's daily life as more normal despite the condition, functional impairment decreased. In other words, child function improved when caregivers viewed their child as more normal despite their ADHD. As condition management ability scores increased (i.e., higher scores also more positive), functional impairment scores decreased (r = -.56, $p < .001$). This confirmed our hypotheses namely, as caregiver-perceived condition management ability improved, child functioning also improved. While these relationships (i.e., child's daily life, condition management ability, child functioning) have been well-established in the chronic illness literature (Knafl et al., 2013; Knafl et al., 2015), this study was the first to examine these relationships exclusively in a sample of children with ADHD.

Conversely, as condition management effort scores increased (i.e., higher scores more negative), functional impairment (as measured by the IRS total summary scores) increased (r = .46, $p < .01$). This positive relationship indicated that as caregivers expend more effort to manage their child's ADHD, perceptions of their child's functional impairment increased. Furthermore, as scores from the view of condition impact scale increased (i.e., higher scores more negative), scores from the total IRS scale increased. As caregivers perceived their child's condition as more serious with greater concern for the future, child functioning was worse. These relationships (i.e., condition management effort, view of condition impact, child functioning) are similar to the findings in other pediatric studies using the family management measure (Deatrick et al., 2014; Knafl et al., 2013). Findings from this study, however, will contribute to the literature on family management for children with ADHD, which has yet to be examined in prior research.

Moreover, the strengths of these relationships revealed interesting findings in the data. Two of the FaMM scales, child's daily life and condition management ability, had the strongest correlations with the main variable of interest. These findings underscore the value of normalizing ADHD within everyday life despite differences between children with and without the condition. These findings also emphasize the importance of caregiver perceptions regarding their ability to manage ADHD in their child's life. On the other hand, the correlation between view of condition impact and functional impairment was the weakest correlation of family management factors in this sample ($r = .33, p < .05$). From qualitative findings, many caregivers thought the future was important to think about, but not nearly as important as the here-and-now for their child or family. Caregivers recognized the worries and fears associated with their child's future, but preferred to focus on what they could do in the present, potentially to circumvent possible negative outcomes in the future. This focus on present life verses future life may account for the low correlation in the dissertation sample.

Finally, in this study, the correlation between condition management effort and total IRS summary score was medium strength (r = .46, $p < .01$), but also clinically relevant in this sample of children with ADHD. Qualitatively, we gleaned from caregivers' experiences the physical, emotional, and psychological work and demands that are needed to manage ADHD. From the interviews, caregivers' persistent effort, however, did not always improve child outcomes, especially in complex academic or family environments. This discrepancy between effort and outcome may be a result of multi-level and multi-systemic factors, such as access and availability to adequate services and supports for ADHD, or other environmental influences within the family. Nonetheless, the correlation suggested that condition management effort relates to child functioning in this sample of children with ADHD.

Use of the Family Management Measure compared to other pediatric studies. In this study, we also compared sample means for the family management measure in this study to other pediatric studies (Deatrick et al., 2014; Knafl et al., 2015; Knafl et al., 2013) to see if the family management measure was an acceptable to instrument to use within the pediatric ADHD population. While our sample size was smaller than the other two studies, the means across samples were very similar. For example, child's daily life and condition management effort scores were very similar between children with ADHD and pediatric chronic illness, which may suggest that caregivers perceive children with chronic illness as overall very similar to children with ADHD despite differences based on their specific chronic condition. Considering ADHD is a condition with management demands that may be similar or parallel other pediatric chronic conditions, this finding is not altogether surprising. In addition, the comparisons provide evidence that the family management measure may be used for children with ADHD. As previously noted, family management theory has been used to guide and facilitate past qualitative research (Conlon, Strassle, Vinh, & Trout, 2008; Kendall & Shelton, 2003), but from our knowledge, research has yet to use the instrument in this population. These study findings provide preliminary evidence for the use of the FaMM in future studies with children with ADHD.

Furthermore, this research may contribute to the conversation surrounding mental health and pediatrics. If an instrument developed for caregivers of children with chronic medical conditions can be used successfully in a sample of children with a mental health condition, then perhaps chronic pediatric medical and mental health conditions are not so different, from a research perspective. Being so, this dissertation study contributes to the normalization of childhood mental health conditions instead of continuing to separate mental health from physical or medical health in children in the literature. Additional studies examining older youth (i.e., 13-18 years) and youth from different geographic areas would also contribute to our understanding of family management within the ADHD population. In future work, family management studies that explore other behavioral health conditions, such as depression, anxiety, or autism, would continue to advance the science and knowledge within nursing and family research.

Discussion of Mixed Methods Results

The tertiary aim of this study was to use a mixed methods approach to integrate the qualitative and quantitative findings and to identify complementary themes within family management that relate to children with ADHD at higher and lower levels of functional impairment. In the following section, each family management factor at higher and lower levels of children's functional impairment in this sample will be discussed using mixed methods findings.

Child's daily life. For child's daily life, caregivers of children both in the higher and lower function categories continued to strive for normalcy in everyday life and focused considerably on viewing and treating children with ADHD similar to other children their age. Even for children with severe ADHD and/or higher functional impairment, caregivers emphasized the importance of maintaining similar expectations and responsibilities for their child despite the condition. Even though caregivers strived for normalcy and held their children accountable, they did not deny the existence of the condition. This diverged from findings from a recent integrative review that found that parents from racial and ethnic minority groups were less likely to recognize and/or perceive ADHD as a valid medical condition or a problem requiring medical treatment (Paidipati, Brawner, Eiraldi, & Deatrick, 2017). As noted in the limitation section within the review, findings may not have reflected recent trends on how caregivers view ADHD. Findings from this dissertation study will enhance the current body of the literature on how racial and ethnic minority parents and families understand and view childhood ADHD.

Condition management effort. For condition management effort, caregivers of children in both higher and lower categories of functional impairment reported the significant amount of work involved in managing a chronic condition, like ADHD. In this study, even caregivers of children with lower functional impairment expressed how management demand was prominent in their families' daily life. This corresponded with the weak to moderate correlation between condition management effort and functional impairment. Of course, it may be that the more effort caregivers devote to their child's ADHD management, the better the child functions. Quantitatively, more sophisticated statistical analyses are required to further understand this relationship between effort and outcome and to examine it from a multivariable perspective. Qualitatively, however, what seemed to differentiate those caregivers and children who were lower functioning were the concerns about the amount of effort and energy that was necessary to sustain management consistency over time and condition severity. As with all chronic illnesses, disease management is not limited to a specified time frame but rather, an ongoing process that places constant demands and burdens on caregivers (Murphy, Christian, Caplin, & Young, 2007; Deatrick et al., 2014). For many caregivers, this persistent demand and effort became tiresome and more burdensome over time. This may provide researchers with a modifiable avenue for developing family-based interventions that aim to reduce caregiver burden, and, to relieve psychological and emotional demands that might arise in the course of caregiving for ADHD children.

Condition management ability. For condition management ability, there was a marked difference for the caregivers of children in the higher versus lower functional impairment category. For families of children with lower function, they were still in the "trial and error phase" of ADHD management and trying to figure out what worked for their child. For these families, caregivers were still trying to negotiate daily routines and management strategies. For families of children who were higher functioning, caregivers reported more consistency within the daily routine and a mastery of management strategies that worked for their child. Condition management ability for families of children at higher and lower levels of functional impairment was inversely and moderately correlated with child functioning, suggesting that as perceptions of condition management ability improves, child function also improves. Similar to condition management effort, condition management ability may be a key modifiable variable and lead to opportunities for intervention with these families. For example, researchers are currently working to develop interventions for caregivers of children with pediatric brain tumors to enhance caregivers' perceptions of their management ability (Deatrick, 2011). This could be an excellent model for researchers who are invested in the caregivers and families of children with ADHD.

View of condition impact. For view of condition impact, caregivers of children in both higher and lower functional impairment categories hoped for a bright future for their child, but with varying levels of concern and worry. For caregivers of children who are higher functioning, the future is marked by promise and opportunity. For other caregivers, however, the future was shadowed by doubt and worry about their child's safety and overall ability to succeed in life. Because the future is uncertain and somewhat daunting, there was a present-focus for many of these families. Many caregivers purportedly put forth their efforts and energies in caring for their child *now* as opposed to focusing and worrying too much about future. This tenuous relationship was reflected with the weak but positive correlation between caregivers' views of condition impact and children's functional impairment, which may be explored further with additional analysis. Altogether, this study has substantial implications, including those for research, practice, and policy.

Implications for Research

The primary aim of the research was to qualitatively explore how families of ethnically diverse children manage ADHD on a daily basis. This study also aimed to explore the perspectives of ethnically diverse children with ADHD and their families Robust and comprehensive interviews from 50 caregiver participants provided extremely rich data. Future secondary research may examine these mixed methods data even further, possibly for dyadic analyses between gendered caregivers, as explored for mothers and fathers of brain tumor survivors (Deatrick, 2016). In addition, prior research suggests how difficult it is to engage racial and ethnic minorities in health-related research (Yancey, Ortega, & Kumanyika, 2006). This was not a barrier for this study. Possible reasons for this may include the minimal risk of the study, the topic of ADHD as central to caregivers and families, and recruitment efforts, which increased the opportunity for previously marginalized groups to participate in health-related research. On the other hand, we were limited in the number of caregivers who self-identified as Latino or Hispanic in this study. Future research should examine the perspectives of

Spanish-speaking families and their views on the management of children with ADHD as they may vary from the current findings.

Along these same lines, this study highlighted the systematic and structural factors affecting children with ADHD and their families, including educational, healthcare, and political factors, emphasizing the importance of ecological perspectives. Future research should broaden these areas and partner with schools, healthcare providers- both in the private and public sector, and policy-makers to gain a further understanding of the issues and explore possible solutions for the barriers and challenges presented in this study. For example, Eiraldi and colleagues (2012) are completing the end of a 5-year study evaluating the effectiveness of school-based interventions within a large urban city. This community-engaged research bridges together researchers and clinicians from two pediatric health systems, teachers and school personnel, and key leaders within the city's public school district. This integrated and multi-level approach to research hopes to improve the lives of children by targeting both individual and family factors, as well as community and environmental factors, which are tied to social determinants of health and health equity frameworks, as discussed earlier in the paper.

Additionally, we collected information on neighborhoods and zipcodes. Future research may include GIS (Geographic Information Systems) mapping studies, in which families of children with ADHD who experience higher levels of functional impairment, greater family management burden, and more extensive barriers or challenges navigating educational, healthcare, and financial systems, may be the focus of additional study and intervention. By identifying children and families with higher need based on geographic location, pediatric, nursing, and mental health researchers may enhance community-based efforts within these communities to enhance child and family health as well as improve partnerships between families and educational and healthcare systems. As evidenced within the interviews, caregivers recommended and advocated for support groups and activities within their own neighborhoods to decrease stigma and increase awareness, which may also serve to build resilience within their communities.

Finally, this study may lead researchers to begin the process of developing and testing family-focused interventions. Family management theory provides a systematic approach to understanding and intervening with families caring for a child with chronic illness. As evidenced by this study and previous ones, there is an established relationship between family management factors and child outcomes (Knafl et al., 2013; Knafl et al., 2011; Deatrick et al., 2014). The findings from this work supports a future study that specifically explores how to improve family management for caregivers of children with ADHD (i.e., developing interventions to improve condition management ability). Alternatively, interventions could focus on how to decrease caregiver burden by providing psycho-social support (i.e., to relieve the emotional or psychological demand). These avenues for future research highlight how theoretically-based descriptive studies may translate into future intervention work that aims to develop theoretically-derived clinical interventions that will provide a solid foundation for evidence-based practice.

Implications for Practice

Findings from this study may inform and influence changes in clinical practice for children with ADHD and their families. Caregivers in this study emphasized the tremendous amount of effort and work involved in managing ADHD and how this demand may impact their psychological and emotional responses to their child as well as their overall health and well-being. To effectively engage with families, clinicians working with children and families should first acknowledge and recognize the demand and burden placed on caregivers and offer support and solutions within their clinical care and treatment plans. At times, this may include recommending mental health counseling or psychosocial services for parents and caregivers, which is aligned with nursing's mission to provide holistic and comprehensive care to children and families. In addition, caregivers described challenges with their extended families in regards to their views on ADHD, how to parent or manage the condition, and negotiating difficult family relationships as well as potential safety issues for their children. Health providers may want to enhance their ADHD tool-kit by including information on how to discuss childhood ADHD with extended family members, extra strategies for managing the condition when family members are present, and boundary-setting when conflicts arise. Clinicians may also want to discuss the role of stigma within mental health and how to navigate through this stigma when it interferes in child and caregiver relationships with extended family members.

Furthermore, caregivers explicitly expressed their frustrations with both educational and healthcare systems regarding the lack of information and guidance from providers for accessing available resources and services for ADHD. Currently, care providers may provide a handout with a list of services or resources, but as this study revealed, caregivers also need help navigating through the complex systems, polices, and procedures related to obtaining these services or supports. A more intensive and hands-on approach is required to develop skills to guide families through this process and facilitate service utilization for children with ADHD. A prime launching point is the ADHD Boot Camp, which is offered for parents and caregivers of newly diagnosed children with ADHD at the Children's Hospital of Philadelphia. This four-session workshop provides families with basic information about ADHD, its treatment, management strategies, and resources available. As a next step, additional sessions could be added to give families key information and anticipatory guidance on how to access and obtain services. These workshops may want to include a mental health clinician (e.g., psychologist, psychiatric nurse practitioner) as well as a case manager, social worker, or pediatric nurse, who understands the landscape of mental health services within the City of Philadelphia). If successful, the ADHD Boot Camp format could be scaled up for implementation in other areas of the country. In addition, when reflecting on the future for their child, caregivers asked about the services and supports available for youth in college or workplaces. As they transition from high school onward, providing caregivers with anticipatory guidance and information on the services and supports available for youth after high school may be incredibly helpful for caregivers of children with ADHD.

Furthermore, caregivers in this study reported specific challenges within the healthcare and educational systems, which could be targets for quality improvement within their respective environments. In the healthcare system, caregivers explained their frustrations when contacting a provider's office and speaking to a different person each time regarding their child's care and treatment. For primary care and developmental pediatrics, this may be common practice due to structure and operating systems within the clinics. Prior research, however, recommends improving the continuity and communication between healthcare providers and families to children with ADHD, especially those within inner-city environments, to be consistent with best practices to integrate mental health into pediatric care (Guevara, 2005; Martini et al., 2012). Furthermore, with current healthcare reimbursement systems weighing more heavily on health outcomes, this may be a desired direction for clinical practices, in general.

Another prominent challenge for caregivers and families was the high turnover rates, especially for mental health therapists and behavioral health workers, as evidenced in the interviews. Practice guidelines and initiatives that focus on the recruitment and retention of mental health clinicians and staff may decrease this high turnover rate and improve the overall patient and family experience within care (Guidelines for Best Practices in Child and Adolescent Mental Health Services, 2007). Within specialty care practices, such as behavioral health, long wait-lists are a significant barrier to access care. Caregivers in this study reported up to a one-year wait-times for an initial appointment with a mental health provider. Children who are undiagnosed or untreated for ADHD are at greater risk for functional impairment, psychiatric co-morbidities, and poor outcomes (Dulcan & Wiener, 2006). These lengthy wait-times may delay diagnosis and subsequent treatment for children with ADHD. Furthermore, for families to be eligible and access certain services, such as in-school or home-based services, a diagnosis of ADHD is required to obtain Medical Assistance. Being so, these long wait-times may also result in a delay of services for children with ADHD. Finally, caregivers mentioned a barrier to attend mental health appointments was the available appointment times within providers' schedules. Based on the findings from this study, expanding practice hours for primary care and behavioral clinics and providers is highly recommended.

Within the educational realm, caregivers discussed the challenges their children faced with different teachers, academic supports, and services available and accessible to them. Caregivers discussed their concerns related to teacher knowledge and skill to manage children with ADHD in the classroom. Providing current teachers and school personnel with the necessary education and training (e.g., in-house workshops, ongoing professional development) and building mental health and ADHD-specific modules into academic programs for elementary and secondary education are essential for improving child outcomes and caregivers' experiences; Eiraldi et al., 2012). For behavioral health workers, who are contracted from different agencies outside school systems (e.g., Community Behavioral Health), additional training may be indicated for professional conduct and verbal de-escalation techniques within home and school environments. During the interviews, several caregivers mentioned the lack of professionalism among these workers and even instances of inappropriate physical aggression towards their child. It is critical to provide these in-home and school-based services for children and families, but they require a safe and ethical approach to be fully effective. Furthermore, children should not be harmed—physically, emotionally, or psychologically—by behavioral health workers, and families should feel confident and secure with the workers who are helping their child in the home or at school. Partnering with agencies, such as

Community Behavioral Health, and providing the necessary training and remodeling as needed, may reduce incidents of professional misconduct.

Implications for Policy

The policy implications for this dissertation research range from grass-roots advocacy to national policy development. First, caregivers discussed the barriers associated with private and public insurance coverage and stressed the challenge of finding accessible services available through their specific insurance type. For some families, accessing services covered by public insurance (i.e., Medical Assistance) was more difficult, but for other families, accessing services provided within the private sector was more challenging. Unfortunately, America continues to have the most complex and costly health care system in the developed world without the best health care outcomes (Davis, Stremikis, Squires, & Schoen, 2014; Emanuel, 2014). While the Affordable Care Act (ACA) offered multiple avenues for greater insurance coverage and essential health care benefits, significant gaps remain for children and families with mental health needs (AACAP, 2013). Advocates of pediatric mental health should continue to advocate for policies that provide essential coverage for children with ADHD. Furthermore, in the absence of mental health parity, a health equity framework that identifies the inequities between health for children with medical versus mental health needs could assist with future policy development. Funding for behavioral health services and research across national, state, and local platforms continues to lag significantly behind other areas of pediatric health and requires a theoretical and practical change in how we view health and wellness for children and families.

This study also provided a keen insight and nuanced understanding of how community-based programs and services, like Medical Assistance (MA) and Supplemental Security Income (SSI), could work for or against families of children with ADHD. For caregivers in this study, many were over the traditional income requirements to be eligible for MA and therefore, were excluded from accessing services that were essential for their child's health and well-being. Increasing the income threshold, which would allow more families to be eligible for MA, would open doors for caregivers to access services that are exclusively covered by MA. With the United States Senate actively discussing proposed budget cuts to Medicaid funding across the country, the future for children with ADHD is concerning. States and counties, however, do have some discretion on how Medicaid funding is allocated across its contingencies. Pediatric, nursing, and mental health advocates and special interest groups can advocate for Medicaid funding through lobbying activities in their local and state communities.

As part of standard treatment for moderately or severely compromised children with ADHD, clinicians should explore discussions with families applying for SSI. This may have a significant impact on caregivers' experiences within the system and help them to readily address any concerns that might arise. In this dissertation study, caregivers described the lengthy time from initially applying to SSI to obtaining services; sometimes this process would take up to a year, if applications were routinely denied multiple times. Working closely with key stakeholders to remove the layers of bureaucracy and decrease the time from application to SSI approval is highly recommended to improve children's outcomes and caregivers' experiences within the system.

The educational system also requires policy changes to ensure positive child and family outcomes. In this study, caregivers described the lack of resources and supports available within the schools, especially within the public-school district. In response to this, we recommend that state governments allocate and spend a greater proportion of their yearly fiscal budget on education within the public-school districts, which would increase the availability of resource capital (e.g., more teachers, mental health professionals, training) per school. Symbolically, this also would communicate a clear message to caregivers, namely, we are invested in your child's education and are willing to dedicate our city's resources to you and your family. If we are going to continue to utilize and integrate behavioral health programs into schools, then we need to be more consistent across and within schools. Otherwise, as families pointed out in this study, these programs may do more harm than good, particularly when they disrupt children's lives and educational trajectories. Furthermore, caregivers also discussed the differences between public, private, and charter schools, specifically regarding the policies on Individualized Education Plans, or IEPs. One caregiver recommended private schools be held to the same standard as public schools in terms of initiating and providing IEPs to eligible children. While the city may not have leverage to change policies within the private education sector, family and professional advocates, lobbyists, and special interest's groups may place pressure on schools to change their policies as to the availability and use of IEPs.

Finally, the stigma surrounding mental health and childhood ADHD was significant in this sample of caregivers and families. Using a grassroots approach to change perceptions on mental health and childhood ADHD, initiating community campaigns throughout the city to decrease stigma and increase advocacy efforts and activities would be worthwhile. In this study, caregivers proposed hosting events or support groups for parents of children with ADHD to increase awareness, share experiences, and provide psychosocial support. Other suggestions were to create support groups, online or in-person, or have monthly newsletters for parents and families of children with ADHD. Caregivers also implied they would like to participate in charity walks for ADHD or engage in other activities with families of children with ADHD. Finally, caregivers were inquiring about a color that represented children with ADHD (e.g., orange) and recommended lighting up with the Philadelphia sky with this color to illuminate ADHD awareness and advocacy.

Limitations and Methodological Considerations

There are inherent limitations and methodological considerations in the design of this study. First, recruiting participants from designated CHOP clinics and using the CRU (or CHOP's Recruitment Registry) may have created a systematic bias in which all participants in this study were linked to the CHOP network. It could be that these caregivers prioritized their connection to academic research and valued research, and therefore, led to their participation in this study. Thus, we may be missing some families who were not connected to the CHOP network. Study results should be interpreted with caution as they may only reflect the perspectives of caregivers and families who are affiliated with this single network of providers. Using the REC for recruitment purposes, however, provided valuable information about recruitment within this population (i.e., caregivers were very interested and willing to participate in research about families with ADHD).

Second, including only English-speaking caregivers in this study limited the variability of diverse families represented and excluded families that otherwise would have been eligible for the study. Specifically, the Spanish-speaking only caregivers of children treated for ADHD at the South Philadelphia CHOP primary care site would have been eligible to participate in the study in the absence of the language requirement. Unfortunately, due to financial constraints for translation and interpreting services as well as the lack of available instruments in different languages, we were not able to include caregivers who did not speak or read English in this research. To include these participants and enhance the diversity and generalizability of study findings, a future study is indicated using Spanish-speaking or multi-lingual researchers, materials, and services.

Third, this study only used caregiver-reported instruments to measure ADHD symptom severity and functional impairment. Routinely, clinician and teacher reports are also used in addition to parent reports to comprehensively and holistically assess, monitor, and evaluate ADHD symptoms and outcomes in clinical practice. From a feasibility standpoint, however, this would have been difficult to do in the context of a dissertation study with a limited time frame. In addition, the primary aims of this study were to understand the perspectives of caregivers of children with ADHD and including only caregiver-reported measures was an appropriate decision considering the overall scope and purpose for the study.

Fourth, when we designed this study we assumed that only one caregiver per family would be interested and able to participate in the research. Surprisingly, 10% of the sample included two caregivers who attended the study appointment about their child with ADHD. After the third occurrence, the lead researcher and qualitative advisor on the study decided to continue having only one caregiver complete the study instruments, but to allow the second caregiver to attend the interview. By doing so, we do not know if the second caregiver influenced or biased the results of the study in some way (i.e., the primary caregiver may have under or over reported during the interviews based on the presence of the secondary caregiver). On the other hand, when analyzing these five interviews, the second caregiver primarily emphasized key points and themes provided by the primary caregiver and did not introduce any new topics to the discussion. This strengthens the validity of the study despite the presence of the secondary caregiver.

Furthermore, the lead researcher (with her optimistic disposition and strengths-focused approach) may have had undue influence on how caregivers discussed their management abilities. While caregivers felt comfortable discussing weaknesses and limitations within their extended families, healthcare, and educational systems, they may not have felt ready to discuss their own perceived personal weaknesses in a research study with limited engagement or opportunities to build trust with the lead researcher. A longitudinal study or a study that incorporates the child's primary ADHD provider may offer additional opportunities to engage with caregivers on how they perceive their management ability.

Fifth, we had children and siblings attend the appointments with 20% of their caregivers. This might have distracted caregivers as they reflected on the study goals. Future research should anticipate this and plan for childcare during research interviews or appointments. Furthermore, during the eligibility screen, we had a number of caregivers who had more than one child who had ADHD and wondered if more than one child could participate. From a methodological standpoint, this would have been difficult, because the same family would have been represented twice in the final sample—once from each child. As a result, caregivers were told that only one child was eligible to participate in the study. Caregivers were comfortable with this decision and chose which child to enroll in the study.

Lastly, there is a danger in characterizing different groups of families together and making generalizations about these groups based on their race or ethnicity. The results of this study should not be used to further stereotypes or negative biases, but to broaden our perspectives of ADHD in diverse populations. The intention of this study was to expand and extend on previous research with diverse children with ADHD to gain a deeper understanding of the barriers and facilitators that diverse caregivers and families may experience. Too often, socioeconomic status and race and ethnicity, are conflated in research with minority populations. In this study, the major barriers and challenges of ADHD management were experienced by families and caregivers across socioeconomic status (SES) and racial and ethnic lines, which may indicate that SES and race/ethnicity are not the primary drivers of health disparities within this population. By including caregivers from diverse backgrounds, the findings from this dissertation hope to move the body of health disparities and health equity research forward by acknowledging and highlighting the social and ecological factors that may influence or impact ADHD management in diverse families. Future research should investigate factors beyond race, ethnicity, and socioeconomic status to further understand health disparities for children and families with ADHD.

Concluding Remarks

This study aimed to investigate the impact of family management on children's functioning and the challenges and successes experienced by caregivers regarding the management of children with ADHD across a spectrum of child functioning. Part of the purpose of this research was to understand how ethnically diverse caregivers managed childhood ADHD in their everyday lives. Qualitatively, caregivers perceive children with ADHD as children first, not identified with their mental health condition. In response to their condition, caregivers are heavily invested and well-resourced in their children's day to day lives, but still struggle to manage ADHD in the face of other competing demands and stigma in regards to their child's condition and treatment. Significant barriers and challenges, especially those within education and healthcare segments, negatively impact caregivers' experiences in regards to managing their child's condition. Research, practice, and policy changes are required to decrease mental health stigma within diverse communities and better support children with ADHD and their families. Quantitatively, this dissertation research aimed to examine the relationships between family management factors and children’s level of functional impairment and revealed significant correlations (<.05; weak to moderate) in hypothesized directions between family management factors and child functioning. Further research is now necessary to build upon these findings. By integrating the findings, this mixed methods study deepens our understanding on family management for caregivers of children at different levels of functional impairment and extends previous research on family management and ADHD in diverse populations. Overall, the knowledge gained from this study builds upon existing knowledge and serves as the basis for a larger program of research that aims to develop family-based interventions or address system level barriers and challenges within diverse communities for children with ADHD and their caregivers.

Appendix

Appendix 1: Recruitment Letter for Emails

The Children's Hospital of Philadelphia® | RESEARCH INSTITUTE

Dear Parent or Guardian,

My name is Cynthia Paidipati, CRNP, and I am a researcher at CHOP. My team and I are trying to learn more about how parents and families living in Philadelphia manage caring for a child with ADHD. Our study is called the FaMM ADHD Research Study.

You received this letter because we are hoping to partner with families who have a child between the age of 5 and 12 with ADHD, or Attention Deficit Hyperactivity Disorder.

Our study is observational, which means that your child will not be asked to make any changes to their daily life.

If you agree to participate, you will be asked to:

- Complete surveys/questionnaires regarding your child with ADHD and your family
- Discuss how you and your family manage ADHD for your child

All participants are compensated for their time.

We are excited about the potential this research has to help other families, and we are looking forward to sharing more information about it with you.

Please contact me by email paidipatic@email.chop.edu or by phone **267-262-9897** (my direct line).

You received this letter due to your affiliation with The Children's Hospital of Philadelphia. If there are specific types of research that interest you, please sign up at our registry at www.chop.edu/trialregistry.

If you prefer to not receive communication from CHOP's recruitment enhancement core you can opt out by contacting us at participantrecruitme@email.chop.edu or calling 267.426.6846.

Sincerely,

Cynthia P. Paidipati

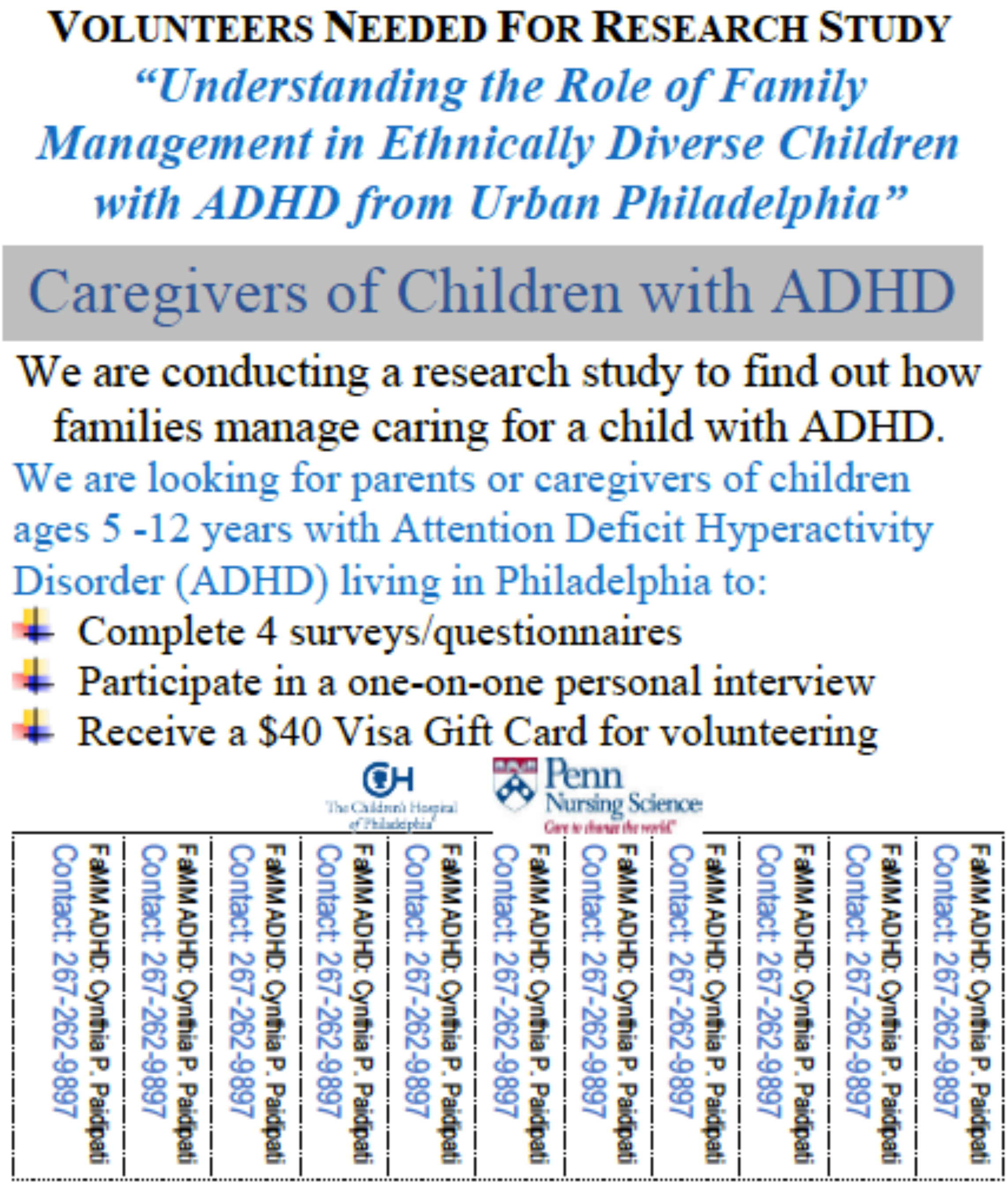
Cynthia P. Paidipati, CRNP-BC
Psychiatric-Mental Health Nurse Practitioner – Board Certified
Department of Child and Adolescent Psychiatry and Behavioral Sciences
The Children's Hospital of Philadelphia

Appendix 2: Recruitment Advertisement “This Week @CHOP” for Employees

“Seeking Participants for the FaMM ADHD Research Study”

The Children’s Hospital of Philadelphia is seeking parents or caregivers of children 5-12 years old with Attention Deficit Hyperactivity Disorder (ADHD) to participate in the FaMM ADHD Research Study. We would like to understand how caregivers and families living in Philadelphia manage caring for a child with ADHD. Participants will be asked to provide information related to their child’s ADHD and what unique experiences and challenges families might face when managing ADHD. The information collected in this study will be used to better understand how family management relates to ADHD symptoms and outcomes in children. Parents and caregivers will receive a gift card and ADHD resource binder for their time. For more information and study details, please contact us by phone 267-262-9897.

Appendix 3: Recruitment Flyer



VOLUNTEERS NEEDED FOR RESEARCH STUDY

"Understanding the Role of Family Management in Ethnically Diverse Children with ADHD from Urban Philadelphia"

Caregivers of Children with ADHD

We are conducting a research study to find out how families manage caring for a child with ADHD.

We are looking for parents or caregivers of children ages 5 -12 years with Attention Deficit Hyperactivity Disorder (ADHD) living in Philadelphia to:

- Complete 4 surveys/questionnaires
- Participate in a one-on-one personal interview
- Receive a $40 Visa Gift Card for volunteering

The Children's Hospital of Philadelphia

Penn Nursing Science

Care to change the world.

FaMMADHD: Cynthia P. Paidipati
Contact: 267-262-9897

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Contact: 267-262-9897

FaMMADHD: Cynthia P. Paidipati
Contact: 267-262-9897

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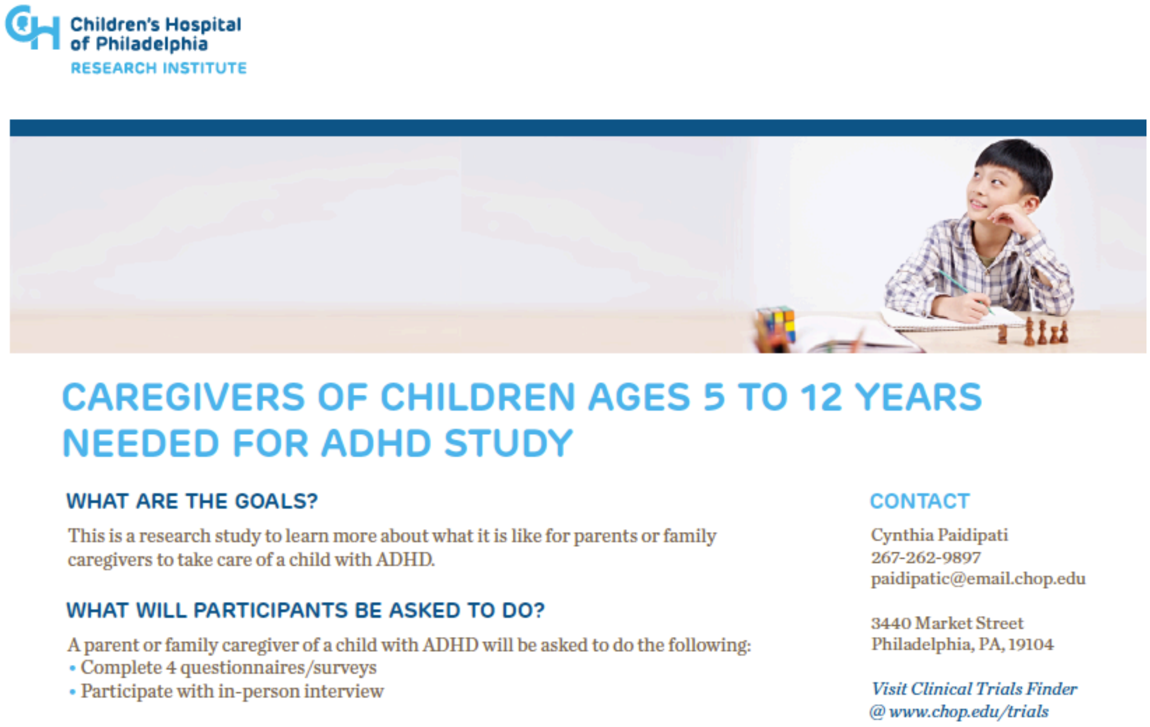
Contact: 267-262-9897

FaMMADHD: Cynthia P. Paidipati
Contact: 267-262-9897

FaMMADHD: Cynthia P. Paidipati
Contact: 267-262-9897

Appendix 4: REC Tear-Pad Flyer



Children's Hospital
of Philadelphia
RESEARCH INSTITUTE

CAREGIVERS OF CHILDREN AGES 5 TO 12 YEARS NEEDED FOR ADHD STUDY

WHAT ARE THE GOALS?

This is a research study to learn more about what it is like for parents or family caregivers to take care of a child with ADHD.

WHAT WILL PARTICIPANTS BE ASKED TO DO?

A parent or family caregiver of a child with ADHD will be asked to do the following:

- Complete 4 questionnaires/surveys
- Participate with in-person interview

CONTACT

Cynthia Paidipati
267-262-9897
paidipatic@email.chop.edu

3440 Market Street
Philadelphia, PA, 19104

Visit Clinical Trials Finder
@ www.chop.edu/trials

Appendix 5: Informed Consent Form and HIPAA Authorization for Screening

Informed Consent Form and HIPAA Authorization for Screening

Study Title:	Understanding the Role of Family Management in Ethnically Diverse Children with ADHD from Urban Philadelphia
Version Date:	November 1, 2016

Principal Investigator:	Ricardo Eiraldi, Ph.D.	Telephone: (215) 590-7759
Lead Investigator:	Cynthia P. Paidipati	Telephone: (267) 262-9897

You and your child, may be eligible to take part in a research study. The information that will be discussed gives you important information about the study. It describes the purpose of this research study, and the risks and possible benefits of participating.

If there is anything you do not understand, please ask questions. You do not have to take part in this study if you do not want to. If you take part, you can leave the study at any time.

The word "we" means the lead investigator of the study and other research staff.

Why are you being asked to take part in this study?

You are being asked to take part in this research study because you are a parent or caregiver of a child with Attention Deficit Hyperactivity Disorder, or ADHD.

What is the purpose of this research study?

We are conducting a research study on how caregivers and families living in Philadelphia manage caring for a child with Attention Deficit Hyperactivity Disorder (ADHD) and what unique experiences and challenges children and families might face. This part of the study is to identify individuals who are interested and eligible for the main study.

There is a second consent form describing the main study. You will have a chance to review that form before making a final decision about taking part.

What is involved in the study?

If you agree to take part in this screening study, we will ask you a few questions about your child's health history to see if you are eligible for the main study.

How long will you be in this study? If you agree, the questionnaire will take about 10 minutes.

What are the risks of this study?

As with any study involving collection of data, there is the possibility your confidentiality information will be shared with others. Every precaution will be taken to secure your personal information to ensure confidentiality.

Are there any benefits to taking part in this study?

There will be no direct benefit from taking part.

Do you need to give your consent in order to participate?

If you decide to take part in this screening study you must tell us that you agree. You do not have to participate in the main study even if you agree to participate in this screening study.

What happens if you decide not to take part in this study?

Participation in this study is voluntary. You do not have to take part in order to receive care at CHOP.

If you decide not to take part or if you change your mind later there will be no penalties or loss of any benefits to which you are otherwise entitled.

Can you stop your participation in the study early?

You can stop the questionnaire at any time.

What about privacy, authorization for use of Personal Health Information (PHI) and confidentiality?

As part of this research, health information about you and your child will be collected. This will include information from questions we ask you. We will do our best to keep your personal information private and confidential. However, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law.

Several people and organizations may review or receive your identifiable information. They will need this information to conduct the research, to assure the quality of the data, or to analyze the data or samples. These groups include:

- Members of the research team and other authorized staff at CHOP and UPenn;
- People from agencies and organizations that perform independent accreditation and/or oversight of research; such as the Department of Health and Human Services, Office for Human Research Protections;

By law, CHOP is required to protect your health information. The research staff will only allow access to your health information to the groups listed above. By verbally agreeing or signing this document, you are authorizing CHOP to use and/or release your health information for this research. Some of the organizations listed above may not be required to protect your information under Federal privacy laws. If permitted by law, they may be allowed to share it with others without your permission.

The identifiable information from this study will be destroyed after study manuscripts are accepted for publication.

Your permission to use and share de-identified information and data from this study will continue until the research study ends and will not expire. Researchers continue to analyze data for many years and it is not possible to know when they will be completely done.

Can you change your mind about the use of personal information?

You may change your mind and withdraw your permission to use and disclose your health information at any time. To take back your permission, it is preferred that you inform the principal investigator in writing.

Ricardo Eiraldi, Ph.D.
The Children's Hospital of Philadelphia
Department of Child and Adolescent Psychiatry and Behavioral Sciences
3550 Market Street, Office 1431
Philadelphia, PA 19104

In the letter, state that you changed your mind and do not want any more of your health information collected. The personal information that has been collected already will be used if necessary for the research. No new information will be collected. If you withdraw your permission to use your personal health information, you will be withdrawn from the study.

Financial Information

There are no costs or payments to participate in the screening part of the study.

Who is funding this research study?

The main study is funded by University of Pennsylvania School of Nursing.

All funding information will be reviewed if you decide to participate in the main study.

What if you have questions about the study?

If you have questions about the study, call the lead investigator Cynthia P. Paidipati at 267-262-9897. You may also talk to your child's health care provider if you have questions or concerns.

The Institutional Review Board (IRB) at The Children's Hospital of Philadelphia has reviewed and approved this study. The IRB looks at research studies like these and makes sure research subjects' rights and welfare are protected. If you have questions about your rights or if you have a complaint, you can call the IRB Office at 215-590-2830.

If verbal consent is obtained over the phone.

Documentation of Verbal Consent to Take Part in this Research Study and Authorization to Use and Disclose Health Information for the Research

Name of Subject

The research study and consent form was explained to:

Person Providing Consent	Relation to subject: ☐ Parent ☐ Legal Guardian

The person who provided consent confirmed that all of their questions had been answered and they agreed to their/their child's participation in this research study.

They confirmed that they were legally authorized to consent to their child's participation.

They agreed to let CHOP use and share their/their child's health information.

Person Obtaining Consent	Signature of Person Obtaining Consent
	Date

If written consent and HIPAA authorization is obtained in person

Consent to Take Part in this Research Study and Authorization to Use and Disclose Health Information for the Research

The research study and consent form have been explained to you by:

Person Obtaining Consent	Signature of Person Obtaining Consent
	Date:

By signing this form, you are indicating that you have had your questions answered, you agree to take part in this research study and you are legally authorized to consent to your child's participation. You are also agreeing to let CHOP use and share your or your child's health information as explained above. If you don't agree to our collecting, using and sharing your or your child's health information, you/your child cannot participate in this study. **NOTE:** *A foster parent is not legally authorized to consent for a foster child's participation.*

Name of Subject

Signature of Subject (18 years or older)	Date
Name of Authorized Representative (if different than subject)	Relation to subject: ☐ Parent ☐ Legal Guardian
Signature of Authorized Representative	Date

Appendix 6: Eligibility Screen/Appointment Set-Up Form

Date: __________
Study Team Member: _________________
Caregiver ID #: _________

Bold Wording indicates actual wording said by the study team member.

1.) <u>ELIGIBILITY SCREEN</u>

I am going to ask you a few questions to see if you are eligible for this study. This will only take a few minutes. Please stop me at any time if you have questions.

1. **First, I will be reading the questions to you in English. Will there be a language barrier for you?**

Yes	No
☐ I'm sorry. We are only conducting the surveys and interviews in English. At a later time, we may have versions in different languages. Thank you for your time and for considering helping out with the study.	☐ Go to question # 2

2. **I would like to confirm that you are the primary caregiver of a child with Attention Deficit Hyperactivity Disorder, or ADHD.**

Yes	No
☐ What is your child's name? ___________________ Go to question # 3	☐ I'm sorry. This study is designed for caregivers of children with ADHD. Thank you for your time and for considering helping out with the study.

3. **Is your child at least 5 but not greater than 12 years of age?**

Yes	No
☐ How old is your child? ________________	☐ I'm sorry. This study is designed for caregivers of children with ADHD who

Go to question # 4	are currently between the ages of 5 and 12. Thank you for your time and for considering helping out with the study.

4. Does your child live with you full-time or least 50% of the time?

Yes	No
☐ Full-time or >50%? ____________ Go to question # 5	☐ I'm sorry. We are only enrolling caregivers whose child with ADHD lives full-time or at least 50% of the time. Thank you for your time and for considering helping out with the study.

5. Is your primary residence within the city of Philadelphia?

Yes	No
☐ What zip-code? ____________ Verify zip-code is within Philadelphia If yes, Go to question # 6	☐ I'm sorry. We are only enrolling caregivers of children with ADHD who live in the city of Philadelphia. Thank you for your time and for considering helping out with the study.

6. Does your child have a severe developmental delay or cognitive impairment?

Yes	No
☐ I'm sorry. We are only enrolling caregivers of children with ADHD without severe developmental delays or cognitive impairment. Thank you for your time and for considering helping out with the study.	☐ Go to question # 7

7. Is your age at least 18 years or older?

Yes	No
☐ Go to Section 2. Appointment Set-Up	☐ I'm sorry. We are only enrolling caregivers of children with ADHD who are older than 18 years of age. Thank you for your time and for considering helping out with the study.

2.) <u>APPOINTMENT SET-UP</u>

Based on our screening, you and your child are eligible to participate in this study. The in-person interview with survey/questionnaire completion will take about 60 to 90 minutes. Let's pick a date and time that works for you.

Appointment Date/Time:

Alternative Date/Time:

We will meet at the CHOP clinic that your child currently receives care.

Appointment Location:

Our study team will call you the evening before and day of the appointment to confirm. If you need to cancel for any reason, or if you have any additional questions or concerns about this study, please call us at # 267-262-9897.

Thank you very much for your time. We look forward to meeting with you!

To be completed by the study team member after the phone call:

Assigned Caregiver ID #: ____________________

☐ Not Interested ☐ Not Eligible

☐ Eligible/Enrolled ☐ Eligible/Not Enrolled

Eligible Zip-Codes within Philadelphia

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Appendix 7: Informed Consent Form and HIPAA Authorization

Informed Consent Form and HIPAA Authorization

Study Title:	Understanding the Role of Family Management in Ethnically Diverse Children with ADHD from Urban Philadelphia	
Version Date:	November 1, 2016	
Principal Investigator:	Ricardo Eiraldi	Telephone: (215) 590-7759
Lead Investigator:	Cynthia P. Paidipati	Telephone: (267) 262-9897

You and your child may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of this research study, and the risks and possible benefits of participating.

If there is anything in this form you do not understand, please ask questions. Please take your time. You do not have to take part in this study if you do not want to. If you take part, you can leave the study at any time.

In the sections that follow, the word “we” means the lead investigator and other research staff.

Why are you being asked to take part in this study?

You are being asked to take part in this research study because you are a parent or caregiver of a child with Attention Deficit Hyperactivity Disorder, or ADHD.

What is the purpose of this research study?

The purpose of this research study is to understand how caregivers and families living in Philadelphia manage caring for a child with Attention Deficit Hyperactivity Disorder (ADHD) and what unique experiences and challenges children and families might face.

How many people will take part?

About 50 caregivers of children with ADHD will take part in this study.

What is involved in the study?

You will be asked to participate in an in-person interview with the lead investigator. You will also be asked to complete 4 surveys/questionnaires. The questions will be about how your family manages caring for your child with ADHD.

How long will you be in this study?

If you agree to take part, your participation will last for one (1) 60 to 90-minute visit, including survey/questionnaire completion, which will take approximately 30 to 45-minutes, and an in-person interview which will also take approximately 30 to 45-minutes.

What are the study procedures?

The study involves the following procedures.

In-Person Visit for Surveys/Questionnaires and Interview and - You will meet in-person with the lead investigator and a study intern at your child's clinic for completion of surveys/questionnaires and an interview. This visit will include the following study procedures:

Survey/Questionnaire: You will be asked to answer questions about your child and your family, including questions about your child's ADHD symptoms, how these symptoms impact your child's functioning at home, school, and with peers, and how your family manages the care of your child's ADHD.

Qualitative interview: After you complete the questionnaires, we will interview you one-on-one and talk more about how you and your family manage your child's ADHD. We want to understand how you view your child's ADHD, what things are easy and which things are difficult to manage regarding your child's condition, and how you think ADHD affects your child's life now and in the future. These interviews will be audio recorded for quality purposes.

What are the risks of this study?

Taking part in a research study may involve risks. If you have any questions about any of the possible risks listed below, you should talk to the lead investigator or your regular health care provider.

There are minimal risks associated with your participation, including time taken away from home or work to meet with the researchers and complete the questionnaires and in-person interview. It is possible that the interview and questionnaires may cause you to think more about your experiences with your child with ADHD and this may be stressful for you. In addition, if your responses in the interview reveal concern about you or your child's health or safety due to thoughts of suicide or significant self-harm, we will refer you or your child to receive the necessary medical attention. If your child is having suicidal thoughts or behavior, we will contact your child's primary care or mental health provider to discuss a suicide safety plan and recommendations. You may choose to not answer questions that you do not want to and still remain in the study. You will also be able to talk with the lead investigator after the interview for any additional questions or concerns to support your child with ADHD and your family.

As with any study involving collection of data, there is the possibility of breach of confidentiality of data. Every precaution will be taken to secure participants' personal information to ensure confidentiality. If you decide to participate in this study, you will be assigned a study identification number. This number will be used on data collection forms and in the database instead of names and other private information. A separate list will be maintained that will links each participant's name to the study identification number for future reference and communication. All data will be stored on a secure server at the University of Pennsylvania School of Nursing.

Are there any benefits to taking part in this study?

There will be no direct benefit to you from taking part in this study. At the end of the study, you will receive a binder of information and resources for ADHD, which may be helpful for you and your family. In addition, your participation may help future families of children with ADHD. We believe caregivers and families are very important to the care and management of ADHD. You were chosen for this study to share your unique experiences of caring for a child with ADHD, and we highly value your participation and opinions.

Do you need to give your consent in order to participate?

If you decide to participate in this study, you must sign this form. A copy will be given to you to keep as a record.

What are your responsibilities?

Please consider the study time commitments and responsibilities as a research subject when making your decision about participating in this study.

What happens if you decide not to take part in this study?

Participation in this study is voluntary. You do not have to take part in order to receive care at CHOP or the University of Pennsylvania (UPenn).

If you decide not to take part or if you change your mind later there will be no penalties or loss of any benefits to which you are otherwise entitled.

Can you stop your participation in the study early?

You can stop being in the study at any time. You do not have to give a reason.

What about privacy, authorization for use of Personal Health Information (PHI) and confidentiality?

As part of this research, health information about you and your child will be collected. This will include information from the in-person interview and surveys/questionnaires. We will do our best to keep your personal information private and confidential. However, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law.

The results of this study may be shown at meetings and published in journals to inform other doctors and health professionals. We will keep your identity private in any publication or presentation.

Several people and organizations may review or receive your identifiable information. They will need this information to conduct the research, to assure the quality of the data, or to analyze the data or samples. These groups include:

- Members of the research team and other authorized staff at CHOP and UPenn;

- People from agencies and organizations that perform independent accreditation and/or oversight of research; such as the Department of Health and Human Services, Office for Human Research Protections;
- A transcription service (Transcribing4You by Charlene J. Sullivan) to transcribe the audio recorded interviews. Audio files will be destroyed when transcription is complete and verified and the study is completed.
- Public health authorities that are required by law to receive information for the prevention or control of disease, injury or disability. Any suspected child abuse or neglect will have to be reported to the authorities, in accordance with state law.

By law, CHOP is required to protect your health information. The research staff will only allow access to your health information to the groups listed above. By signing this document, you are authorizing CHOP to use and/or release your health information for this research. Some of the organizations listed above may not be required to protect your information under Federal privacy laws. If permitted by law, they may be allowed to share it with others without your permission.

The identifiable information from this study will be destroyed after study manuscripts are accepted for publication.

Your permission to use and share de-identified information and data from this study will continue until the research study ends and will not expire. Researchers continue to analyze data for many years and it is not possible to know when they will be completely done.

Can you change your mind about the use of personal information?

You may change your mind and withdraw your permission to use and disclose your health information at any time. To take back your permission, it is preferred that you inform the principal investigator in writing.

Ricardo Eiraldi, Ph.D.
The Children's Hospital of Philadelphia
Department of Child and Adolescent Psychiatry and Behavioral Sciences
3550 Market Street, Office 1431
Philadelphia, PA 19104

In the letter, state that you changed your mind and do not want any more of your health information collected. The personal information that has been collected already will be used if necessary for the research. No new information will be collected. If you withdraw your permission to use your personal health information, you will be withdrawn from the study.

Financial Information

While you are in this study, the cost of your usual medical care – procedures, medications and doctor visits – will continue to be billed to you or your insurance.

Will there be any additional costs?

There will be no additional costs to you by taking part in this study.

Will you be paid for taking part in this study?

Parents/participants will be paid $40 for their time and effort. This will be in the form of a $40 Visa Gift Card.

Who is funding this research study?

The University of Pennsylvania School of Nursing is funding this research.

What if you have questions about the study?

If you have questions about the study, call the lead investigator Cynthia P. Paidipati at 267-262-9897. You may also talk to your child's health care provider if you have questions or concerns.

The Institutional Review Board (IRB) at The Children's Hospital of Philadelphia has reviewed and approved this study. The IRB looks at research studies like these and makes sure research subjects' rights and welfare are protected. If you have questions about your rights or if you have a complaint, you can call the IRB Office at 215-590-2830.

Consent to Take Part in this Research Study and Authorization to Use and Disclose Health Information for the Research

The research study and consent form have been explained to you by:

______________________________ ____________________________________

Person Obtaining Consent Signature of Person Obtaining Consent

____

Date

By signing this form, you are indicating that you have had your questions answered, you agree to take part in this research study and you are legally authorized to consent to your child's participation. You are also agreeing to let CHOP use and share the health information that will be collected for this study, as explained above. If you don't agree to the collection, use and sharing of health information, you cannot participate in this study. **NOTE:** *A foster parent is not legally authorized to consent for a foster child's participation.*

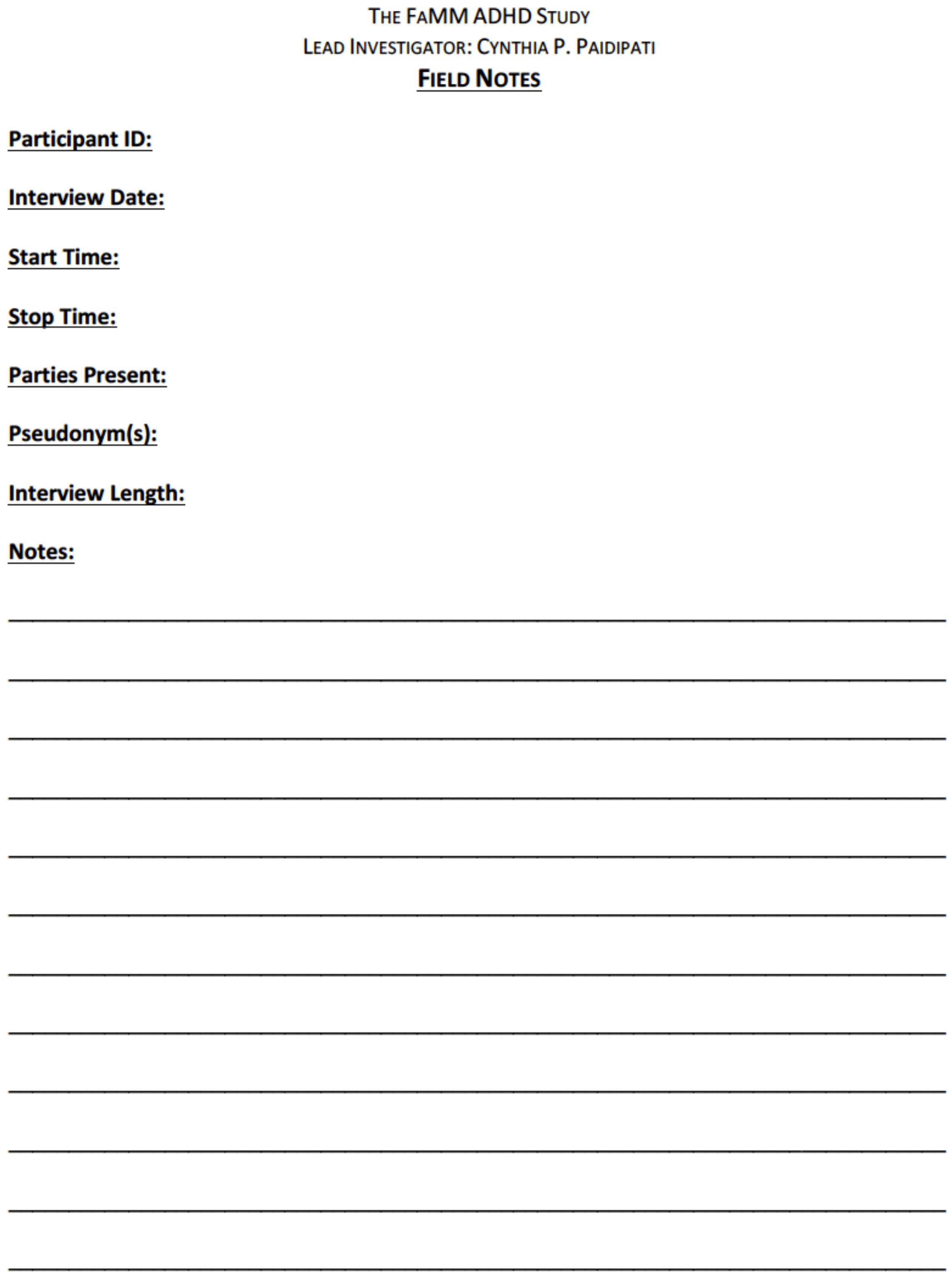
____

Name of Subject

___________________________________ ______________________________

Signature of Subject Date

Appendix 8: Field Notes Template



The FaMM ADHD Study

Lead Investigator: Cynthia P. Paidipati

Field Notes

Participant ID:

Interview Date:

Start Time:

Stop Time:

Parties Present:

Pseudonym(s):

Interview Length:

Notes:

Appendix 9: Interview Debrief/Thank You/Compensation Form

Date: __________

Study Team Member: _________________

Caregiver ID #: _________

Bold Wording indicates actual wording said by the study team member.

1.) INTERVIEW DEBRIEF:

We have reached the end of the study. Do you have any additional comments or concerns? We are happy to answer any questions that you have.

Yes	No
☐ Answer the caregiver's questions. For additional clinical concerns, please provide contact information for CHOP's Center for Management of ADHD # 1-800-879-2467.	☐ Go to next section (thank you/ compensation)

2.) THANK YOU/ COMPENSTATION:

Thank you for completing the study interview and surveys/questionnaires on "Understanding the Role of Family Management in Ethnically Diverse Children with ADHD from Urban Philadelphia". We would like to give you a "Thank You" card and a $40 Visa Gift Card your participation in this study. We would also like to give you a binder of information and resources on ADHD for you and your family. Thank you again for participating in this study. We greatly appreciate your interest and input.

Study team member will:

1. Place $40 Visa Gift Card into a "Thank You" card
2. Seal the envelope and give to the caregiver
3. Give ADHD Binder with information and resources to the caregiver
4. Say "Thank You" again

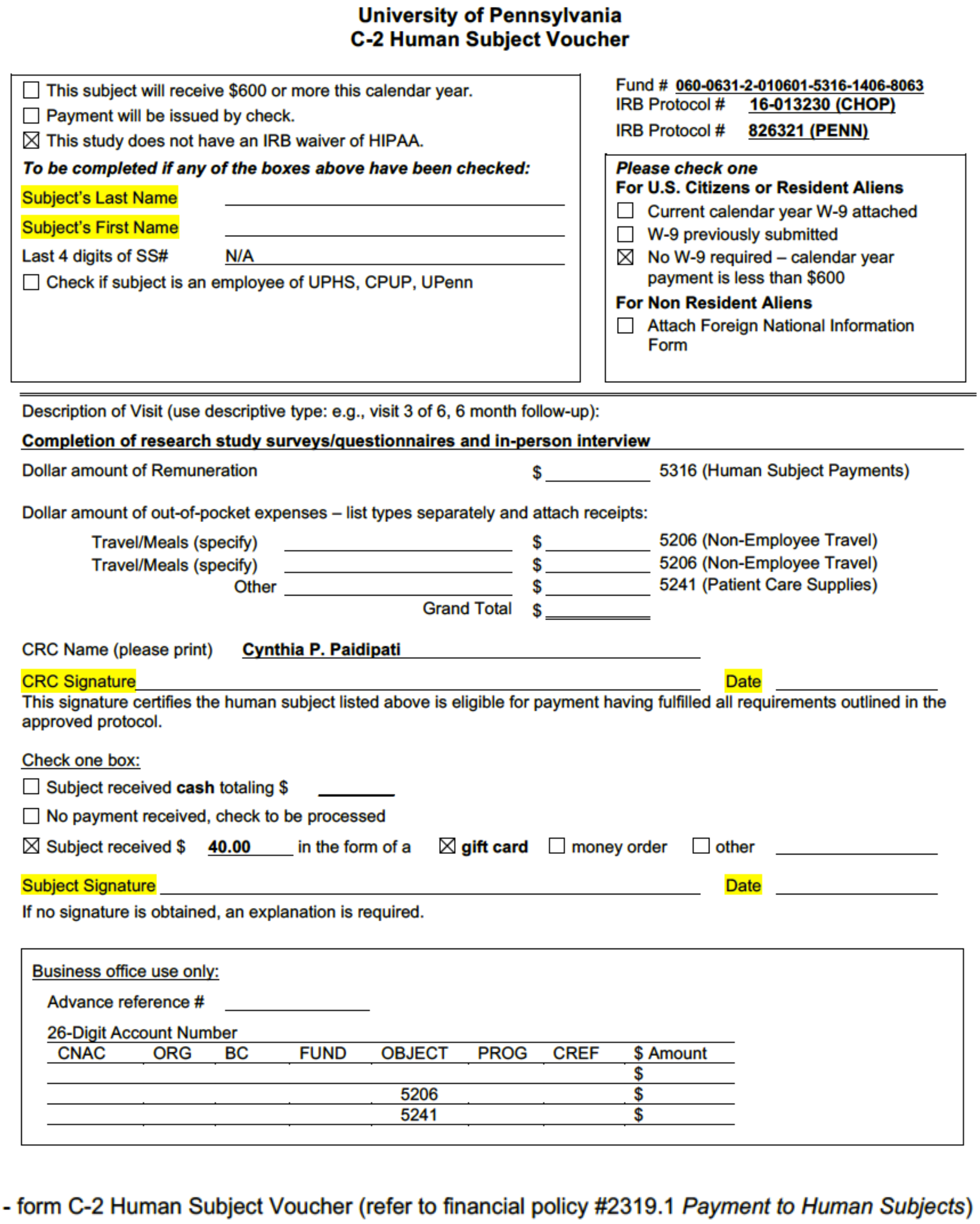
Appendix 10: Table of Contents for ADHD Information and Resources Binder

ADHD Information and Resources for Families

Table of Contents

1. ADHD Fact Sheet – from NIMH (National Institutes of Mental Health)
2. Facts for Families - "Children Who Can't Pay Attention/ADHD" – AACAP
3. Caring for Your Child – "What is ADHD? Information for Parents"
4. Caring for Your Child – "Parenting Children with ADHD"
5. Caring for Your Child – "Educational Rights for the Child with ADHD"
6. Caring for Your Child – "Constructing a Daily Report Card"
7. Caring for Your Child – "Treating ADHD with Behavior Management"
8. Caring for Your Child – "Stimulant Medications"
9. Caring for Your Child – "Atomoxetine"
10. Caring for Your Child – "Alpha-2 Adrenergic Agonists"
11. "Strategies for Teaching Children with ADHD"
12. "How to Establish a School-Home Daily Report Card"
13. "Effective Instructions and Time Out"
14. "Parent-Doctor Collaboration on ADHD Treatment Options Works Best"
15. "ADHD: Avoiding Misdiagnosis"
16. Center for Management of ADHD Health Resources - from CHOP Website
17. Additional ADHD Resource List

Appendix 11: University of Pennsylvania C-2 Human Subject Voucher Form



University of Pennsylvania
C-2 Human Subject Voucher

☐ This subject will receive $600 or more this calendar year.
☐ Payment will be issued by check.
☒ This study does not have an IRB waiver of HIPAA.

To be completed if any of the boxes above have been checked:

Subject's Last Name ____________
Subject's First Name ____________
Last 4 digits of SS# N/A
☐ Check if subject is an employee of UPHS, CPUP, UPenn

Fund # **060-0631-2-010601-5316-1406-8063**
IRB Protocol # **16-013230 (CHOP)**
IRB Protocol # **826321 (PENN)**

Please check one
For U.S. Citizens or Resident Aliens
☐ Current calendar year W-9 attached
☐ W-9 previously submitted
☒ No W-9 required – calendar year payment is less than $600
For Non Resident Aliens
☐ Attach Foreign National Information Form

Description of Visit (use descriptive type: e.g., visit 3 of 6, 6 month follow-up):
Completion of research study surveys/questionnaires and in-person interview

Dollar amount of Remuneration		$	5316 (Human Subject Payments)

Dollar amount of out-of-pocket expenses – list types separately and attach receipts:

Travel/Meals (specify)		$	5206 (Non-Employee Travel)
Travel/Meals (specify)		$	5206 (Non-Employee Travel)
Other		$	5241 (Patient Care Supplies)
Grand Total		$	

CRC Name (please print) **Cynthia P. Paidipati**

CRC Signature ____________ Date ____________
This signature certifies the human subject listed above is eligible for payment having fulfilled all requirements outlined in the approved protocol.

Check one box:
☐ Subject received **cash** totaling $ ______
☐ No payment received, check to be processed
☒ Subject received $ **40.00** in the form of a ☒ **gift card** ☐ money order ☐ other ______

Subject Signature ____________ Date ____________
If no signature is obtained, an explanation is required.

Business office use only:

Advance reference # ____________

26-Digit Account Number

CNAC	ORG	BC	FUND	OBJECT	PROG	CREF	$ Amount
							$
				5206			$
				5241			$

- form C-2 Human Subject Voucher (refer to financial policy #2319.1 *Payment to Human Subjects*)

Appendix 12: Semi-Structured Interview Guide

QUESTION 1: Tell me more about how your child is different or similar from other children his/her age, because of the ADHD. **(Family Management Factor: Child's Daily Life)**

Probes:

- How is your child's *everyday life* different or similar than other children?
- Does your child take part in activities he/she wishes to despite having ADHD? If not, why?
- Are your child's friendships different because of the condition? If so, how?

QUESTION 2: How have you (or haven't you) developed a routine for taking care of your child's ADHD? **(Family Management Factor: Condition Management Ability)**

Probes:

- Tell me an example of a time when you felt like you were doing a good job taking care of your child's ADHD.
- Do you ever feel unsure about what to do to take care of your child's ADHD? If so, in what circumstances?
- Does your family have goals or definite ideas on how to manage your child's ADHD? If so, like what?

QUESTION 3: Tell me about the time and work involved in your (son or daughter's) daily ADHD care? What do you specifically have to organize? **(Family Management Factor: Condition Management Effort)**

Probes:

- Does your child's ADHD take a great deal of time to manage? If so, how do you typically handle this?
- Is managing your child's ADHD like a roller coaster with lots of ups and downs? Or more like a merry-go-round (slow and steady, but always moving)?
- How often does your child go to the doctor or clinic to manage his/her ADHD?

QUESTION 4: Tell me more about how you worry (or don't worry) about your child's future in relation to the ADHD condition? **(Family Management Factor: View of Condition Impact)**

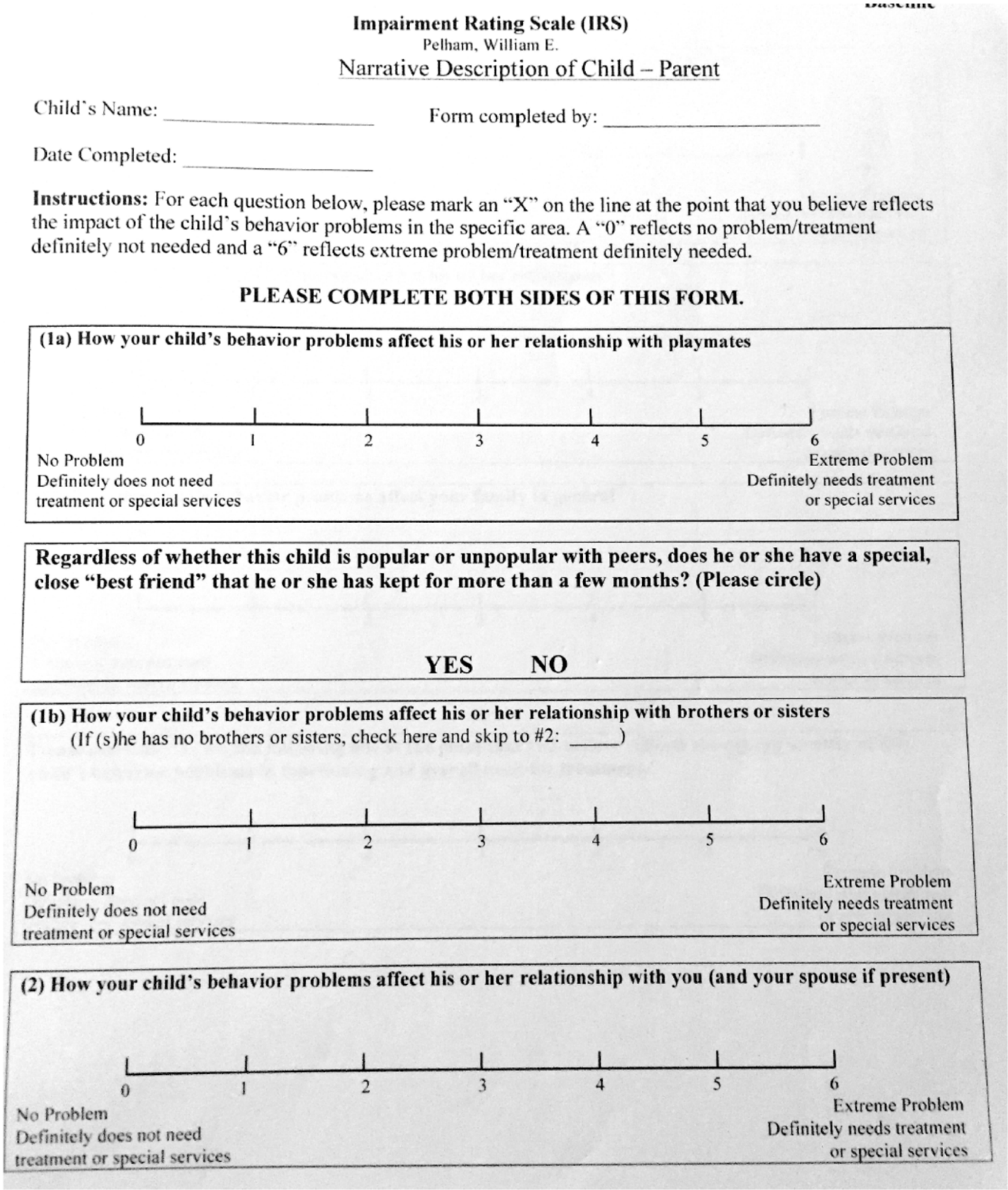
Probes:

- Do you believe your child's ADHD will be harder or easier to take care of in the future? How so?
- Are other childhood conditions more serious than your child's ADHD?
- Do you feel confident about taking care of your child's ADHD? And, why?

QUESTION 5: What are the major barriers or challenges faced by you or your family when it comes to your child's ADHD? **(Major Barriers/Challenges related to Family Management of ADHD)**

QUESTION 6: What are the major strengths of you and your family when it comes to managing your child's ADHD? **(Major Strengths/Facilitators Related to Family Management of ADHD)**

Appendix 13: Impairment Rating Scale (IRS)



Impairment Rating Scale (IRS)
Pelham, William E.
Narrative Description of Child – Parent

Child's Name: ____________________ Form completed by: ____________________

Date Completed: ________________

Instructions: For each question below, please mark an "X" on the line at the point that you believe reflects the impact of the child's behavior problems in the specific area. A "0" reflects no problem/treatment definitely not needed and a "6" reflects extreme problem/treatment definitely needed.

PLEASE COMPLETE BOTH SIDES OF THIS FORM.

(1a) How your child's behavior problems affect his or her relationship with playmates

0 1 2 3 4 5 6

No Problem Definitely does not need treatment or special services	Extreme Problem Definitely needs treatment or special services

Regardless of whether this child is popular or unpopular with peers, does he or she have a special, close "best friend" that he or she has kept for more than a few months? (Please circle)

YES NO

(1b) How your child's behavior problems affect his or her relationship with brothers or sisters
(If (s)he has no brothers or sisters, check here and skip to #2: _____)

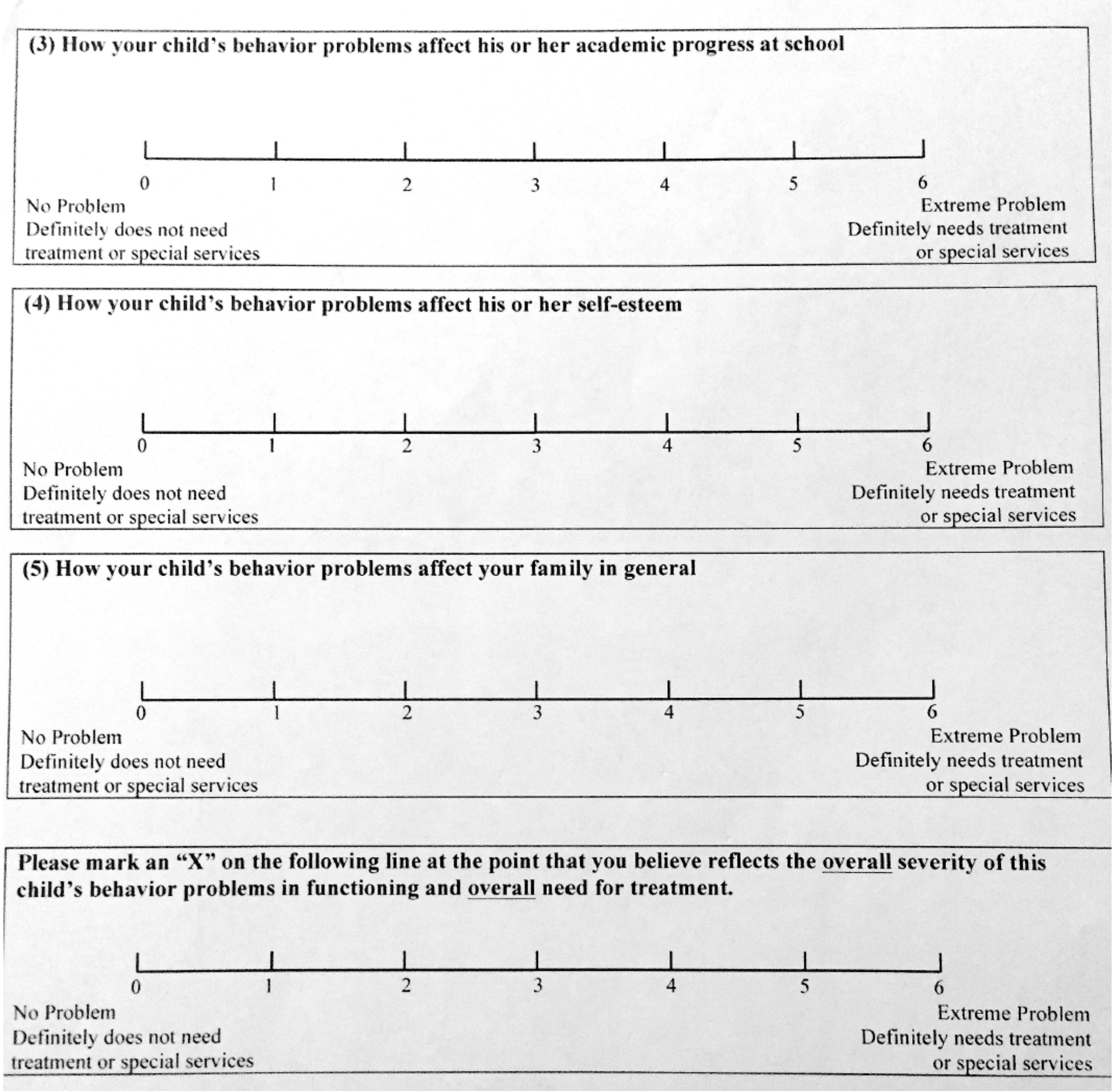
0 1 2 3 4 5 6

No Problem Definitely does not need treatment or special services	Extreme Problem Definitely needs treatment or special services

(2) How your child's behavior problems affect his or her relationship with you (and your spouse if present)

0 1 2 3 4 5 6

No Problem Definitely does not need treatment or special services	Extreme Problem Definitely needs treatment or special services



(3) How your child's behavior problems affect his or her academic progress at school

0 1 2 3 4 5 6

No Problem	Extreme Problem
Definitely does not need	Definitely needs treatment
treatment or special services	or special services

(4) How your child's behavior problems affect his or her self-esteem

0 1 2 3 4 5 6

No Problem	Extreme Problem
Definitely does not need	Definitely needs treatment
treatment or special services	or special services

(5) How your child's behavior problems affect your family in general

0 1 2 3 4 5 6

No Problem	Extreme Problem
Definitely does not need	Definitely needs treatment
treatment or special services	or special services

Please mark an "X" on the following line at the point that you believe reflects the overall severity of this child's behavior problems in functioning and overall need for treatment.

0 1 2 3 4 5 6

No Problem	Extreme Problem
Definitely does not need	Definitely needs treatment
treatment or special services	or special services

Appendix 14: Family Management Measure (FaMM)

FAMILY MANAGEMENT MEASURE

Kathleen Knafl, PhD
Janet Deatrick, RN, PhD
Agatha Gallo, RN, PhD
Jane Dixon, PhD
Margaret Grey, RN, PhD

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FAMILY MANAGEMENT MEASURE

This questionnaire is about how your family manages caring for a child with a chronic condition.

INSTRUCTIONS

For each statement in this questionnaire, you are asked to rate your response to the statement on a scale of 1 to 5, with 1 indicating "Strongly disagree" and 5 indicating "Strongly agree". Please respond to each statement in this questionnaire based on what you think, not on how you think others might respond. If your child has more than one chronic condition the word "condition" refers to all of their diagnoses together. Also, many of these questions use the word "family". This refers to those people living in your household that you think of as family.

Section 1: to be completed by everyone
Please check the boxes with your answers.

	Strongly Disagree 1	**2**	**3**	**4**	**Strongly Agree 5**
1. Our child's everyday life is similar to that of other children his/her age.	☐	☐	☐	☐	☐
2. Our child's condition gets in the way of family relationships.	☐	☐	☐	☐	☐
3. Our child's condition requires frequent visits to the clinic.	☐	☐	☐	☐	☐
4. In the future we expect our child to take care of the condition.	☐	☐	☐	☐	☐
5. Our child enjoys life less because of the condition.	☐	☐	☐	☐	☐
6. Taking care of our child's condition is often overwhelming.	☐	☐	☐	☐	☐
7. Our child's condition is like a roller coaster with lots of ups and downs.	☐	☐	☐	☐	☐

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
8. Our child's condition is the most important thing in our family.	☐	☐	☐	☐	☐
9. It is very hard for us to take care of our child's condition.	☐	☐	☐	☐	☐
10. Our child takes part in activities he/she wishes to despite the condition.	☐	☐	☐	☐	☐
11. Because of the condition, we worry about our child's future.	☐	☐	☐	☐	☐
12. Our child's condition doesn't take a great deal of time to manage.	☐	☐	☐	☐	☐
13. We have some definite ideas about how to help our child live with the condition.	☐	☐	☐	☐	☐
14. Despite the condition, we expect our child to live away from home in the future.	☐	☐	☐	☐	☐
15. We have enough money to manage our child's condition.	☐	☐	☐	☐	☐
16. Our child is different from other children his/her age because of the condition.	☐	☐	☐	☐	☐
17. It is difficult to know when our child's condition must come first in the family.	☐	☐	☐	☐	☐
18. We are looking forward to a happy future with our child.	☐	☐	☐	☐	☐
19. When something unexpected happens with our child's condition, we usually know how to handle it.	☐	☐	☐	☐	☐
20. Our child's friendships are different because of the condition.	☐	☐	☐	☐	☐

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
21. We expect to be devoting less time to our child's condition in the future.	☐	☐	☐	☐	☐
22. A condition like the one our child has makes family life very difficult.	☐	☐	☐	☐	☐
23. Our child's condition rarely interferes with other family activities.	☐	☐	☐	☐	☐
24. Our child's condition requires frequent hospital stays.	☐	☐	☐	☐	☐
25. We feel we are doing a good job taking care of our child's condition.	☐	☐	☐	☐	☐
26. People with our child's condition have a normal length of life.	☐	☐	☐	☐	☐
27. It's often difficult to know if we need to be more protective of our child.	☐	☐	☐	☐	☐
28. We often feel unsure about what to do to take care of our child's condition.	☐	☐	☐	☐	☐
29. Our child's condition will be harder to take care of in the future.	☐	☐	☐	☐	☐
30. We think about our child's condition all the time.	☐	☐	☐	☐	☐
31. It seems as if our child's condition controls our family life.	☐	☐	☐	☐	☐
32. Many conditions are more serious than our child's.	☐	☐	☐	☐	☐
33. It is hard to get anyone else to help us with our child's condition.	☐	☐	☐	☐	☐
34. We have not been able to develop a routine for taking care of our child's condition.	☐	☐	☐	☐	☐

	Strongly Disagree 1	2	3	4	Strongly Agree 5
35. It takes a lot of organization to manage our child's condition.	☐	☐	☐	☐	☐
36. We are sometimes undecided about how to balance the condition and family life.	☐	☐	☐	☐	☐
37. It is hard to know what to expect of our child's condition in the future.	☐	☐	☐	☐	☐
38. Even though our child has the condition, we have a normal family life.	☐	☐	☐	☐	☐
39. Our child would do better in school if he/she didn't have the condition.	☐	☐	☐	☐	☐
40. We are confident that we can take care of our child's condition.	☐	☐	☐	☐	☐
41. We have goals in mind to help us manage our child's condition.	☐	☐	☐	☐	☐
42. It is difficult to fit care of our child's condition into our usual family routine.	☐	☐	☐	☐	☐
43. Dealing with our child's condition makes family life more difficult.	☐	☐	☐	☐	☐
44. We know when our child needs to be a child.	☐	☐	☐	☐	☐
45. A condition like the one our child has makes it hard to live a normal life.	☐	☐	☐	☐	☐

This ends Section 1.

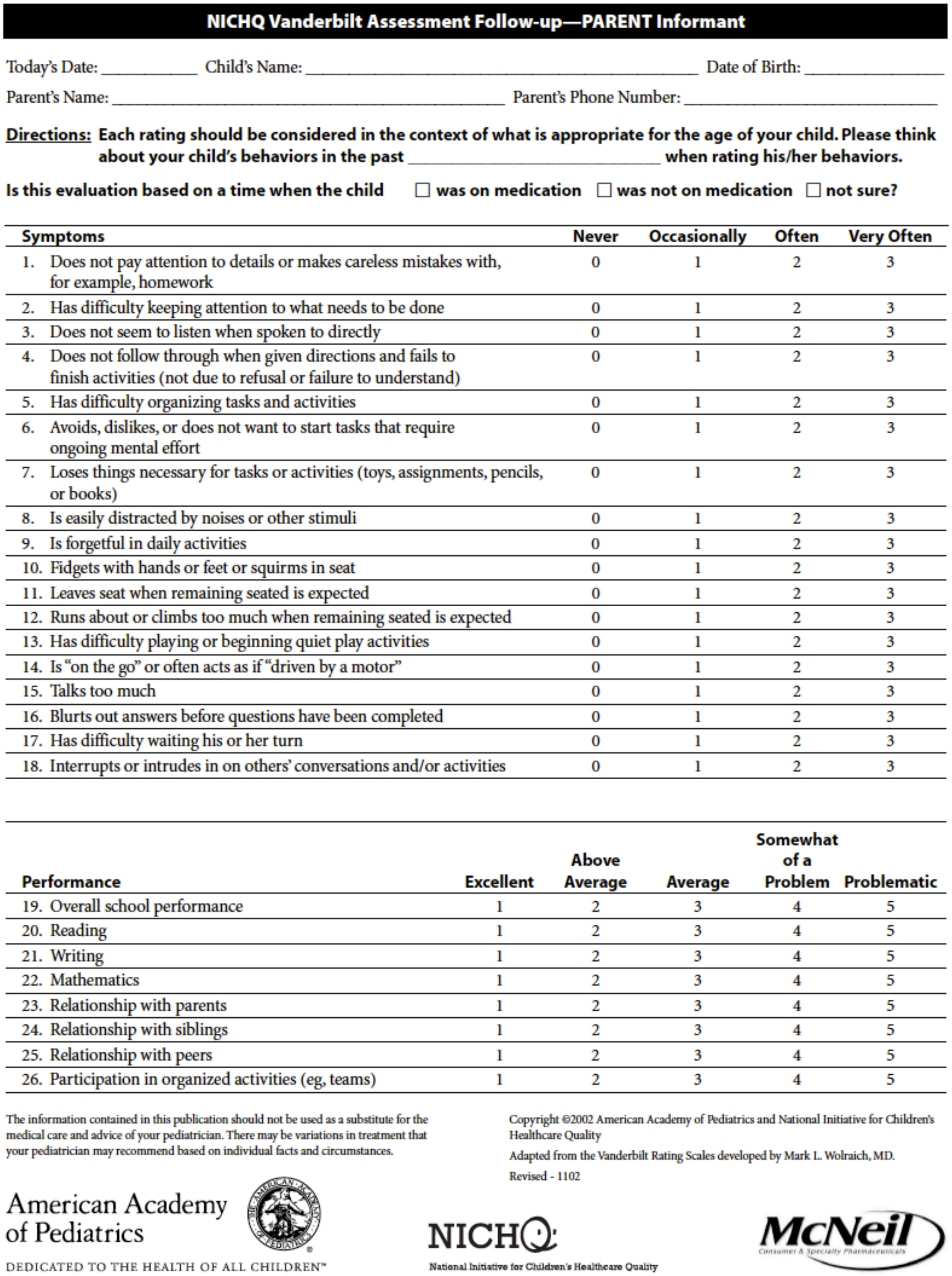
Section 2 covers aspects of family management when there are adult partners in a household. The term "partner" refers to a spouse or partner living in the same household. If you currently have a partner, please proceed to the next page. If you do not have a partner, please stop here.

Section 2

The questions in the next section relate to you and your partner. For each statement in this section, rate your response to the statement on a scale of 1 to 5, with 1 indicating “Strongly disagree” and 5 indicating “Strongly agree”. Again, please respond to each statement in this questionnaire based on how YOU feel, not on how you think your partner or others might respond.

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
46. We are a closer family because of how we deal with our child’s condition.	☐	☐	☐	☐	☐
47. My partner and I have different ideas about how serious our child’s condition is.	☐	☐	☐	☐	☐
48. I am pleased with how my partner and I work together to manage our child’s condition.	☐	☐	☐	☐	☐
49. My partner and I argue about how to manage our child’s condition.	☐	☐	☐	☐	☐
50. My partner and I consult with each other before we make a decision about our child’s care.	☐	☐	☐	☐	☐
51. My partner and I have similar ideas about how we should be raising our child.	☐	☐	☐	☐	☐
52. I am unhappy about the way my partner and I share the management of our child’s condition.	☐	☐	☐	☐	☐
53. My partner and I support each other in taking care of our child’s condition.	☐	☐	☐	☐	☐

Appendix 15: Vanderbilt ADHD Assessment Follow-Up Scale



NICHQ Vanderbilt Assessment Follow-up—PARENT Informant

Today's Date: __________ Child's Name: ______________________________ Date of Birth: ____________

Parent's Name: ______________________________ Parent's Phone Number: ____________________

Directions: **Each rating should be considered in the context of what is appropriate for the age of your child. Please think about your child's behaviors in the past ____________________ when rating his/her behaviors.**

Is this evaluation based on a time when the child ☐ **was on medication** ☐ **was not on medication** ☐ **not sure?**

Symptoms	**Never**	**Occasionally**	**Often**	**Very Often**
1. Does not pay attention to details or makes careless mistakes with, for example, homework	0	1	2	3
2. Has difficulty keeping attention to what needs to be done	0	1	2	3
3. Does not seem to listen when spoken to directly	0	1	2	3
4. Does not follow through when given directions and fails to finish activities (not due to refusal or failure to understand)	0	1	2	3
5. Has difficulty organizing tasks and activities	0	1	2	3
6. Avoids, dislikes, or does not want to start tasks that require ongoing mental effort	0	1	2	3
7. Loses things necessary for tasks or activities (toys, assignments, pencils, or books)	0	1	2	3
8. Is easily distracted by noises or other stimuli	0	1	2	3
9. Is forgetful in daily activities	0	1	2	3
10. Fidgets with hands or feet or squirms in seat	0	1	2	3
11. Leaves seat when remaining seated is expected	0	1	2	3
12. Runs about or climbs too much when remaining seated is expected	0	1	2	3
13. Has difficulty playing or beginning quiet play activities	0	1	2	3
14. Is "on the go" or often acts as if "driven by a motor"	0	1	2	3
15. Talks too much	0	1	2	3
16. Blurts out answers before questions have been completed	0	1	2	3
17. Has difficulty waiting his or her turn	0	1	2	3
18. Interrupts or intrudes in on others' conversations and/or activities	0	1	2	3

Performance	**Excellent**	**Above Average**	**Average**	**Somewhat of a Problem**	**Problematic**
19. Overall school performance	1	2	3	4	5
20. Reading	1	2	3	4	5
21. Writing	1	2	3	4	5
22. Mathematics	1	2	3	4	5
23. Relationship with parents	1	2	3	4	5
24. Relationship with siblings	1	2	3	4	5
25. Relationship with peers	1	2	3	4	5
26. Participation in organized activities (eg, teams)	1	2	3	4	5

Adapted from the Vanderbilt Rating Scales developed by Mark L. Wolraich, MD.

Revised - 1102

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

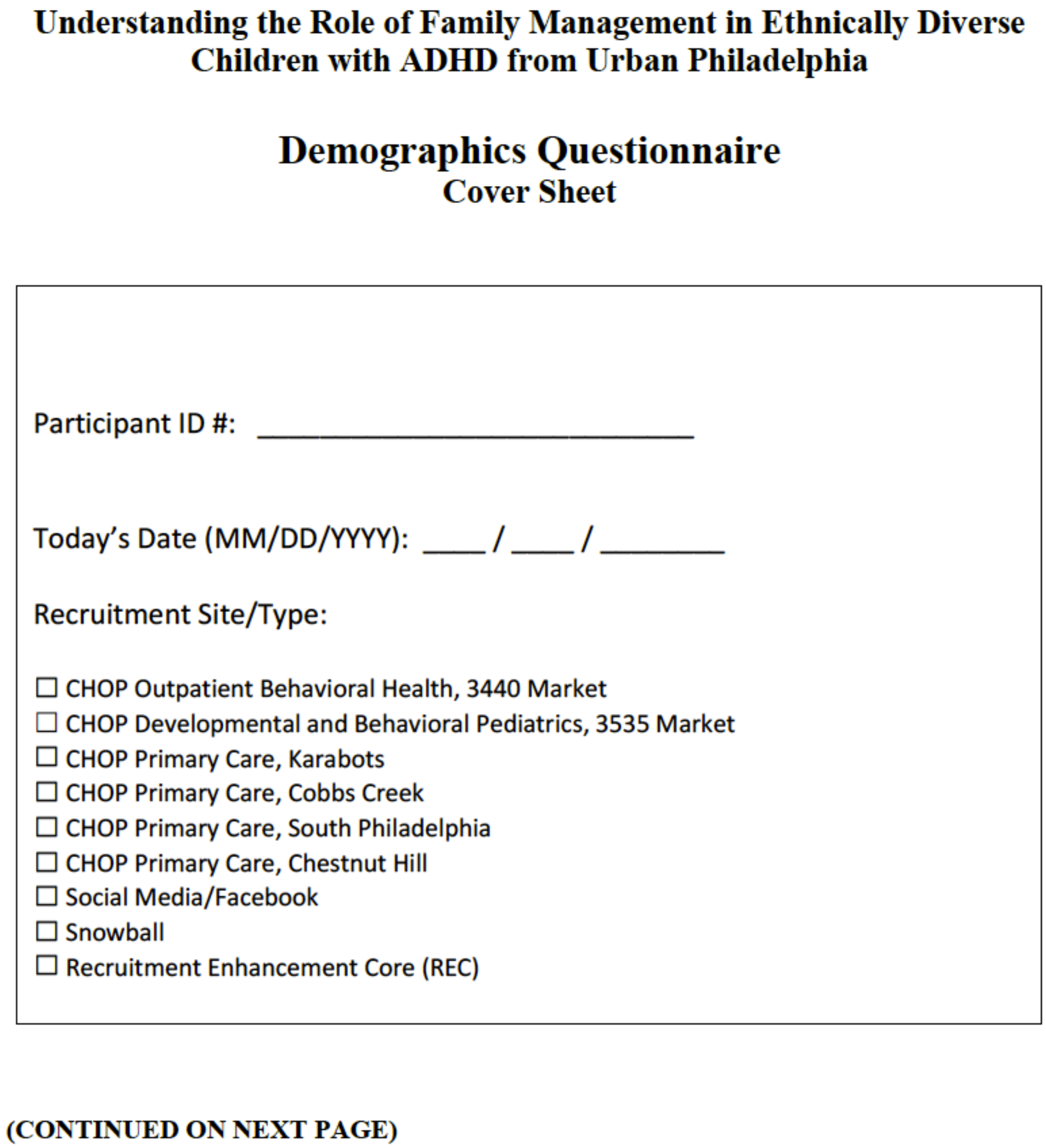
NICHQ

National Initiative for Children's Healthcare Quality

McNeil

Consumer & Specialty Pharmaceuticals

Appendix 16: Demographic Questionnaire



Understanding the Role of Family Management in Ethnically Diverse Children with ADHD from Urban Philadelphia

Demographics Questionnaire

Cover Sheet

Participant ID #: ____________________________

Today's Date (MM/DD/YYYY): ____ / ____ / ________

Recruitment Site/Type:

☐ CHOP Outpatient Behavioral Health, 3440 Market
☐ CHOP Developmental and Behavioral Pediatrics, 3535 Market
☐ CHOP Primary Care, Karabots
☐ CHOP Primary Care, Cobbs Creek
☐ CHOP Primary Care, South Philadelphia
☐ CHOP Primary Care, Chestnut Hill
☐ Social Media/Facebook
☐ Snowball
☐ Recruitment Enhancement Core (REC)

(CONTINUED ON NEXT PAGE)

CHILD INFORMATION

Child Birthdate ____________________

Child Gender
☐ Female ☐ Male ☐ Other

If you had to put your child in one of the following categories, which would you choose?

Child Race (Select one)
☐ American Indian/Alaskan Native ☐ Asian ☐ Native Hawaiian/Pacific Islander
☐ Black/African American ☐ White ☐ More Than One Race ☐ Other ☐ Prefer Not to Answer

Child Ethnicity (Select one)
☐ Hispanic or Latino(a) ☐ Non-Hispanic or Latino(a)

In addition, how you would describe your child's cultural or national associations, if any. Please select all that apply, or write in your own words in the "other" section.
☐ Mexican ☐ Cuban ☐ Puerto Rican ☐ Dominican
☐ Russian/Ukrainian ☐ Irish ☐ Italian ☐ Polish ☐ Jewish
☐ Nigerian ☐ Liberian ☐ Haitian ☐ Jamaican ☐ Trinidadian ☐ Bajan
☐ Vietnamese ☐ Korean ☐ Chinese ☐ Hmong ☐ Indian
☐ Lebanese ☐ Iranian ☐ Egyptian ☐ Iraqi ☐ Saudi ☐ Syrian ☐ Afghan
☐ Lenapehoking
☐ Other____ ☐ None

Is your child currently being treated for ADHD with medications? Yes / No (please circle one)

Is your child currently being treated for ADHD with therapy? Yes / No (please circle one)

Does your child have any of the following mental health conditions? If so, please check off which ones apply to your child.
☐ Depression ☐ Anxiety ☐ Oppositional Defiant Disorder ☐ Conduct Disorder
☐ Autism Spectrum Disorder ☐ Intellectual Disability ☐ Bipolar Disorder
☐ Other ________________________________ ☐ Unsure or Do Not Know ☐ None

What kind of school does your child attend?
☐ Public ☐ Private ☐ Charter ☐ Home School ☐ Other (please circle one)

What grade is your child in? ____________________

Child's Primary Residence
☐ Single parent home ☐ Two parent home ☐ Other: ____________________

(CONTINUED ON NEXT PAGE)

CAREGIVER INFORMATION

What is your relationship to the child above?

☐ Biological Mother ☐ Adoptive Mother ☐ Foster Mother ☐ Grandmother
☐ Biological Father ☐ Adoptive Father ☐ Foster Father ☐ Grandfather
☐ Legal Guardian ☐ Other Family Member ________________________________
(please write how you are related to the child (i.e., aunt, uncle. etc.)

Caregiver Birthdate ____________________

Caregiver Gender
☐ Female ☐ Male ☐ Other

If you had to put yourself in one of the following categories, which would you choose?

Caregiver Race (Select one)
☐ American Indian/Alaskan Native ☐ Asian ☐ Native Hawaiian/Pacific Islander
☐ Black/African American ☐ White ☐ More Than One Race ☐ Other ☐ Prefer Not to Answer

Caregiver Ethnicity (Select one)
☐ Hispanic or Latino(a) ☐ Non-Hispanic or Latino(a)

In addition, how you would describe your cultural or national associations, if any. Please select all that apply, or write in your own words in the "other" section.
☐ Mexican ☐ Cuban ☐ Puerto Rican ☐ Dominican
☐ Russian/Ukrainian ☐ Irish ☐ Italian ☐ Polish ☐ Jewish
☐ Nigerian ☐ Liberian ☐ Haitian ☐ Jamaican ☐ Trinidadian ☐ Bajan
☐ Vietnamese ☐ Korean ☐ Chinese ☐ Hmong ☐ Indian
☐ Lebanese ☐ Iranian ☐ Egyptian ☐ Iraqi ☐ Saudi ☐ Syrian ☐ Afghan
☐ Lenapehoking
☐ Other____ ☐ None

What zip code do you (and your child) currently reside in? _______________

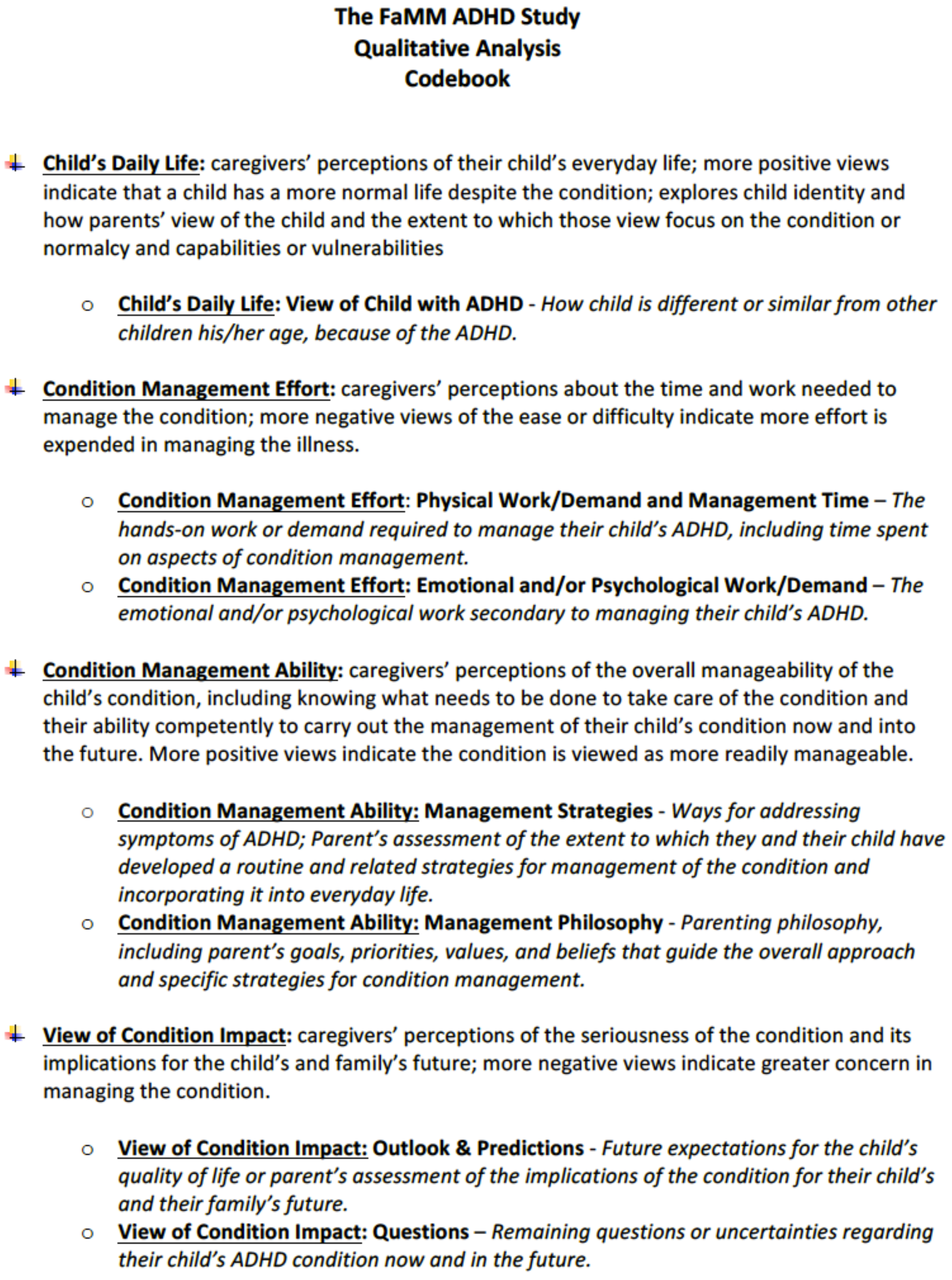
What neighborhood do you live in the City of Philadelphia? __________________

What is the highest level of education you've completed?

☐ Middle School ☐ High School Diploma ☐ High School GED
☐ Technical or Vocation School ☐ Community College ☐ University College ☐ Graduate Degree
☐ Other ____________________________ ☐ Unsure or Do Not Know

Approximate Household Yearly Income (of child's primary residence):
☐ Up to $10,000
☐ $10,001- 20,000
☐ $20,001- 30,000
☐ $30,001- 40,000
☐ 40,001- 50,000
☐ 50,001- 60,000
☐ 60,001- 70,000
☐ 70,001- 80,000
☐ 80,001- 90,000
☐ 90,001- 100,000
☐ over $100,000

Appendix 17: Codebook for Qualitative Interviews



The FaMM ADHD Study
Qualitative Analysis
Codebook

- **<u>Child's Daily Life</u>:** caregivers' perceptions of their child's everyday life; more positive views indicate that a child has a more normal life despite the condition; explores child identity and how parents' view of the child and the extent to which those view focus on the condition or normalcy and capabilities or vulnerabilities
    - **<u>Child's Daily Life</u>: View of Child with ADHD** - *How child is different or similar from other children his/her age, because of the ADHD.*
- **<u>Condition Management Effort</u>:** caregivers' perceptions about the time and work needed to manage the condition; more negative views of the ease or difficulty indicate more effort is expended in managing the illness.
    - **<u>Condition Management Effort</u>: Physical Work/Demand and Management Time** – *The hands-on work or demand required to manage their child's ADHD, including time spent on aspects of condition management.*
    - **<u>Condition Management Effort</u>: Emotional and/or Psychological Work/Demand** – *The emotional and/or psychological work secondary to managing their child's ADHD.*
- **<u>Condition Management Ability</u>:** caregivers' perceptions of the overall manageability of the child's condition, including knowing what needs to be done to take care of the condition and their ability competently to carry out the management of their child's condition now and into the future. More positive views indicate the condition is viewed as more readily manageable.
    - **<u>Condition Management Ability:</u> Management Strategies** - *Ways for addressing symptoms of ADHD; Parent's assessment of the extent to which they and their child have developed a routine and related strategies for management of the condition and incorporating it into everyday life.*
    - **<u>Condition Management Ability:</u> Management Philosophy** - *Parenting philosophy, including parent's goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management.*
- **<u>View of Condition Impact</u>:** caregivers' perceptions of the seriousness of the condition and its implications for the child's and family's future; more negative views indicate greater concern in managing the condition.
    - **<u>View of Condition Impact:</u> Outlook & Predictions** - *Future expectations for the child's quality of life or parent's assessment of the implications of the condition for their child's and their family's future.*
    - **<u>View of Condition Impact</u>: Questions** – *Remaining questions or uncertainties regarding their child's ADHD condition now and in the future.*

- **<u>Parent Mutuality</u>:** caregivers' perceptions of support, shared views, and satisfaction with how the partners work together to manage the child's condition; more positive views indicate mostly a shared response and greater satisfaction with how the partners works together to manage the condition; parent's beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy and their approach to condition management

    - **<u>Parent Mutuality</u>: Diagnosis/Condition** – *How partners view the ADHD diagnosis and condition.*
    - **<u>Parent Mutuality</u>: Treatment** – *How partners view the treatment for ADHD, including medication management, behavioral therapy, and school interventions.*
    - **<u>Parent Mutuality</u>: Management Approach to Condition Management** – *How partners view their approaches to condition management.*
    - **<u>Parent Mutuality</u>: Parenting Philosophy Overall** – *How partners view parenting, in general, for their child.*

- **<u>Barriers/Challenges</u>:** caregivers' perceptions of the barriers or challenges faced when managing their child's ADHD

    - **<u>Barriers/Challenges</u>: Immediate Family** – *The barriers or challenges related to the primary caregiver, secondary parents or caregivers, child with ADHD, or siblings within the household.*
    - **<u>Barriers/Challenges</u>: Educational** – *The barriers or challenges related to factors within the schools or educational system.*
    - **<u>Barriers/Challenges</u>: Healthcare** – *The barriers or challenges related to factors within the healthcare system and services.*
    - **<u>Barriers/Challenges</u>: Financial/Insurance/Policy** – *The barriers or challenges related to economic systems, insurance issues, and policies regarding ADHD care and services.*
    - **<u>Barriers/Challenges</u>: Extended Family** – *The barriers or challenges related to extended family members outside of the immediate family.*
    - **<u>Barriers/Challenges</u>: Stigma** – *The barriers or challenges related to stigma surrounding ADHD, condition management, or the precursors to accessing and utilizing care/services.*

- **<u>Facilitators</u>:** caregivers' perceptions of the facilitators of ADHD management for their child

    - **<u>Facilitators</u>: Educational** – *The helpers or facilitators related to factors within schools or the educational system.*
    - **<u>Facilitators</u>: Healthcare** – *The helpers or facilitators related to factors within healthcare services or systems.*
    - **<u>Facilitators</u>: Family** – *The helpers or facilitators related to aspects or activities within the immediate or extended family.*
    - **<u>Facilitators</u>: Community** – *The helpers or facilitators related to community supports and services.*

- **Child Strengths:** caregivers' perceptions of the child's strengths

  - **Child Strengths: Personality Traits** – *Child's strengths regarding their character, temperament, or personality.*
  - **Child Strengths: Hobbies/Activities** – *Child's strengths regarding their hobbies, activities, or interests.*
  - **Child Strengths: Academic Strengths** – *Child's strengths regarding their academics.*
  - **Child Strengths: Tasks** – *Child's strengths regarding their ability to do tasks.*
  - **Child Strengths: Likes** – *Child's strengths regarding their likes and sources of enjoyment.*

- **Caregiver Strengths:** caregivers' perceptions of the caregiver's strengths

  - **Caregiver Strengths: Qualities** – *Caregiver's strengths regarding their personal qualities or individual attributes.*
  - **Caregiver Strengths: Actions/Behaviors** – *Caregiver's strengths regarding their actions or behaviors.*

- **Advice/Recommendations:** caregivers' perceptions of what may be helpful for parents or caregivers of children with ADHD

  - **Advice/Recommendations: What parents/caregivers can do** – *Advice, recommendations, or suggestions for parents or caregivers of children with ADHD*
  - **Advice/Recommendations: What healthcare providers can do** – *Advice, recommendations, or suggestions for providers or entities within the healthcare system.*
  - **Advice/Recommendations: What educational providers can do** – *Advice, recommendations, or suggestions for providers or entities within the educational system.*

Appendix 18: C-SSRS Suicide Risk Assessment Form

COLUMBIA-SUICIDE SEVERITY RATING SCALE
(C-SSRS)

Already Enrolled Subjects

Version 1/14/09

Posner, K.; Brent, D.; Lucas, C.; Gould, M.; Stanley, B.; Brown, G.; Fisher, P.; Zelazny, J.; Burke, A.; Oquendo, M.; Mann, J.

Disclaimer:

This scale is intended to be used by individuals who have received training in its administration. The questions contained in the Columbia-Suicide Severity Rating Scale are suggested probes. Ultimately, the determination of the presence of suicidal ideation or behavior depends on the judgment of the individual administering the scale.

Definitions of behavioral suicidal events in this scale are based on those used in ***The Columbia Suicide History Form****, developed by John Mann, MD and Maria Oquendo, MD, Conte Center for the Neuroscience of Mental Disorders (CCNMD), New York State Psychiatric Institute, 1051 Riverside Drive, New York, NY, 10032. (Oquendo M. A., Halberstam B. & Mann J. J., Risk factors for suicidal behavior: utility and limitations of research instruments. In M.B. First [Ed.]* Standardized Evaluation in Clinical Practice*, pp. 103 -130, 2003.)*

For reprints of the C-SSRS contact Kelly Posner, Ph.D., New York State Psychiatric Institute, 1051 Riverside Drive, New York, New York, 10032; inquiries and training requirements contact posnerk@nyspi.columbia.edu

SUICIDAL IDEATION		
Ask questions 1 and 2. If both are negative, proceed to "Suicidal Behavior" section. If the answer to question 2 is "yes", ask questions 3, 4 and 5. If the answer to question 1 and/or 2 is "yes", complete "Intensity of Ideation" section below.	**Prior to Study Entry: Time He/ She Felt Most Suicidal**	**Since Study Start:**
1. Wish to be Dead Subject endorses thoughts about a wish to be dead or not alive anymore, or wish to fall asleep and not wake up. ***Have you wished you were dead or wished you could go to sleep and not wake up?*** If yes, describe:	**Yes No** ☐ ☐	**Yes No** ☐ ☐
2. Non-Specific Active Suicidal Thoughts General non-specific thoughts of wanting to end one's life/commit suicide (e.g., *"I've thought about killing myself"*) without thoughts of ways to kill oneself/associated methods, intent, or plan during the assessment period. ***Have you actually had any thoughts of killing yourself?*** If yes, describe:	**Yes No** ☐ ☐	**Yes No** ☐ ☐
3. Active Suicidal Ideation with Any Methods (Not Plan) without Intent to Act Subject endorses thoughts of suicide and has thought of at least one method during the assessment period. This is different than a specific plan with time, place or method details worked out (e.g., thought of method to kill self but not a specific plan). Includes person who would say, *"I thought about taking an overdose but I never made a specific plan as to when, where or how I would actually do it…and I would never go through with it."* ***Have you been thinking about how you might do this?*** If yes, describe:	**Yes No** ☐ ☐	**Yes No** ☐ ☐
4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan Active suicidal thoughts of killing oneself and subject reports having <u>some intent to act on such thoughts</u>, as opposed to *"I have the thoughts but I definitely will not do anything about them."* ***Have you had these thoughts and had some intention of acting on them?*** If yes, describe:	**Yes No** ☐ ☐	**Yes No** ☐ ☐
5. Active Suicidal Ideation with Specific Plan and Intent Thoughts of killing oneself with details of plan fully or partially worked out and subject has some intent to carry it out. ***Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?*** If yes, describe:	**Yes No** ☐ ☐	**Yes No** ☐ ☐
INTENSITY OF IDEATION		
The following features should be rated with respect to the most severe type of ideation (i.e., 1-5 from above, with 1 being the least severe and 5 being the most severe). For prior to study entry, ask about time he/she was feeling the most suicidal. Prior to Study Entry - ***Most Severe Ideation:*** ______ ______________________ ***Type # (1-5)*** ***Description of Ideation*** Since Study Start - ***Most Severe Ideation:*** ______ ______________________ ***Type # (1-5)*** ***Description of Ideation***	Most Severe	Most Severe
Frequency ***How many times have you had these thoughts?*** (1) Less than once a week (2) Once a week (3) 2-5 times in week (4) Daily or almost daily (5) Many times each day	____	____
Duration ***When you have the thoughts how long do they last?*** (1) Fleeting - few seconds or minutes (2) Less than 1 hour/some of the time (3) 1-4 hours/a lot of time (4) 4-8 hours/most of day (5) More than 8 hours/persistent or continuous	____	____
Controllability ***Could/can you stop thinking about killing yourself or wanting to die if you want to?*** (1) Easily able to control thoughts (2) Can control thoughts with little difficulty (3) Can control thoughts with some difficulty (4) Can control thoughts with a lot of difficulty (5) Unable to control thoughts (0) Does not attempt to control thoughts	____	____
Deterrents ***Are there things - anyone or anything (e.g., family, religion, pain of death) - that stopped you from wanting to die or acting on thoughts of committing suicide?*** (1) Deterrents definitely stopped you from attempting suicide (2) Deterrents probably stopped you (3) Uncertain that deterrents stopped you (4) Deterrents most likely did not stop you (5) Deterrents definitely did not stop you (0) Does not apply	____	____

Reasons for Ideation ***What sort of reasons did you have for thinking about wanting to die or killing yourself? Was it to end the pain or stop the way you were feeling (in other words you couldn't go on living with this pain or how you were feeling) or was it to get attention, revenge or a reaction from others? Or both?*** (1) Completely to get attention, revenge or a reaction from others (2) Mostly to get attention, revenge or a reaction from others (3) Equally to get attention, revenge or a reaction from others and to end/stop the pain (4) Mostly to end or stop the pain (you couldn't go on living with the pain or how you were feeling) (5) Completely to end or stop the pain (you couldn't go on living with the pain or how you were feeling) (0) Does not apply	____	____

SUICIDAL BEHAVIOR *(Check all that apply, so long as these are separate events; must ask about all types)*	**Prior to Study Entry**	**Since Study Start**
Actual Attempt: A potentially self-injurious act committed with at least some wish to die, *as a result of act*. Behavior was in part thought of as method to kill oneself. Intent does not have to be 100%. If there is ***any*** intent/desire to die associated with the act, then it can be considered an actual suicide attempt. ***There does not have to be any injury or harm***, just the potential for injury or harm. If person pulls trigger while gun is in mouth but gun is broken so no injury results, this is considered an attempt. Inferring Intent: Even if an individual denies intent/wish to die, it may be inferred clinically from the behavior or circumstances. For example, a highly lethal act that is clearly not an accident so no other intent but suicide can be inferred (e.g., gunshot to head, jumping from window of a high floor/story). Also, if someone denies intent to die, but they thought that what they did could be lethal, intent may be inferred. ***Have you made a suicide attempt?*** ***Have you done anything to harm yourself?*** ***Have you done anything dangerous where you could have died?*** ***What did you do?*** ***Did you______ as a way to end your life?*** ***Did you want to die (even a little) when you_____?*** ***Were you trying to end your life when you _____?*** ***Or Did you think it was possible you could have died from_____?*** ***Or did you do it purely for other reasons / without ANY intention of killing yourself (like to relieve stress, feel better, get sympathy, or get something else to happen)?*** (Self-Injurious Behavior without suicidal intent) If yes, describe:	**Yes No** ☐ ☐ Total # of Attempts ______	**Yes No** ☐ ☐ Total # of Attempts ______
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	**Yes No** ☐ ☐	**Yes No** ☐ ☐
Interrupted Attempt: When the person is interrupted (by an outside circumstance) from starting the potentially self-injurious act *(if not for that, actual attempt would have occurred).* Overdose: Person has pills in hand but is stopped from ingesting. Once they ingest any pills, this becomes an attempt rather than an interrupted attempt. Shooting: Person has gun pointed toward self, gun is taken away by someone else, or is somehow prevented from pulling trigger. Once they pull the trigger, even if the gun fails to fire, it is an attempt. Jumping: Person is poised to jump, is grabbed and taken down from ledge. Hanging: Person has noose around neck but has not yet started to hang - is stopped from doing so. ***Has there been a time when you started to do something to end your life but someone or something stopped you before you actually did anything?*** If yes, describe:	**Yes No** ☐ ☐ Total # of interrupted _____	**Yes No** ☐ ☐ Total # of interrupted _____
Aborted Attempt: When person begins to take steps toward making a suicide attempt, but stops themselves before they actually have engaged in any self-destructive behavior. Examples are similar to interrupted attempts, except that the individual stops him/herself, instead of being stopped by something else. ***Has there been a time when you started to do something to try to end your life but you stopped yourself before you actually did anything?*** If yes, describe:	**Yes No** ☐ ☐ Total # of aborted _____	**Yes No** ☐ ☐ Total # of aborted _____
Preparatory Acts or Behavior: Acts or preparation towards imminently making a suicide attempt. This can include anything beyond a verbalization or thought, such as assembling a specific method (e.g., buying pills, purchasing a gun) or preparing for one's death by suicide (e.g., giving things away, writing a suicide note). ***Have you taken any steps towards making a suicide attempt or preparing to kill yourself (such as collecting pills, getting a gun, giving valuables away or writing a suicide note)?*** If yes, describe:	**Yes No** ☐ ☐	**Yes No** ☐ ☐
Suicidal Behavior: Suicidal behavior was present during the assessment period?	**Yes No** ☐ ☐	**Yes No** ☐ ☐
Suicide:		**Yes No** ☐ ☐

Answer for Actual Attempts Only	Most Recent Attempt Date:	Most Lethal Attempt Date:	Initial/First Attempt Date:
Actual Lethality/Medical Damage: 0. No physical damage or very minor physical damage (e.g., surface scratches). 1. Minor physical damage (e.g., lethargic speech; first-degree burns; mild bleeding; sprains). 2. Moderate physical damage; medical attention needed (e.g., conscious but sleepy, somewhat responsive; second-degree burns; bleeding of major vessel). 3. Moderately severe physical damage; *medical* hospitalization and likely intensive care required (e.g., comatose with reflexes intact; third-degree burns less than 20% of body; extensive blood loss but can recover; major fractures). 4. Severe physical damage; *medical* hospitalization with intensive care required (e.g., comatose without reflexes; third-degree burns over 20% of body; extensive blood loss with unstable vital signs; major damage to a vital area). 5. Death	*Enter Code* ______	*Enter Code* ______	*Enter Code* ______
Potential Lethality: Only Answer if Actual Lethality=0 Likely lethality of actual attempt if no medical damage (the following examples, while having no actual medical damage, had potential for very serious lethality: put gun in mouth and pulled the trigger but gun fails to fire so no medical damage; laying on train tracks with oncoming train but pulled away before run over). 0 = Behavior not likely to result in injury 1 = Behavior likely to result in injury but not likely to cause death 2 = Behavior likely to result in death despite available medical care	*Enter Code* ______	*Enter Code* ______	*Enter Code* ______

Appendix 19: NIH Definitions for Reporting Race and Ethnicity

Categories defined from the NIH policy on reporting race and ethnicity (NIH, 2001).

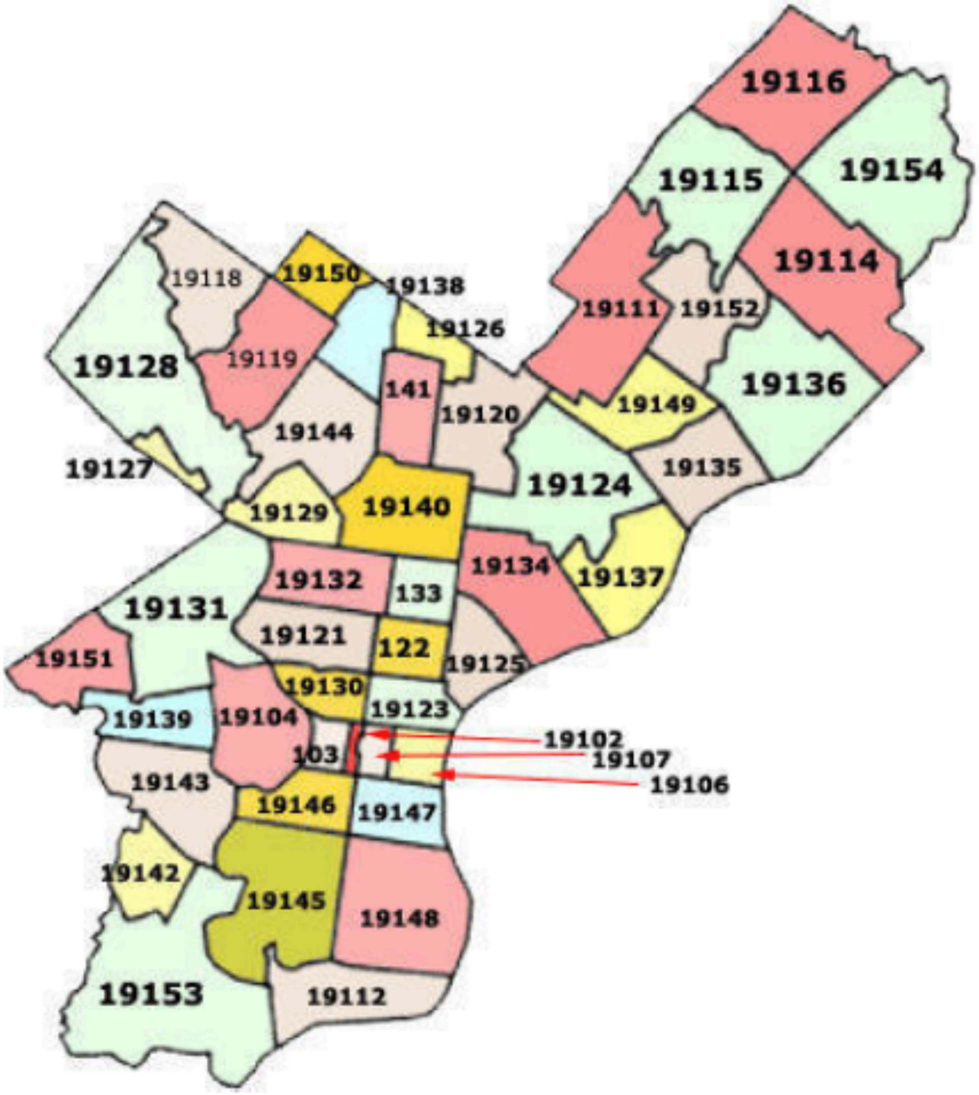
Ethnic Categories**:**

- *Hispanic or Latino:* A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can also be used in addition to "Hispanic or Latino."
- *Not Hispanic or Latino*

Racial Categories**:**

- *American Indian or Alaska Native:* A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliations or community attachment.
- *Asian:* A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. (Note: Individuals from the Philippine Islands have been recorded as Pacific Islanders in previous data collection strategies.)
- *Black or African American:* A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
- *Native Hawaiian or Other Pacific Islander:* A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- *White:* A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Appendix 20: City of Philadelphia Map with Zipcodes



Child and Caregiver Zipcodes within Sample (N=50)

19119= 3 (6%), 19120= 2 (4%), 19121= 1 (2%), 19124= 1 (2%),
19126= 1 (2%), 19128= 4 (8%), 19129= 1 (2%), 19131= 1 (2%),
19136= 1 (2%), 19137= 1 (2%), 19139= 3 (6%), 19140= 1 (2%),
19143= 5 (10%), 19144= 4 (8%), 19145= 3 (6%), 19146= 5 (10%),
19147= 5 (10%), 19148= 4 (8%), 19152= 1 (2%), 19153= 2 (4%), 19154= 1 (2%)

Appendix 21: Quotations Reference Table from Qualitative Interviews

Major Factors for Children with ADHD	Quotations
Child's Daily Life	***Different Yet Similar/Normalize*** *"From my look, she's not as much different than other kids… I feel like she's the average kid. I feel like she has a normal life."* *"Because of the ADHD, I think that she's a little bit different than other children her age. Kids say 'Why are you so hype all the time, or why are you so extra?'"* *"I don't feel like he's, like, different from other children. Like, he can be hyper where, at times, but, if he was playing with a group, it's not a major difference in this behavior versus another kid behavior."* *"Yeah, like if she was sitting here she'd be able to talk and be normal and that would be fine. But it's just in certain circumstances she can't deal."* *"He's different in a lot of ways, but to me, I'm looking at this normal kid."* *"She's going through the normal kid phase. It's amazing to see five-year-old drama."* *"It's just a piece of him… it's not who he is."* *"He's pretty much the same as any other child. Like you really wouldn't know when you look at him-that he has ADHD- until you get into a setting where you have to sit down and you have to pay attention."* *"He's different because he definitely struggles with school and sitting still and paying attention; whereas, some other kids can easily do that."* *"I think he's pretty similar. I mean obviously, the ADHD makes it a little different in certain aspects, but for the most part, I think he's similar."* *"I feel like some things are normal child behavior."* *"I think sometimes it takes her a little bit of time to pick up things, but we don't really make her feel like she has a condition."* *"He's still a kid at the end of the day."* ***What's ADHD & What's Being a Kid*** *"Like you're trying to figure out what is six-year old behavior and what's the ADHD."* *"You know, being an ADHD child, you can't fit into a nice little box."* *"So part of that is, is it the ADHD or is it him just being a boy?"* ***Holding Accountable for Actions*** *"I don't think he's less of a child, like I expect the same from him that I would any other six-year-old."* *"She is still Jada. She is still like other kids and she still has consequences."* *"He has ADHD, but I'm gonna hold him up to his responsibilities."* *"In my book, at times, just because you have this problem, no, you're not going to use this to get over."* *"I don't make excuses for him, because he has a condition. But I still recognize that he has one."* *"I'm trying to get her to the place that's okay- I know I have this disability but I'm not going to allow it control me."*

Condition Management Effort	***Physical Demand*** *“It’s a lot of reminders… it’s a lot for us to stay on top of.”* *“There’s a lot of like probing or asking for verification going on.”* *“Even when we go out, the boy’s like a little ninja… he could be here, then he’s right behind you. You have to constantly watch him.”* *“Even though we are on the medicine, we still have constant reminders.”* *“Some days we have the fight with the medicine.”* *“A lot goes into it because he goes to therapy every week, so I have to take him every week. And, then, he also has monthly medication appointments, because of the type of medicine he receives. Then, we go to the pharmacy every 30 days to get a refill of the medication.”* *“It does require me to have to tell him twenty thousand times do this, do this, do this, do it now, do it, do it, do it now.”* *“I work really hard with him. It’s a lot of studying. I make up tests, too.”* *“It’s just… constant repeating over and over and over.”* *“You gotta constantly check [that he’s taking the medication every day].”* *“We have to visit his school like every couple of days just to see if he’s still on task. Constant conversations with teachers. We’re always texting and calling each other back and forth.”* *“I repeat myself a million times a day.”* *“Mornings actually depend on me, because if I have everything laid out exactly… like every single thing, then it’s pretty good.”* *“So homework is really a challenge. He need to be constantly re-directed.”* *“He needs extra, extra, extra. I have to constantly repeat myself.”* *“I do frequent pop-ups up at the school to find out what’s going on.”* *“It’s everyday life. Redirecting every single second. Every single day. Every single moment- redirecting.”* *“The mornings can be tough even with the medicine. It’s constant reminders.”* *“We still have to constantly say what do you have for homework?”* *“Homework time. The medication has worn off, and it’s usually a struggle.”* *“I manage a lot. His behavior and medication and everything. I have a lot on my plate. I always have things to do. I’m in school full time. I work full time.”* *“You have to tell him the same thing about twenty five times, and he’s like constantly moving, going, saying, speaking, like just doing. Like all the time.”* *“It’s a lot of work making sure we stick to the schedule.”* *“Mornings… sometimes it’s tough. It’s like sometimes he still puts his clothes on backwards, shoes on the wrong foot, and don’t really know how to tie his sneakers all like that. It just be a lot.”* *“I definitely need to know all of his homework, which becomes complicated, because every teacher’s on a different website. You have to go to all their sites, write down… I actually put on a calendar that you have this, this, and this.”* *“Yeah, I have to stay on top of him. I am a constant reminder for him. Even with the schedule and reminders in his phone.”* *“Some people, they’ll say to me, you gotta keep him busy at all times. But you must understand, keeping him busy means keeping me busy.”* *“Normally I have to constantly repeat, repeat, repeat. If I told a directive, within that five seconds, she’ll forget what I’ve told her.”* ***Emotional/Psychological Demand*** *“I act as her executive function and it’s very taxing. I’m a very organized person and so I can handle it, but, you know, after a while…”* *“It’s hard work. You’ll be exhausted some days. Like some days are rough and*

	you are overwhelmed. Some days everything is a struggle. It wears me out to say the same thing over and over." *"Sometimes I find myself like repeating, repeating, repeating, and then, I'm just like fussing."* *"Stresses me out because he's so busy – he's all over the place."* *"It's a real challenge. Sometimes it's really hard. It's really exhausting. Sometimes just the day in and day out… It's tiresome."* *"It can be really frustrating at times. Sometimes it's like chaos, and it's difficult. It's a constant balancing act. That's our struggle."* *"I'm just tired. It just be frustrating. I be like, ugh. It's just a lot."* *"Sometimes it's hard. I will admit, sometimes it's hard. Some days he would bring me to tears over something."*
Condition Management Ability	***Management Strategies*** *"I mean it's not a perfect routine, and it's a very loose routine."* *"Bryce has to have a detailed routine. I can't switch up- it has to be the same thing every day. Everything has to be planned. I notice that helps him."* *"Since we've been on the medicine, the morning routine has been better… More flowy and less choppy."* *"We have a pegboard at home, so now she follows the schedule."* *"Everyone knows the routine in the house. We have to stay on task. Consistency is key."* *"Some days it'll be smooth and other days it won't be smooth."* *"This is the first time dealing with it. Every step of the way is guessing."* *"I try my best to have a consistent schedule with him."* *"You have to give clear directions and split them up into smaller pieces."* *"Activity on a regular basis has been helpful… Gets rid of the extra energy."* *"We figured out that when he doesn't take his medication it doesn't really turn out great."* *"We really just manage it, just get by the best we can. Like the routine is not a routine. Everything is different, new adventure every day. We just go with the flow."* *"Structure. Consistency. Positive Praise."* *"We'll create activities and we set goals."* *"It's different day by day with him. You have to kind of press whatever button and you know just try things until they work with him."* *"Post-it notes all over the house with reminders… I need post-it's all over me."* *"Sometimes I feel like I'm winging it."* *"I make things into a game. Hyping them up, but also getting them to learn."* *"I'm kind of a sticky note person. I put my stuff on a sticky note, I have a calendar on the refrigerator. I am a journal writer, I take notes of everything."* *"A lot of things will go day by day. Some days it just goes."* *"Well, there's been a lot of trial and error."* *"It's all about routine, routine, routine, schedule, schedule, schedule."* *"I constantly feel like we're just flying by the seat of our pants."* *"We had a sticker chart with a jar. You have to be very consistent and keep the goals very small."* *"We try to have a routine. We know our morning routine, we know our afternoon routine, so I try to keep things in order."* *"Everyday changes. What works one day may not work the next. What works in the morning may not work in the afternoons."* *"We tried goals. If you do XYZ, then you can get a reward… Or some type of*

	positive reinforcement, like an incentive, and he responds very well to that." *"It's a very clear understanding. These are the rules. You know what the rules are, if you break the rules, these are the consequences. It's just that simple."* *"If they're kind of wild, we sit them down in a peace corner and set them up with a little mediation or music."* *"When there are times when he gets crazy, I dim the lights, shut it down, lower the music, whatever it is. It helps."* *"Positive reward works better, especially with ADHD, it really does."* ***Management Philosophy*** *"We really have to try and just be open and flexible and try new things. Like, okay, that's not working, keep on moving."* *"Tomorrow is the next day, and it's a brand new day, and we're gonna try harder tomorrow than we did today, and we're just gonna keep trying harder than we did the previous day until we have a straight flow."* *"I mean that's the best I can do, because at the end of the day, I want to feel good that I tried my best."* *"You have to look at it like you're the one that's got to do the work first. You have to change before you can help your child learn to manage what they have."* *"Yeah, I had to think kind of, like, out of the box on what we could do. There's so much information out there, you just got to find it. The more you know, the better you can manage."* *"I'd like to be more consistent, but there are things that prevent that in the real world. It's like.. I'm not sitting down & saying let's work on the [behavior] chart. The point system falls behind, but he still gets rewards, it's just not done consistently."* *"I don't care what it takes. We're gonna learn this condition that he has, and I'm willing to give whatever I got to help him."* *"We have routines, but I don't make it so rigid that it can't change."* *"He really doesn't want to be on the medication, so I'm like okay, then you gotta learn to control your behavior. So, it's learning to adjust to that and work through solutions."*
View of Condition Impact	***ADHD not the worst thing*** *"For us, it's like a walk in the park compared to other parents with children who have worse conditions."* *"ADHD is not easy, but it's not the worst."* *"…In the grand scheme of things it's not horrible."* *"Everyone has problems, and for him, it's ADHD."* *"This isn't a disease you fight. It's a disease you have to understand."* ***ADHD not going to hold kids back/Caregivers instrumental for this*** *"That's the only future for my son… I want him to grow up, and I want him to know that you can do what anybody else does even with this condition."* *"There's no excuse not to succeed. It's no excuse, because we're gonna put everything in place, and he has to succeed. He has ADHD, but I'm gonna hold him up to his responsibilities… and I'm definitely gonna hold all the adults that are in his life accountable for what they need to do too."* *"I definitely believe that he can be whatever he desires to be, and I have every intention on aiding him, down that path… I don't feel like there's a limitation to anything that he can do… Anything is possible."*

	"Even though you got a condition you still gotta learn that you have to be independent and handle things on your own, but we still gonna be there to help you out no matter what." *"I keep telling myself, when you think positive, it becomes positive. He's going to fine. ADHD is going to be a thing of the past. He's going to find his way to the top. Regardless of what it takes."* *"I think she's going to be the one to soar. She's going to go far. Yes, you have this disability, but it's not going to allow her to use it as a handicap that prevents her from doing what she wants to do in life."* ***Bright Futures*** *"We always tell her that the sky's the limit. Whatever you want is what you'll achieve. There's no limitations to what you can and cannot do. You may have to work harder than other kids at times, but that doesn't mean it can't be done."* *"I'm trying to teach her how to use her hyperactiveness as an advantage to work in a field where having ADHD can actually help you excel and do very well."* *"I always tell him that he can be whatever he wants to be."* *"I think he's going to be some person that does something huge and later thanks Mom for staying calm and patient when he was bouncing off the walls."* *"If she's going to be anything, she's going to be a leader."* *"As a parent, I just hope for the best. I don't know what's going to happen. I can only try for improvement and hope it does improve."* *"His future, well… Success and happiness. Happiness with what he's doing and happiness with whatever he decides to follow… I see a very bright future ahead of him. It's just guiding, harnessing, nurturing, and helping him along the way."* *"I have no question that he is going to be a success in life."* *"He's going to do something great. Really make a positive impact and make a difference in whatever he loves to do… God has a great purpose for him."* ***Growing Out of It*** *"It's not a condition that will go away with time. No matter how old he gets, it will still be a part of him. It will be something that affects him for the rest of his life. He will constantly be different, but everyone is different in one way or another."* *"Hopefully, as he ages, he won't need the medicine anymore."* *"Like, is he going to be okay? Is he going to grow out of it? Or, are we going to be down this road with mental stuff as he gets older? I don't know."* *"I want the breakthrough. I want him to try to break through on his own instead of ya'll services and medication. Function and do anything on his own without the help… My thing is, like, I want the breakthrough."* *"So, I am hoping. She might be able to grow out of this and not need medicine ever again. That's my goal."* *"I'm hoping that either it stays where it is now or it becomes more manageable with just a little bit of medication. Or, hopefully, he'll outgrow it at some point, like, that's what I'm hoping for."* *"I see him not needing the medication eventually and essentially growing out of it."* ***Worries/Concerns*** *"Not to say the future doesn't matter, but tomorrow isn't promised."*

	“We’re just tryin’ to make it through the year… I’m just worried… Anything could happen… I’m concerned that it’s gonna get worse as she gets older.” *“(sigh). I don't know, because at home I can get him to follow directions. At school it’s not so much. I try to explain to him all the time… these are small consequences, in the real world there are bigger consequences that I cannot save you from.”* *“I’m like terrified. I have so much fear that he’s gonna get hurt somehow… It’s just other people around him and surrounding him around the neighborhood and stuff that I don’t trust.”* *“Well, at this time, I haven't looked too far into it. I’m just hoping to get my baby to the next grade.”* *“It's scary to think about the medication piece. Do we keep upping the medication, then what happens? Does he hit the end of where the highest dose is?”* *“I’m worried because if you can’t control yourself now with authority figures, what’s gonna happen when you’re out in the streets and I’m not around you? What’s gonna happen in you get locked up or something worse.. Or if you get into something with somebody in the street, the way that people is these days, are you gonnna make it? … That’s what really scares me.”* ***Needing Support to Succeed*** *“She’s still gonna need some kind of structure or guidelines or support over time… like ongoing check-ins or something…”* *“My hope is that he'll have supports and develop coping skills for high school and college. We all learn differently anyhow, so it's just trying to figure out what works best for him, so he'll be successful.”* *“I think he’s always going to need to talk to someone, like a therapist or outside source.”*
Parent Mutuality	***Diagnosis/Condition*** *“I think he thinks that our son is fine. He’s doesn’t see so much of a problem as I do.”* *“Dad is in the picture but dad does not believe ADHD. Nothing is wrong with his son.”* *“As far as seeing the condition, I think we view it the same way.”* *“So the problem is his father doesn’t even want to admit that he has anything wrong. Like, it’s a label, he’s just a regular kid, he’ll grow out of it.”* *“When it comes to the actual diagnosis, I don’t think we disagree at all.”* *“Now my mom, she was in denial for a very long time.”* *“I don’t know if he doesn’t accept it, but he very much doesn’t want to buy into it. He believes Roosevelt is Roosevelt and that’s who he is.”* ***Treatment*** *“We disagreed with giving the kids medicine, but I’m with them more. I’m gonna give her the medicine. If it doesn’t work, then we can try something else.”* *“His dad was real against medication. Just not being a believer in medicating. He’ll either grow out of it or he’ll cope or he’ll learn… not everything needs a fix… he needs to do this on his own.”* *“That was kind of our conflict. He does not like him on the medicine.”* *“So her father didn't kind of want to come to terms with the fact that she had it or that she was going to start medication. So that's kind of something with a*

	conflict in our relationship." *"His father and I completely different ideas about how to treat this."* *"One thing we both agree on is no medication."* ***Condition Management & Parenting Philosophy*** *"We're definitely on the same page. It's just… his approach sometimes is different than mine... Our strategies are different."* *"Because there's two of us, you're allowed to take a break… So some days I could be like, I just can't take him anymore. Like, you need to take him."* *"We do things differently at certain times. We have disagreements on how to deal with it."* *"Yeah, we co-bossing it together."* *"I tend to get a little frustrated, we both do but, sometimes-it's like, you burn out on it a little bit and you have to just tag team and be, like, okay, your turn."* *"Like, he doesn't have that level of patience. He just can't do it."* *"I am more informed than him. So he's getting a lot of knowledge of it now."* *"Well, I think we definitely try and approach it together."* *"Yeah, like if he sees me ready to like lose it, he's like let's swap out. Yeah, jump in. We call it like the good parent, bad parent. Like good cop, bad cop."* *"I'm the one that does all the phone calls and the emails and the scheduling and the getting everything ready. He's onboard with everything like as far as coming here and the doctor's appointments. We pretty much do all the appointments together if we can."* *"We really try to approach it as a team…"* *"I think our strengths together is that when one breaks down, the other one picks up where the other one broke down. So I think we're good that way."* *"We argue in regards to parenting. Discipline."* *"He's more of a disciplinary type."* *"My boyfriend and I… We see eye to eye. Not on every single thing but we have the same set of values."* *"My husband and I are just different… I'm more, my darling, give me a hug, let's calm down and he's more, like, just go to your room."* *"Daddy doesn't play. Mommy's more conversational, let's work it out, let's talk it out."* *"He could be softer to get more results. He takes the more authoritative approach, like I'm the dad, but that doesn't work with the condition so well."* *"My husband, He kind of tends to lean on me and just allow me to kind of take over and do everything because I'm in the medical field, so he thinks, oh she's a nurse so she knows everything so I'm just going to follow."*
Barriers/ Challenges	***Immediate Family*** *"My health's not too good."* *"His biological mother suffers from depression, bipolar disorder…"* *"We don't live in the best of neighborhood."* *"Her mother… has mental health issues. Wasn't fit to be her guardian. Her father hasn't been in her life…" [grandmother is legal guardian]* *"I think the ADHD adds a little bit of a challenge to it- [sibling relationship]."* *"Got diagnosed with MS, that didn't help."* *"She's got bipolar disorder..." [biological mother]* *"We was in a shelter for a year and a half."* *"We have a really hard time because of the divorce."* *"Because it's just me. It ain't like me and the father. It's just like me."*

	“Their father died…” ***Extended Families*** *“As far as family-wise, I had to cut some relationships off. I don’t think that’s a healthy situation for my son to be in.”* *“The biggest thing really is family. That’s probably been the hardest thing, just hearing things from them as far as my parenting… Like we are too educated, our parenting techniques are different, and that’s why he’s so off the wall.”* *“Just those few family members… They don’t understand… That’s our hardest issue.”* *“My mom and them don’t have the patience with him. A lot of my family and them didn’t want him around because of it...”* *“The only things is, like, how other family members deal with it. It’s hard with other family members trying to figure how to manage it. That can be hard.”* *“Certain people, I know what they can tolerate, what they can’t tolerate. My son’s family, they tried having him over sometimes before, but Alexander is just too much for them. So they’re like, we can’t do this no more.”* *“I had other family members judge me saying, he doesn't have ADHD. He's just a boy. Why are you medicating him? You know, that kind of thing.”* *“My family and out of town family, extended family. It’s hard for them to understand his condition. So, that has been a huge challenge.”* ***Stigma*** *“There’s all these stories about kids and pushing around ADHD medication.”* *“Some people think that therapy is taboo.”* *“He said, the teacher said I was bad today. Or I was good today. So I said, kids aren’t good or bad. They don’t listen or they did listen.”* *“Well, my whole thing was… I didn’t want them to be walking around in a zombie state for them to keep still...”* *“Because in African American families, they seem to think medicine or going to speak to psychologists and psychiatrists… they’re kind of voodoo… Like, we don’t do that.”* *“I’m Caucasian and sometimes think that people look at my son and know that his father’s African American and that’s what a lot of people thought was going on at the school before this… Like being the typical little African American boy, this is how they behave and kind of stereotyping him.”* *“I mean I know how the world is; people judge and people have different perceptions of what is okay and what isn’t okay.”* *“Yes, definitely with ADHD with little boys… but I think other people have more of a stigma.”* *“Especially being Black… there’s a lot of stigma with ADHD.”* *“People are judging you, and they’re like, you’re not disciplining him enough.”* *“Me personally, had to learn to ignore… negativity… because they don’t know our story…. They don’t know what my child is going through.”* *“This is the kid that’s labeled ADHD so the blame automatically gets shifted onto them.”* *“I never wanted to apply for SSI or anything like that there. I never knew what it was. I hear people, their version of it, which isn’t a good version for me.”* *“I know a lot of parents probably don’t want to put them on the medication. ‘Cause I definitely was opposed- you just feel like you don’t want them being all drugged up. ‘Cause her medication is a narcotic.”* *“The other teachers. They thought it was a disciplinary issue, so they would*

	say, maybe you need to discipline her a little bit more and things like that." *"I don't want to take away her personality with the medicine."* *"The horror stories of all the medications out there and they're bad long term. Like drug use later and stuff."* *"I read some studies, like some parents, I mean even the child who has ADHD, doing some test or major examination, they ask the doctor to prescribe them to take the medication to concentrate or study, that's what I heard anyway."* *"They are not bad kids. Sometimes make bad decisions, but you are not bad."* *"It's not a bad thing putting your kids on meds. But people are so against it."* *"People look at ADHD and meds for it as like a dirty topic."* *"It [IEP] ties him down, they say. That's what they told us at school. It gives -- it labels him more with that. It labels the child."* *"He gets very embarrassed taking his medication in front of people."* *"They don't carry it [a type of stimulant medication] because people take it to stay up studying and lose weight."* *"That's our main concern is not to make a him a zombie…"* *"Especially in the African-American community, for your children to have some type of mental disorder, like, we don't like that kind of stuff. But you have to get them help or they're not going to be able to thrive throughout their life."* *"A lot of people be like… I don't want my child taking meds, or meds slow them down and they be like zombies. Like a lot of people told me that before I gave him medication. They was like, you don't want to give him medication 'cause he's gonna be a total different person. He's gonna be sluggish, a zombie. He's not like that. He's just calmer. Like he's not like a zombie. Like he's not like sluggish. He's just calmer. Like he still likes to do stuff."* *"You hear people's opinions all the time telling me I'm doing the wrong thing. Strangers tell me I shouldn't medicate my child."* *"Because they find out it's a controlled substance, they immediately put up a weird vibe, and they don't understand that it's not… he's not abusing it."* *"Medicine for ADHD, but they don't want negative side effects. The zombie effect… You can be normal like you'd regularly be, but just not as hyper."* *"…Why I didn't want to get him on medicine is because of the stories that I hear… I don't want my son not being my son. I don't want him not being him."* *"I have a cousin whose daughter has it. Nobody knows, it's a secret."* *"He's probably been told he's aggressive so much that he kind of shirks back. You know what I'm saying? Now he's really cautious about it. Very cautious."* *"I wish that people took this as serious as it is, meaning-when they hear it, most people think it's… oh, it's just… it's made up. It's a behavior issue. They just need a spanking. They just need more discipline. It's much more than that. Even with my family. Because everybody in my family does not know. They don't even know he's on medication because, number one, I didn't want the stigma for him."* *"I don't know if they were a doctor or a therapist, but they had made a comment almost as though this was an excuse for parents to not do what they're supposed to do as parents. And I'm just like, no, if you've ever dealt with it…"* ***Education*** *"One or two of her teachers now, they're very strict, but they don't have the empathy and they come off as very dismissive."* *"In a charter school or even public schools sometimes their resources are really limited or… how they're allowed to do things are not so flexible."* *"The whole school has changed now, because last year we had a whole*

	different administration… because they got a new principal, new staff, everything. So they don't really know her now. The other people knew her well." *"She really needs supports in school right now but… it takes so long to get a worker. It took us like a year and a half just to get that worker."* *"I don't really feel like he's actually gettin' those type of helps that he need to get those improvements."* *"I think the education system is a big barrier… it was a disaster one year. You really have to push to get what you need…"* *"The teachers at his school that he goes to now… They don't understand."* *"Just the school behavior. She was discharged from five schools prior to this, so this is her sixth school she's been in within a year's timeframe."* *"I think that a lot of times the teachers are not really equipped to deal with it. Either they don't know the right techniques or… there's other kids that have other issues. So it puts a pretty big burden on them to try to deal with it."* *"When they don't follow the IEP, it causes issues."* *"Every year it's a different challenge, every single grade… like up and down."* *"He's been at three different schools now. Two of the schools that he was at didn't provide the support he needed due to his ADHD."* *"We've had very bad experiences. We actually left the school because of it. The teacher and him just butted heads. She basically said that he's never going to learn because of disabilities. Right after we left the school, we realized that it wasn't him; it was her. He's flourishing now with his new school/teacher."* *"I think one of the other struggles that no one really recognizes is, especially in the city, is the lack of support from the school systems."* *"Like, for instance, prior years, we were good, we were stable. And then sixth and seventh grade, they start changing classes. So, now, that's a whole new dynamic we have to get him adjusted to."* *"There were too many people in the pot. With all his teachers, a counselor, this one, that one, and we're, like, we're not on the same page. This is really hard to get all these people on the same page."* *"So then I transferred him over to a different school and it was the polar opposite experience."* *"In certain schools it's like, okay, I need to know who's gonna really want to help take care of my child."* *"School… fourth grade was horrific for him… His teacher… although she might have been familiar with ADHD, she wasn't trained."* ***Healthcare*** *"She's literally on her third therapist. Not because she didn't like them or whatever, but the therapist just moved on…"* *"It's like six… seven years almost. And seven therapists."* *"I can't imagine that constant turn-over. I'm talking about things- I've opened up to you and I've expressed things to you that are hurtful and you're leaving."* *"It just brought tears to my eyes. He was literally crushed, like, I am going to miss you. He was just, really crushed [when child's favorite therapist left]."* *"Every therapist has their own tactic. It really just depends on the therapist."* *"Honestly, sometimes the pharmacy doesn't have the medication or we've run out and we don't get on it."* *"We've changed so many therapists over the time because they always quit, or either we lose the services or either one girl I just had to fire because she would come to the house and she would talk to me the whole time…about her boyfriend and her life and her job and she was going to school.. but I'm like*

	you’re here for an hour to talk to Domino and give her services.” *“I only came here the one time to get the diagnosis… I felt like I didn’t really know what to do next. I got this form and he was like, oh, well, you can come and bring him to therapy or this group or something, but what I was looking for was more support, like either at home or in the school or something like that.”* *“We were on a wait list for almost a year, actually.”* *“Originally it was a fifteen-month waiting list or something like that.” -* *“They had to switch locations, so now we’re trying to find him another doctor to prescribe him the medicine.”* *“Michael’s psychologist he’s had for the last three years… just left, so he’s got a new psychologist.”* *“We've tried to get into X multiple times, and the wait list was just so long.”* *“…the provider's office... It's like multiple hands in the pot. You're calling one person and they're telling you one thing. Then, you call up, you get another person, and they're telling you something different. There's no consistency...”* *“The biggest - on the healthcare side. There's no consistency from who you're talking to and who's prescribing this medicine.”* *“Not that these organizations and all aren’t good, but no one really tells you what to do. They really don’t. Like they go here’s your diagnosis. And you’re like great, what do I do with this, you know?”* *“That's the one thing I don't like- there's too many doctors… We don't see just one doctor.”* *“So if there's a big turnover, even a doctor can turn things into an issue because now he feels like oh, we got to start all over again and they have to learn who I am.”* *“For mental health… it's just hard to find services or it's hard to find services that you can afford and really get the help that you need.”* *“’Oh, it could be a twelve month wait list.’ And I’m like, ‘What?’”* *“We wanted to do XXX but the wait list was way too long.”* *“It was a lot of turnover. She had three therapists within, like, four months.”* *“In order to get her medication, I had to take her every month and they only had appointments at 1:00… That means I have to take a day off of work. I have to take her out of school… That’s not helpful.”* *“It was a little bit hard for me to get there all the time. They didn’t really have transportation. I wasn’t working at the time, so I wasn’t able to get him and me there, with me having to pay for him and stuff. And then once I started working it was just like, okay, I don’t want to be missing days because of this.”* *“I find sometimes that ADHD support groups were pretty depressing. I went to one meeting and said never again will I go… I just really find that they’re really missing the mark. I think a lot of places do.“* *“I don’t feel like they were listening to me. Like I would leave messages and nobody would call me back.”* *“Well, I would have to say, when it comes to like mental health, trying to get services, that is a huge barrier. Even trying to navigate through that.”* *“…We just felt like it was kind of too much… driving out there…”* ***Financial/Policy/Insurance*** *“There’s CHIP, but CHIP has no behavioral health.”* *“Everybody saying that my child needs help and I’m telling you I need help, and I’m telling you as a parent… I need help, and then you just keep saying no.”* *“Because my income is too high, so to be eligible for the services that Philadelphia wants to offer, you have to basically be eligible for welfare, and*

	I'm not… Private health insurance doesn't get you very far. Doesn't get you pretty much no help… With my income, to get welfare, you have to literally fight a very long fight. So, my fight to get health insurance for her through the state took a year and it involved going to court, appeals and stuff like that." *"My final option was to either sell my house or rent it out, move to XX- that's the only place that's willing, with my income, to say okay, we still can offer you help, but in Philadelphia, it was a very big struggle."* *"We live in a two-parent household and they say we make too much money and some of the benefits, we were overqualified for, which doesn't make sense to me because I'm not asking for money. We can take care of our kids our self. Like I'm not asking for money. I need the services."* *"In order to qualify for these services… this is what I told the lady on the phone… I said, so 'I need to be a single parent, I need to be poor, and my child needs to be dumb for me to get what I need to get for him.'"* *"So they went through all these other things, so now he qualifies because ADHD is a disability. They have to provide him things because, if not, then you're discriminating against him."* *"It was a struggle going through all the different health insurances to get it [the TSS worker] approved."* *"We keep getting kicked off the system 'cause what happens is when my income changes then we get kicked off the Medicare… And when they kick off the Medicaid, the place where we go only takes Medicaid patients."* *"So then we have to find a new doctor and a new therapist every time, because CBH, you can only have CBH if you're on Medicaid."* *" I was telling him about how we keep getting kicked off and then she keeps losing the benefits and then we have to change doctors all over, and they said to apply for disability for the kids. And he said then you won't get kicked off because they're automatically given medical assistance, and no matter what your income is they won't be able to kick them off."* *"So I've applied. It's been declined or whatever. Like it was not approved. But then he said keep it appealing it. They said they always deny people at first, couple times, and then you'll get it."* *"My income… you know when you're retired, it ain't enough."* *"The main challenge was, because I do work, I was ineligible for MA."* *"Most of the providers that, you know, specialize in her conditions only take MA. A lot of children's childcare treatment centers, they only take MA. They don't take private insurance. She had CHIP. But still nobody wanted it."* *"I almost lost my job because FMLA wouldn't cover it without a diagnosis. In order to take FMLA for your child-- You have to have a diagnosis- -or a doctor's note, and a doctor can't give you a note without a diagnosis."* *"So once she got diagnosed, I now have MA because of the diagnosis."* *"They just denied him, they flat out… XXX is getting a lot stricter with the hours [for behavioral health/TSS workers], and it's basically like we're going to deny you the first maybe two times and then we'll give it to you."* *"And then our insurance changed, so then we had to go somewhere else."* *"So I applied him for disability. And because he has the disability, he got approved for it. They now have to give him insurance, so he has Medicaid."* *"Even though we're over income, but because he's disabled, they give the Medicaid. He's going to have that insurance forever. So that's good."* *"So it's been hard finding services that take private insurance these days."* *"It's, like, if you work hard, you can't get nothing. But if you don't work hard, you get everything."* *"When I first went to the shelter, I didn't really have no help like with him."*

	"They had behavior and development [services] at the school but my insurance didn't cover it." *"I've been like trying to work on the process for like years, and it's difficult."* *"It was more so fighting for services and dealing with school interactions with the agencies that denied services involved with his care."* *"I've always wanted to get him in there, but he doesn't take insurance, so you've got to pay out of pocket. They offer so many resources, different types of therapies he could benefit from, but who has got money to pay for that."*
Facilitators	***Family/Community*** *"I do look online for a lot of like techniques or different approaches."* *"We have a really supportive community at the school and our friends…"* *"They say it takes a village to raise a child… My village has stepped up for me -- everybody, like, friends, family, everybody."* *"One of the key things that I believe holds it all together is the support."* *"The help that we get from outside the community and with our family, that helps."* *"I have had to rely on friends and informal communications with people I know to try to get tapped into some of these things."* *"My girlfriends. I can talk to them. And, the church."* *"I joined this Facebook mom group, and it's for ADHD… The support groups really help."* *"One of our strengths is we are a tight family. We're a small family, but we're a tight family."* *"I have support with my friends and some good friends I talk with when I get stressed."* *"My best friend had similar stuff with her son. So she kind of like paved the way. She was like you need to do this, this, this and this."* *"My aunt is a director of a daycare center… She's knowledgeable about this type of stuff, so she helps me. She guides me in the whole process."* *"I have a nice support system."* *"Well, my church family, they are very supportive of my daughter. I reach out to my church family and my best friend, because her son has ADHD too and we vent to each other."* *"A couple friends… They just point me in the right direction to go to."* *"I have my best friend. I have cousins, sisters, brother, his dad, his family." Everybody's just rooting for him."* ***School*** *"The teachers are really, really great. They're very willing to help."* *"They have a new counselor at the school. She understands what's going on."* *"He has a really good teacher who is very attuned to all the ADHD stuff."* *"The school's been great with all the supports inside the school."* *"It's been kind of rough with Michael and they've been there for us."* *"Overall, we have really good communication. They're really helping me. Everybody is on board."* *"The school was a big help with getting us in touch with the right people."* *"He has a lot of support at school with the teachers and the special education teacher that works directly with me to make sure everything is going as smoothly as can be."* *"I think the biggest part that helped us was forming the relationship with the teacher… that partnership with the school."*

	"Finally, I was able to get him into the same school that his sister is in, there are much more resources available for him. Resources are huge for us." *"His teacher this year, I mean, she's been real helpful letting me know what's going on with him every step along the way."* *"I think he has a good, positive relationship with his primary teachers."* *"I love the school. I love the curriculum. I love her team."* ***Healthcare*** *"We have access to good doctors."* *"The pediatrician… she's so good. She was like, do you trust me? And I was like, yes."* *"I'm in constant contact with them because I can't do all of this without them helping me."* *"A few weeks ago we had a really, really bad day, so we had to call the doctor. I was like, I don't know what's going on. I'm crying. So he called the teacher and spoke to the teacher on a Sunday, which means that not only does he care, but she cares."* *"He had a male therapist before and I could literally see why he loves this therapist."* *"So we try and work with one [provider] specifically because she seems to be really open and listens to what we feel and will work with us and say, well, how about we do this, like, she has very good suggestions."* *"So we have a really good relationship. She's had the same therapist for three years. If there's a problem I can call the therapist and her doctor now that prescribes her medication, he's very flexible."*
Child Strengths	***Personality Traits*** *"Definitely creative."* *"He's smart as a whip."* *"He's definitely a sweetheart."* *"Artistic. Creative."* *"Just unbelievable sweet. Very empathetic, very sympathetic."* *"She's a really amazing person. Very street smart, if you will."* *"She's smart. Assertive."* *"More of a thinker… She's really a critical thinker."* *"He's a very positive kid… A really sunny disposition."* *"He's a great helper… he saw a homeless woman on the train, and he had gave her a dollar and his little box…"* *"He has a lot of emotions. He's very sensitive."* *"She's really bright. Really intellectual."* *"He's sweet. He will make you feel like you are the only person in the world."* *"Very inquisitive child. Very curious."* *"He's super intelligent. Very smart, drive. A budding leader."* *"He's pretty smart. A good problem solver."* *"Very nurturing. Very caring. Very affectionate."* ***Hobbies/Activities*** *"Dancing, cheerleading, acrobatic gymnastics."* *"Very good at ballet."* *"She likes to dance, sing. Now she's into sewing and art. She's a mime at church. And on the choir."* *"He's very involved in sports. He plays baseball and ice hockey."*

	"Basketball and lacrosse. Hiking. Camping. Fishing. Swimming. Scooters. He has a bicycle, roller skates, ice skates, everything and anything that he can go on, pogo stick." *"Playing the guitar… the violin. She's a Girl Scout. Dance classes, like hip hop, ballet, jazz, tap, and acrobatics."* ***Academic Strengths*** *"He's been second place in this program called First in Math."* *"She gets straight As on her report card for math."* ***Tasks*** *"Yeah, he's actually pretty good with his medicine; he'll come to me and say, oh, mom, is it time to take my medicine, and I'm like, sure is."* *"Actually he wants to have chores at home."* *"He does clean up and help me with the cat."* *"She'll start her homework in the car."* ***Likes*** *"He loves building and doing volcanoes."* *"Likes to read and learn new things."* *"Loves dogs and animals. Loves the ocean. Loves the National Geographic Channel."* *"Loves building things. He has a fascination with science."*
Caregiver Strengths	***Qualities*** *"I would say patience. My other strength I would have to say is being a good communicator."* *"I'm a very involved parent. I am very goal oriented, positive. I'm very strong."* *"I'm a very educated person. I'm their advocate. I was just designed to be a very strong person."* *"It's patience, communication, and love."* *"I am very patient. It's patience, patience, patience."* *"My strengths? Well, I think, number one, just being his biggest advocate. I think that is the most important thing that a mom can do for a child."* *"I know I'm their only advocate, so it's on me."* ***Actions/Behaviors*** *"Really being persistent…"* *"I just do what a Mom's supposed to do."* *"I support him. I listen to him. I understand him."* *"For me, first God, second family, so to me that's a priority in doing everything I can do. They're our children, and to invest into their future is everything."* *"I think my strength is that I don't give up. I don't care what it takes. I'm willing to give whatever I got to help him."*
Advice/ Recommendations	***For Parents/Caregivers*** *"Just know that it'll get better…"* *"Like, don't ignore the signs… help her now before she gets too far gone."* *"Some people don't believe in medication and there are different things. And, if*

	that works, that's fine. But if it doesn't, don’t do your child a disservice by not doing it.” *“You have to definitely have patience, but you also have to have a plan. You have to have a good a course of action and how you address it, how you deal with it and, put things in order and get help.”* *“Do the research on it. Do all the research on the medicine, before you do it.”* *“We, as parents, don’t need to feel ashamed or embarrassed of what’s going on. When you out in public, don’t feel as though you have to explain yourself. “* *“I keep telling these parents, “We need to learn to listen to our kids.’ We have to listen to our children. Whether we want to or not. Whether it makes sense or not. They’re still trying to send out a message.”* *“Just try to educate yourself and know that there’s other people going through it.”* *“Try to educate people or talk to people it’s not a bad thing putting your kids on meds. You know what, you put them on meds, you can always take them off.”* *“I say to people you’re not alone. There are so many networks. I’ve met so many people. I’m on a Facebook group. I can ask questions about what to do.”* *“I would say, make time for yourself or for yourself as a couple, whatever the case may be. Because if you don't, you're going to absolutely drive yourself crazy.”* *“Read about it. Get as much information as possible.”* *“You have to get help. You don't have to go tell everybody, oh, my child got ADHD or something like that. But just, like, help them.”* *“Show appreciation for the people who are part of that network for your child. Be there for them because they're also dealing with your child too.”* *“Take time out for yourself when you have to. If you feel like you're about to break down, then take that time out for yourself. Because if you're not no good, you're not no good for your child.”* *“And don't be afraid to ask for help. Because that's real important, it's really important.”* *“It’s either gonna get better or worse, so the only thing I can say is the medicine, ‘cause it does help. But if you don’t want to take the medicine, just have patience with them and find out what he likes, and do what he likes with him… or her.”* *“Find an outlet that helps you, like, somebody else that’s going through the same thing. Because it definitely helps talking to other parents that have similar things. Like, it’s not just me.”* *“Just being knowledgeable about the ways you can, the different methods you can use, therapy, things that you can just do at home as parents.”* *“Consistency is probably the best and then getting support when you need it.”* *“Don’t give up. Keep searching. There is no right answers. Your child is unique and what works for child A may not work for child B and that’s okay. Medicines not always the first go to. Do research. Take your time. Listen to your child, and just keep fighting until something works.”* *“You need a lot support. You need someone to talk to.”* *“I feel as parents, we shouldn’t give up. We should always try our hardest and find new ways.”* *“Just be persistent, be proactive.”* *“I would just say continue to stick it through and get as much outside resources as possible, and maybe even join some kind of support group- where, you know, they can give advice to each other and-really, you know, put it out thre… your story and get feedback.”* *“Sacrifice the time. A lot of times we get so caught up… [but] make the time.*

	Put in the time, the effort to… just think about it, if it was you, wouldn't you want somebody to do the same thing for you?" **For Community, School, & Healthcare Systems** *"I wonder why they don't do ADHD walks… It's definitely something I would participate in."* *"…if you had a little bit more guidance or support in terms of setting things up for school and at home, that would be helpful."* *"I think more support groups, even if it's just like a monthly newsletter or something like that."* *"One of the things that's not focused on enough is the fact that the private schools need to be held to the same standard as the public school as far as IEPs and the standard of care goes."* *"If there were options or opportunities to connect with other parents who live in the area, that would be huge."* *"Like I was thinking like, wow, they have colors for kids with autism, like Light Up Blue Day. Why don't we have that for children with ADHD? Because there's a lot of children that has it."* *"I wish that we could meet and do like an activity with kids."* *"I wish we had an event that we could do once a month or once a year, just something for parents."*

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