Adolescent perceptions of factors related
to engagement in ADHD care:

A qualitative study at an urban safety net hospital

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Abstract

The treatment engagement experiences of adolescents from diverse backgrounds and with Attention Deficit Hyperactivity Disorder (ADHD) are largely absent from the literature on ADHD. Guided by what research exists on ADHD in adolescence and on how adolescents engage with ADHD care, the present study explored what factors and experiences adolescents in treatment for ADHD at an urban safety-net hospital in Boston perceived as affecting their engagement with care. As part of the larger study, *Assessing Preferences for and Barriers to ADHD Treatment Among Diverse Families*, a cross-case, secondary analysis of eleven interviews with adolescents from underserved and minority families was conducted. Thematic analysis delineated by Braun and Clarke (2006) revealed that “engagement in care,” as it is traditionally defined in the literature, ought to be redefined to incorporate the unique life circumstances and self-esteem and insight levels of adolescents. Four styles of engagement – proactive, anxious, apathetic and actively rejecting engagement – were identified and their clinical implications were discussed. These findings confirm the importance of treating adolescents as a population with unique clinical needs and invite future researchers to investigate how to optimally transition adolescents with ADHD into adult care.

Keywords: Attention Deficit Hyperactivity Disorder (ADHD), adolescent, engagement in care, illness insight, self-esteem, illness management

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Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is the most common mental health diagnosis that children and young people between the ages of 4 and 17 years in the United States receive (Perou et al., 2013). Individuals can be diagnosed when, before the age of 12 years old, they exhibited 6+ symptoms of inattention and/or 6+ symptoms of hyperactivity and impulsivity in 2+ settings that persisted over at least six months and interfered with functioning and/or development (American Psychiatric Association, 2013). For individuals over 17, only the presence of 5 of either type of symptom is necessary for diagnosis. According to parent reports collected by Danielson et al. (2018), an estimated 6.1 million (9.4%) of all children and young people between the ages of 2 and 17 years in the U.S. had ever been diagnosed with ADHD as of 2016. Disparities in prevalence statistics exist between various social and economic groups. Boys are more likely to receive a diagnosis of ADHD than girls; the poor are more susceptible to ADHD than the wealthy; and Latinx Americans are less likely to receive a diagnosis of ADHD than African or Caucasian Americans (Visser et al., 2013). It should not be taken for granted that ADHD often persists into adulthood. The most recent estimate of adult ADHD prevalence is that 4.4% of adults (aged 18 to 44) experience ADHD symptoms (Kessler, 2006).

As the prevalence of ADHD only appears to be increasing (at a rate of approximately 5% per year), the importance of high-quality and easily accessible treatment cannot be understated (Visser et al., 2013). This is especially true for adolescents. Adolescence is a particularly tumultuous stage of human development known for biological maturation, intra- and inter-personal conflicts and identity formation (Faraone et al., 2015). Adolescents with ADHD are disadvantaged in their ability to positively engage with this naturally difficult time period due to

frequently overlooked but persistent inattentive symptoms (Hurtig et al., 2007) and a high likelihood of experiencing severe symptoms. In fact, Merikangas et al. (2010) estimated that approximately half of all teens (13–18 years old) ever diagnosed with ADHD are severely impaired. Since negative outcomes associated with ADHD become graver as the severity of an individual's symptom's increases, this population is especially vulnerable (Edbom, Granlund, Lichtenstein & Larson, 2008).

Impairments associated with ADHD include academic failure, substance abuse, risky sexual behaviors, health problems and criminality in adolescence, as well as unemployment, lower socioeconomic status and incarceration in adulthood (Faraone et al., 2015; Gau et al., 2010; Nigg, 2013). Adolescents from disadvantaged and underrepresented minority groups are likely to experience these adverse outcomes most acutely; they are especially likely to suffer from educational failure and substance abuse (Basch, 2011). A growing desire to make decisions independently from their families and their own lack of insight or knowledge into the benefits of ADHD care contribute to poor treatment adherence (Brinkman et al., 2011; Bussing et al., 2012). Adolescents are known to experiment with halting their medications and begin dropping out of treatments (Brinkman et al., 2012; Robb & Findling, 2013). If we, as a society, hope to generate positively contributing global citizens then it is imperative that we support adolescents through this especially difficult stage of life in a way that encourages them to continue engaging with ADHD care.

However, despite adolescents' higher than average likelihood of having severe ADHD (and, thus, poor outcomes across the lifespan) and being difficult to engage in treatment, this vulnerable population is largely neglected in the literature. Studies related to engagement experiences is scarce (Stevens, Harman and Kelleher, 2004); those related to self-stigma and

transitioning teens into adult care is in its early stages (Bussing & Mehta, 2004; Robb & Findling, 2013); and literature on racial differences suffer from many methodological limitations (Stevens, Harman & Kelleher, 2004). The present study, therefore, aims to shed light on the lived experiences and help-seeking behaviors of a diverse set of teenagers with ADHD. The opinions, beliefs and attitudes of adolescents towards ADHD will be investigated in order to identify what factors impact an adolescent's ability to engage in the ADHD care process. In doing so, the results of this study will contribute to an underdeveloped research area, as well as provide ways for adolescents, families and practitioners to overcome the barriers that prevent adolescents from fully engaging in ADHD treatment.

Literature Review

ADHD in Adolescence

Studies with children make up the bulk of ADHD literature. While some studies do focus on ADHD in adults, research on adolescents with ADHD in a variety of settings (particularly in primary care and secondary school settings) (Lynch, 2016; Brahmbhatt et al., 2016); as they pertain to symptom measurement scales (Vazquez, Sibley, & Campey, 2018); and related to the viewpoints of adolescents themselves are scarce and poorly synthesized (Bussing, Zima, Mason, Porter & Garvan, 2011). Due to the dearth of current research on adolescents with ADHD, it can be tempting to generalize findings about children and adults to this population. However, doing so would be both inappropriate and irresponsible. Adolescents are likely to present with different symptoms than younger children, as well as face challenges and pressures unique to their age group. The treatment needs of children and adolescents are especially dissimilar, calling for the acknowledgement of adolescent ADHD as a distinct phenomenon (Antshel & Olszewski, 2014).

Adolescent ADHD symptom presentation. To this end, it is essential to consider how ADHD is experienced by adolescents. Researchers have estimated that about 80-85% of preteens (10 to 12-year olds) with ADHD continue to experience symptoms as teenagers and 30-60% of teens continue to experience symptoms as adults (Biederman et al., 1996; Roman-Urrestarazu et al., 2016). In other words, ADHD that persists into adolescence is likely to persist into adulthood. This understanding of ADHD as a lifelong disorder is contrary to the field's previous conception of ADHD as a childhood disorder, and is reflected in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (American Psychiatric Association, 2013) revision of ADHD diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) (American Psychiatric Association, 2000). This updated criterion is more sensitive to the expression of ADHD in adolescents and young adults and is expected to result in higher diagnosis rates – and, therefore, higher treatment rates – for these populations (Faraone et al., 2015).

Revising ADHD's diagnostic criterion is only one step in fully appreciating the experience of ADHD in adolescence. Symptoms of hyperactivity and impulsivity tend to alter in expression or decrease in frequency and intensity as children age, while symptoms of inattention remain stable and are likely to persist over time (Clarke et al., 2001). Where young children appear hyperactive or impulsive, adolescents may present with inner restlessness, impulsiveness or antisocial behavior (Haprin, 2005). Inattentive symptoms do not appear to undergo this same kind of qualitative change. However, the consequences of poor attention or hyperfixation (the primary types of attention dysfunction) become more serious than they were in elementary school. Inattentive symptoms – such as being easily distracted, making careless mistakes, and

having poor organizational skills – have been associated with negligent driving and academic and occupational failures (Hurtig et al., 2007; Harpin, 2005).

Researchers and clinicians have noticed that the various symptoms of ADHD cluster to develop in an individual as one of three ADHD subtypes. The inattentive subtype is most common in adolescents, followed by combined subtype, and then the hyperactive/impulsive subtype. Adolescents with the combined subtype of ADHD are most likely to experience a higher quantity and increased severity of both types of symptoms (Hurtig et al., 2007).

Particularities around symptom severity for youth are not only related to subtype, but also to prevalence. While Danielson et al. (2018) found that 14.5% of all children were reported to have severe ADHD, Merikangas et al. (2010) estimated that approximately half of all adolescents (13–18 years old) diagnosed with ADHD are severely impaired. In sum, adolescents are especially likely to experience persistent and severe functional impairments due, at least in part, to a higher likelihood of severe symptoms and the pervasiveness of inattentive symptoms.

Adolescent outcomes. Negative outcomes unique to adolescence can be operationalized as the result of interactions between an adolescent's own ADHD and their personality, personal history, and socioeconomic resources as they are embedded within a developmental period characterized by biological maturation, intra- and inter-personal conflicts and identity formation. Adolescents with ADHD are less equipped than the average teen to meet the increasingly complex social, emotional, and intellectual demands of life (Faraone et al., 2015). Neurological dysfunctions characteristic of ADHD include poor insight into one's own ADHD symptomology and its associated consequences, as well as to an overestimation of one's abilities known as self-perception bias (Beck et al., 2004; Brinkman et al., 2011). Faraone et al. (2015), provides an exceptional literature review on the impairments associated with ADHD across one's lifetime.

Dr. Faraone and colleagues identified the following as emerging in adolescence and continuing into adulthood: unplanned pregnancies, reduced occupational performance and success, rates of suicidal ideation, attempts and completion, marital discord, criminality and incarcerations, health problems, negligent driving and early death. A literature review by Nigg (2013) further contextualizes the nature of health problems that begin to appear, such as smoking, obesity and comorbid medical illnesses.

The high psychiatric comorbidity of ADHD with other diagnoses is a huge contributing factor to the appearance of these adverse outcomes. To investigate the connection between ADHD and other disorders, Gau et al. (2010) compared 185 youth between the ages of 11 and 17 without ADHD to 296 adolescents with ADHD. Youth with ADHD were more likely to have oppositional defiant disorder (ODD) (at a rate of 57.3%), conduct disorder (CD) (at a rate of 21.7%), mood disorders, anxiety disorders, tics, past and regular use of substances, substance use disorders and sleep disorders. The comorbidity rates they found were reflective of the larger literature (Biederman et al., 1996; as cited in Faraone et al., 2015). The association between ADHD and CD is particularly problematic as CD is believed to mediate the link between ADHD and higher rates of substance abuse, risky sexual behavior and mood disorders (Gau et al., 2010; Biederman, Newcorn, & Sprich, 1991).

ADHD is not only correlated with the presence of comorbidities, but with limitations related to relationship with adults, relationships with siblings and peers, and school functioning (Mannuzza, Klein, Quay & Hogan, 1999). Relationships with adults often suffer due to an adolescent's noncompliance and inability to meet developmentally appropriate expectations, as well as an adolescent's own frustration with feeling unheard, misunderstood or unfairly judged (Eccleston, Williams, Knowles & Soulsby, 2019). Meanwhile, negative symptomatic behaviors

(i.e., being overbearing, intrusive, aggressive) have been observed to damage peer and sibling relationships, as well as put an adolescent at a higher risk for being victimized (Harpin, Mazzone, Raynaud, Kahle, & Hodgkins, 2013). This victimization could take on the form of serious bullying, or of stigmatization perceived as isolating. A study by Jones and Hesse (2018) considered the impact of an ADHD diagnosis on an adolescent's negotiations of self-image and identity. They found that stereotypes promoted by peers (an adolescent with ADHD is "weird" or a "problem child") contributed to adolescent's own negative self-concepts. In fact, an adolescent tends to view oneself more negatively as symptom severity increases (Edbom, Granlund, Lichtenstein & Larson, 2008). Finally, impaired school functioning is characterized by disruptive behaviors and poor academic achievement. One study found that students with ADHD were more likely than students without ADHD to receive poor grades and experience increased rates of detention and expulsion, which eventually resulted in lower rates of high school graduation and postsecondary education (Loe & Feldman, 2007). Social and academic dysfunctions is suspected to be closely related to adolescents increased likelihood of low self-esteem, the development of a negative self-concept and depression (Biederman, 2005).

Trends in adolescent treatment. Despite these unique qualities of adolescence, national ADHD treatment guidelines do not currently have any recommendations on how care should be tailored for adolescents and young adults (as cited in Bussing, Zima, Mason, Porter & Garvan, 2011). Currently, three primary types of interventions for ADHD exist: behavioral therapies (which include parent education and training), medications, and school accommodations and interventions (Center for Disease Control and Prevention, 2019). The goal of each of these interventions is to lessen the frequency of unwanted behaviors and strengthen the frequency of positive, prosocial behaviors. These interventions employed in combination – also known as a

multimodal approach – engender favorable outcomes for clients of all ages (Enns et al., 2017). However, recent evidence suggests that behavioral interventions may be most useful in improving parent-child relationship dynamics in the long-term and less successful than pharmacological treatments in directly treating ADHD symptoms. Therefore, it is most efficacious to use behavioral interventions to compliment, but not replace, pharmacological treatments (as cited in Faraone et al., 2015).

These primary approaches are proven to be effective for children but are often not employed or designed in a way that caters to or addresses the needs of adolescents and young adults. To account for this discrepancy, cognitive-behavioral therapy and life management skills coaching have recently been recommended for adolescents because they more directly address the social, emotional and cognitive struggles adolescents face (Antshel & Olszewski, 2014). The skills provided by these interventions include problem solving, self-instructional self-control training, the use of compensatory strategies, diaries or time schedules and social communication coaching (Knouse & Safren, 2010). Although the efficacy of these approaches has not yet been fully investigated, the acknowledgements that (1) adolescents require different interventions than children and (2) that skills related to their personal independence must be fostered are both groundbreaking and necessary.

Trends in adolescent transition to adult care. A final but exceedingly important trend in adolescent treatments is the lack of a well-developed model of transition from pediatric to adult care for ADHD. Broadly speaking, the U.S. Department of Health and Human Services recommends that any adolescent transitioning from pediatric to adult care be primed for the transition beginning at age 12, and then adolescents be transferred to adult services between the ages of 18 and 22 years old (Office of Adolescent Health, 2019). In a scoping review by Swift,

Sayal, and Hollis (2014), it was found that although these guidelines and recommendations for adolescent patients with ADHD exist, very little research demonstrates how well the transition process is implemented. Where the research is lacking for ADHD, it is not for other chronic health conditions. Comprehensive models of transition exist for diabetes, cystic fibrosis and congenital heart disease (Stroud, Walker, Davis, & Irwin, 2015). Diabetes, in particular, has many empirically supported services for children, young people and adults, and the transition from pediatric to adult care often takes place in clearly defined stages (Allen et al., 2010). For adolescents with ADHD, the transition to adult care is often described as abrupt and there is a lack of relevant and empirically supported services in young adulthood (Swift, Sayal, & Hollis, 2014).

Children and adolescents with ADHD are often treated using a “wraparound services” approach that includes significant family involvement and communication between a variety of service providers, such as those in mental healthcare, special education and child welfare. Contrarily, adult mental health takes a more insular approach with treatment occurring within the mental health system rather than in partnership with other systems. This disconnect in care coordination may contribute to adolescents’ disengagement from treatment (Davis et al., 2012). Further challenges to transitioning adolescents into adult care include a lack of (1) available adult providers, (2) training in childhood-onset conditions among adult providers, (3) pediatrician’s educating adolescents on the adult system, (4) communication between pediatric and adult providers and (5) opportunities for adolescents to form relationships with general practitioners (Stroud, Walker, Davis, & Irwin, 2015; Kordonouri, 2017). All of these challenges contribute to the startling and deeply problematic statistic that engagement in ADHD care wanes as adolescents age; less than half of adolescents continue to take their medications (even though up

to 90% remain functionally impaired) and a majority do not utilize mental health services (Brinkman et al., 2012; Robb & Findling, 2013).

Factors Related to Adolescent Engagement in ADHD Care

The term ‘engagement’ in healthcare has been used increasingly over time and across a variety of disciplines and countries, rendering its exact definition elusive. To complicate matters, engagement in care is sometimes conflated with treatment adherence or retention (O'Donohue, Larry & Snipes, 2017). To resolve these discrepancies and clarify the field's understanding of engagement, Higgins, Larson and Schnall (2017) conducted a robust concept analysis of 96 studies. They defined engagement as, “the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care” (p. 30). The inclusive nature of this definition captures the idiosyncratic treatment needs of individual patients across the healthcare system. It also necessitates that active participation and treatment compliance enables patients to maximize their own positive outcomes. Although no similar definition for engagement in care exists explicitly for adolescents with ADHD, the remainder of this section will examine factors distinct to this population that may compliment or enrich this definition.

Understanding the plethora of factors related to adolescents' engagement in ADHD care is a multi-dimensional undertaking best understood using Ecological Systems Theory (Bronfenbrenner, 1977). This theory embeds a child within increasingly broad ecological systems in order to demonstrate the essential role of context in human development. The most pervasive ecological systems (i.e., societal expectations, cultural values and norms) are influential across multiple institutions and settings, shaping smaller ecological systems. An

adolescent indirectly or directly interacts with smaller ecological systems (e.g., the healthcare system, one's healthcare team) in ways that fundamentally shape barriers and facilitators to engagement with ADHD treatment. Finally, the biopsychological development of an adolescent in conjunction with the neurobiological development of their ADHD shapes their every experience with and perception of engaging with ADHD care.

Among the larger ecological systems, the societal expectations that teens grapple with, the ways different cultural groups perceive ADHD, the media, and the field's current understanding of ADHD stigma all impact adolescents' help-seeking behaviors. Among the smaller ecological systems, institutional and systemic factors – which greatly influence the way many adolescents' experience the process of engaging in treatment (in this paper, discussed as one's illness career) – familial factors and biopsychological factors acutely shape an individual adolescent's ability and desire to engage with ADHD treatment. While all these constructs are related and often interact in complex ways, we will first consider how societal expectations affect help-seeking behaviors.

Societal expectations. A thematic synthesis of 11 peer-reviewed articles (166 participants) from six different countries confirms the underlying influence of societal expectations (Eccleston, Williams, Knowles & Soulsby, 2019). The authors relay, in detail, how young people with ADHD often described feeling pressured to 'fit in' with societal rules and expectations. When they could not meet expectations – particularly those around academic success and developmentally appropriate behavior – adolescents expressed feeling frustrated that others did not value or appreciate their uniqueness. In some cases, they chose to disengage from therapies and pharmacological treatment. Adolescents' inability to meet expectations was associated with feelings of incompetence, failure and inadequacy, which the authors describe

more concisely as low self-esteem. Self-esteem, broadly, has been defined as an individual's cognitive and emotional concept of self. A more detailed definition is still being debated in the literature, but most researchers agree that self-esteem involves feelings of competence, achievement, and a judgment of self-worth (Mazzone et al., 2013). Low self-esteem may contribute to feelings of shame and defeat, which inhibit some adolescents' help-seeking behaviors (Kranke, Floersch, Townsend & Munson, 2010).

Other adolescents with low self-esteem may, instead, seek out less conventional forms of help. Gould, Munfakh, Lubell, Kleinman & Parker (2002) found that adolescents with mental health disorders are more likely than their peers to utilize the internet for information and support rather than from mental health professionals. Adolescents may do so to change themselves, or to seek reassurance, care and approval from peers (Trefflich, Kalckreuth, Mergl & Rummel-Kluge, 2015). Unfortunately, Gould, Munfakh, Lubell, Kleinman & Parker (2002) suggest that these sites, which are usually nonprofessional and unmoderated, offer an anonymity that may delay or prevent adolescents' seeking empirically grounded treatment. In this way, an inability to meet societal expectations may leave vulnerable adolescents – including those with ADHD – feeling isolated and turning to less reliable sources of assistance. Fortunately, where societal expectations can be softened and adolescent needs are catered to, adolescents with ADHD may be more likely to engage with care (Gallichan & Curle, 2008). Environmental adaptations may be especially helpful for students from minority cultures.

Culturally grounded beliefs and biases. In a country as diverse as the United States of America, the cultural values of different groups deserve to be investigated for their impact on adolescents' engagement in ADHD care. Two of the largest groups of people differently affected by cultural biases are men and women. U.S. society socializes girls to be quieter and “more

docile" than boys. These beliefs, in combination with the physiologically-related finding that girls are more likely to present as inattentive than hyperactive, have resulted in (1) less suspicion of ADHD underlying female behaviors by informants and (2) a higher likelihood that symptoms will be considered less severe in nature (Quinn & Madhoo, 2014). This puts females at a higher risk for underdiagnosis of ADHD or misdiagnosis of comorbid disorders; both prevent females from engaging with appropriate care.

Individuals can also be grouped by race and ethnic origins in order to examine how culturally grounded beliefs impact adolescents' engagement with care. For instance, being a Caucasian American facilitates engagement with care. Individuals in this group are significantly more likely than minority groups to receive ADHD-related services (i.e., therapy and medication), suggesting, to at least some degree, acceptance of its existence as a credible disorder (Visser et al., 2013). Due to the minority status of most adolescents in the current study (approximately half identify as being of Hispanic origin and 18% identify as African American), a closer look at how Hispanic and African Americans perceive ADHD will be useful in understanding the experiences and perspectives of our adolescents.

Stevens, Harman, and Kelleher (2004) found that Hispanic American youth were the least likely racial group to receive an ADHD diagnosis and/or stimulant medication prescription for ADHD from primary care physicians. This was found to be true even though primary care settings are the most accessible to minority families for mental health care (as opposed to specialists). Further evidence suggests that Hispanic American mothers, relative to Caucasian American mothers, do not see their children's ADHD symptoms as problematic or feel it appropriate and/or necessary to discuss behavioral issues with health care providers (Schmitz &

Velez, 2003). Provider bias has also been correlated with the disproportionately quick dismissals of Hispanic American complaints regarding ADHD (Flannagan, Pillow & Wise, 2002).

More research has been done on ADHD in the African American community than in the Hispanic American community. Although African American children are identified as having behavior problems less often by pediatricians and receive less stimulant medication than children of other races (as cited in Stevens, Harman and Kelleher, 2004), teachers have traditionally rated black boys as higher in academic and behavior problems than white students (Power et al., 2015). This, compounded by centuries of historical injustices, has led to a legitimate fear in African American communities that labeling children with ADHD may be used as a form of discrimination (Davidson & Ford, 2001). Furthermore, Hillemeier et al. (2007) found that many parents within this group, similar to Hispanic American parents, view symptoms of ADHD as unproblematic or normal to childhood. A lack of, incorrect, or incomplete knowledge of ADHD also contributes to the various types of social stigma that prevent families from seeking treatment for their children, and adolescents from cooperating with and adhering to treatments (Bussing et al., 2012; Davidson & Ford, 2001).

Stigma. Three primary types of stigma against ADHD exist within our society: public stigma, courtesy stigma and self-stigma. Each one plays a distinct and dramatic role in adolescent help-seeking behaviors. Public stigma refers to prejudicial beliefs and discriminatory actions that people direct at those with ADHD. Courtesy stigma refers to expressions of public stigma directed towards those that associate with the affected individual (Goffman, 1963) and will be discussed later in this paper as a familial factor to engagement. Self-stigma can be characterized as an adolescent's reaction to both public and courtesy stigma (Bussing & Mehta, 2013) and will be discussed later in this paper as a biopsychological factor to engagement.

Individuals of all ages with ADHD face substantial amounts of stigma, but adolescents with ADHD are most likely to be stigmatized by others in their age group (Lebowitz, 2013; O'Driscoll, Heary, Henessy & McKeague, 2012). Youth faced with public stigma have reported being called, "careless," "lonely," "crazy," and "stupid" by both peers and adults (Bussing et al., 2012). They are also actively avoided due to others' false beliefs that ADHD is caused by a lack of discipline from parents or bad character, that the adolescent is merely seeking attention, and that ADHD is not a credible mental illness (Martin et al., 2007; Pescosolido et al., 2008; Williamson, Koro-Ljungberg & Bussing, 2009; Bussing et al., 2012). Pescosolido et al. (2007) found, using a sample of 1152 adults, that participants believed teens with ADHD were more likely than adolescents with "normal troubles" to be dangerous towards themselves and others. Although ADHD medications have been proven to lessen the frequency and severity of maladaptive behaviors that contribute to the bias above (Center for Disease Control and Prevention, 2019), taking medications for ADHD is a stigmatized act with serious consequences. Medication stigma has been highly correlated with the findings that more than half of all adolescents with ADHD discontinue medication and underutilize mental health services (Bussing et al., 2012). Adolescents may disengage from ADHD care in order to avoid social rejection and feelings of shame (Brinkman et al., 2012; Robb & Findling, 2013; Kranke, Floersch, Townsend & Munson, 2010).

Fortunately, combatting and lessening stigma is an ongoing effort in the mental health community. Anti-stigma and psychoeducation programs designed for ADHD are not numerous but, for those that do exist, are effective in several domains. They have been shown to increase participants knowledge about ADHD, alter their attitudes and behaviors to be more positive towards those with ADHD, and – as is applicable to the current study – improve children and

adolescents opinions of medication and their medication adherence (Bai, Wang, Yang & Niu, 2015; Montoya, Colom & Ferrin, 2011). Every person educated in the realities of ADHD is another community member able to support an adolescent with the disorder, as well as facilitate their engagement with care. Since adolescents in one study cited educated family members and informative school environments as vital protective barriers against medication stigma, the power of this paradigm cannot be understated (Kranke, Floersch, Townsend & Munson, 2010).

Systemic and Institutional factors. The most impactful systems and institutions in the lives of adolescents with ADHD are the economic, educational and healthcare systems that indirectly affect their overall development, as well as the minutia of their daily lives. The capitalistic nature of our economic system breeds inequalities and injustices that negatively impact disadvantaged groups. Bussing, Zima, Gary, and Wilson-Garvan (2003) established that ‘non-poor’ children and adolescents are more likely to receive ADHD treatment than their ‘impoverished’ peers. In addition, impoverished adolescents are disproportionately likely to be from minority backgrounds (as cited in Hillemeier et al., 2007). Low socioeconomic status (SES) negatively impacts the social and emotional wellbeing of parents – they are more likely to experience psychological distress and depression as well as exhibit negligent or abusive behaviors that, ultimately, have damaging effects on children’s wellbeing (Evans, 2004). Finally, less wealthy families are often unable to reap the benefits of optimal healthcare or send their children to well-resourced schools.

School systems within the United States have recently adapted Common Core as a standard curriculum across states (Common Core: State Standard Initiatives, n.d.), but do not share access to the same number or quality of resources. Supporting the average child with ADHD – whom is entitled to appropriate services under the Individuals with Disabilities with

Education Act (IDEA) – is expensive and schools that lack resources often find it difficult to carry out services promised to the child (Pelham, Foster & Robb, 2007). Behavior modification services, providing extra time on tests and one-to-one support and may be underperformed, if performed at all. The U.S. healthcare system, while standardized to a greater degree than U.S. school systems, still has noteworthy shortcomings. This system is easier to access for those with a higher SES and can be so complex to navigate that families and adolescents feel intimidated by and then give up on obtaining treatment (Gulliford et al., 2001).

Familial factors. Where systems and institutions indirectly impact an adolescent's development, the family unit encompasses interactions between parents and adolescents that directly impact adolescents' development (Bronfenbrenner & Morris, 2006). Quantitative studies have determined that adolescents' disengagement from treatment is associated with single parent families, low income families, and families that have experienced stressful life events such as death or divorce (as cited in Oruche et al., 2014). Much less research has been done on the qualitative questions that might intrigue researchers such how parental engagement preferences, beliefs, knowledge and insight into their own ADHD impact these same constructs in their adolescent children. However, studies on parental ADHD, parental treatment beliefs and knowledge, as well as courtesy stigma in relation to child and adolescents' treatment engagement have been completed.

Parent-adolescent interactions do not only exist where others can observe them; they also exist at the genetic level. A review of 20 studies on twins estimated the heritability rate of ADHD to be 76% (Faraone et al., 2005). This implies that a good portion of adolescents with ADHD are likely to have at least one parent with ADHD. Studies describing the insight of parents into their own ADHD do not currently exist in the literature, but studies do exist in

relation to their parenting. In general, positive parenting has been characterized as responsive, authoritative, warm and empathetic, and has been associated with positive treatment engagement and higher levels of self-esteem for both children and adolescents (Swift et al., 2013; Bench, 2019). While parents with or without ADHD are less likely to display positive parenting towards children with ADHD, parents with ADHD face special challenges in doing so (Johnston & Lee-Flynn, 2011). In a study by Babinski et al. (2016), mothers with ADHD reported more frequent and intense conflict with their adolescent children, less knowledge and monitoring of their location, less consistent discipline and more ineffective discipline strategies than mothers without ADHD. The authors note that these adolescents are less likely to experience academic success. Since adolescents often correlate academic success with efficacious treatment (Eccelston, Williams, Knowles & Soulsby, 2019), being unable to achieve this success may undermine pharmacological treatments.

Parental attitudes and beliefs about medication may also undermine the efficacy of pharmacological treatments. A grounded theory analysis of 48 qualitative interviews by DosReis, et al. (2009) found that most parents (80%) were relatively open to putting their children or adolescent on medication, with 20% finding medication unacceptable due to skepticisms such as believing that medication is overused or only meant to “control” a child. For parents who found medication to be (1) “generally acceptable” due to the commonality of medications or (2) unacceptable, most of their children within the study were either never given or discontinued medication after 12 months. For parents who viewed medication as (1) a medical treatment fit for ADHD, a medical problem, or (2) a way to stabilize problematic behaviors, most of their children initiated and then continued to engage in treatment 12 months later. They were also the most likely to trust and/or form partnerships with their doctors, as well as turn to them for

information. In the instances where psychoeducation can be effectively delivered to skeptical parents, adolescent's medication adherence may increase (Bai, Wang, Yang & Niu, 2015).

Courtesy stigma also plays a large role in this phase since adolescent outcomes are so intimately tied to their social world, and particularly their family's dynamics and SES (Montoya, Colom, & Ferrin, 2011). Mothers are often accused of poor parenting and over-medicating their children (Bussing & Mehta, 2013). In response, one study found that mothers were likely to feel socially rejected and perceive healthcare providers and school officials as unsupportive or dismissive of their concerns. These feelings of isolation and dismissal are correlated with decreased help-seeking behaviors by family members and the adolescents themselves (DosReis, Barksdale, Sherman, Maloney & Charach, 2010).

Process of engagement. As was discussed, Higgins, Larson and Schnall (2017) define patient engagement as achieved by accommodating patient needs; requiring patients' active participation and cooperation in treatment; and essential for the presence of positive health outcomes. Upon content analysis of almost 100 studies, they also identified four defining attributes of successful patient engagement. These are (1) personalized care for the patient, (2) patient ability to access necessary resources, (3) patient commitment to pursuing quality care and (4) nurturing patient-provider relationships that support shared goals. These attributes are crucial underlying tenants that permeate successful engagement, but do not delineate a universal process of engagement. To examine how the engagement process unfolds for many individuals with chronic illness, the application of the 'illness career' framework described by Pescosolido (1991) and applied to youth with chronic mental health conditions by Watson, Kelly and Vidalon (2009) is most useful.

Adolescents ability to influence their own engagement in ADHD care becomes possible as they navigate their illness careers (Watson, Kelly & Vidalon, 2009). An illness career related to lifelong ADHD consists of the following five phases that can be moved into and out of in dynamic fashion: (1) recognition of the problem, (2) the decision to seek care, (3) initial compliance, (4) positive and negative outcomes (e.g. improvement in attention, antisocial behaviors), and (5) following a long-term treatment regimen. One researcher suggests the concept of an ‘illness career’ is meant to encourage individuals to take ownership of their disease by acknowledging that it takes personal “work,” as well as cooperation with healthcare officials to optimally manage their disorder (Grue, 2016). At any point in an adolescent’s illness career, they can choose to opt out of or opt into treatment. This choice is highly mediated by their age, their level of autonomy in treatment, family unit, peer relationships, school, and healthcare team. The relationships and interactions between these systems are telling but understudied. Fortunately, it is possible to synthesize various research into an overview of how these factors interact and affect the process of adolescent’s engagement with ADHD treatment using the illness career framework.

Phase I. The first phase of one’s illness career is arguably the most important because successful navigation of this phase leads to utilizing other phases. To partake in this phase, an adolescent must be able to recognize the existence of ADHD in themselves and appreciate it as problematic. Unfortunately, neurobiological dysfunctions characteristic of ADHD, the conflation of their personality with ADHD and the pervasive false belief that one ‘outgrows’ ADHD, can all prevent adolescents from identifying the challenging aspects of their disorder (McQuade et al., 2011; as cited in Robb & Findling, 2013). Fortunately, research demonstrates that this poor insight can be corrected through various forms of psychoeducation. A literature review by

Montoya, Colom and Ferrin (2011) indicated that psychoeducation applied to parents and children/adolescents led to increased knowledge of ADHD, as well as improvements in children and adolescents' opinions of medication and their actual medication adherence levels. Research related to the effectiveness of different modes of ADHD information-giving is scarce in the literature but is important to consider. Bussing et al. (2012) found that both parents and adolescents showed a strong preference for internet sources. Parents were more likely to rely on doctors than adolescents, and adolescents preferred to gather information from their social networks and school/teachers. It is possible that utilizing these preferred information sources may be an influential way to help families and adolescents identify ADHD.

Phase II. The second phase in an illness career refers to a patient's decision to seek care, although the seeking of care is often less easy for disadvantaged and minority families than for those with higher SES. Many families and their affected adolescents cannot access treatment due to language barriers and a dearth of non-English diagnostic and assessment materials (Visser et al., 2013; Schimitz & Velez, 2003). Providers themselves may make decisions that prevent adolescents from engaging in care. Many primary care physicians – the type of provider that low SES families are most likely to see (Stevens, Harman & Kelleher, 2004) – are unfamiliar with prescribing ADHD medications or doubt the validity of ADHD as a disorder (as cited in Robb & Findling, 2013). Courtesy stigma also plays a large role in this phase since adolescent outcomes are so intimately tied to their social world, and particularly their family's dynamics and SES (Montoya, Colom, & Ferrin, 2011). Mothers who feel persecuted for medicating their children or blamed for their children's "poor" behaviors are less likely to seek help from providers or school officials on their adolescent's behalf (Bussing & Mehta, 2013; DosReis, Barksdale, Sherman, Maloney & Charach, 2010).

Phase III. The third phase of one's illness career is, like phase two, at least somewhat dependent upon one's success in the first and second phases. This refers to compliance with one's initial treatment plan. This construct is, for better or for worse, closely linked to academic performance. Multiple studies report adolescents defining the helpfulness of their medication exclusively in terms of academic improvement. This can be viewed as motivating to those who value education but may be less motivating to adolescents that prioritize other things, such as their social life (Eccelston, Williams, Knowles & Soulsby, 2019). When schools disregard the importance of one's social life, they may unwittingly instigate adolescents' noncompliance in treatment. In one study, being identified as an adolescent with ADHD in front of peers provoked negative feelings related to stigma and subsequently poor treatment engagement (Sayal et al., 2010). Oruche et al. (2014) cites long waits at counseling appointments, frequent changes in staff, and negative staff attitudes as other critical factors that lead adolescents to drop out from treatment. Conversely, they found that having staff who showed respect, involved adolescents and their parents in the counseling sessions, and communicated timely helped to decrease dropout rates.

Phase IV and V. The fourth phase consists of treatment outcomes that may deter or promote the engagement of adolescents in the fifth phase of an illness career. In this fifth phase, youth follow and assist with modifying a long-term treatment regimen. Brinkman and his colleagues (2011) found that it was common for adolescents to evolve from silent bystanders in treatment, to ambivalent reporters, to active reporters and shared-decision makers. It is natural for adolescents, especially older adolescents, to grapple with autonomy at this phase in their lives and desire a more active role in their treatment (Eccelston, Williams, Knowles & Soulsby, 2019). Unfortunately, not all adolescents – especially older adolescents – undergo this transformation

(as cited in Oruche et al., 2013). Individualizing care, collaborative provider-adolescent communications, psychoeducation, and the development of a model of transition would assist in building an adolescent's sense of agency and, therefore, their desire and ability to continue with long-term treatment.

Some adolescents have identified that they rely on their parents' involvement in their treatment to ensure the continuity of their care (Swift et al., 2013). This proclamation may not be a result of feeling unprepared or lacking agency, but an acknowledgment of the neurobiological and behavioral limitations they perceive to be associated with their ADHD (McQuade et al., 2011). Thus, it has been suggested that providers should be flexible in their approach to parental involvement and base their decisions not on an adolescent's age, but on their needs and preferences (Swift et al., 2013). Understanding the idiosyncrasies of an adolescent is one feature of a successful clinical relationship. 'Listening' is another. Qualitative studies have consistently identified that adolescents who feel listened to are more likely to feel respected and valued, and more able to engage with treatment (Price et al., 2011). Feeling valued was paramount in a qualitative study by Eccelston, Williams, Knowles and Soulsby (2019). Adolescents who felt supported and empowered by parents, providers and teachers were able to take on an active role in treatment. They emphasized the importance of feeling acknowledged, understood, validated and taken seriously. Where this did not happen, participants were more likely to become non-compliant with treatment. One noteworthy way to foster patient agency and build disease insight is through structured trials stopping medication. Brinkman and his colleagues (2011) suggest that this treatment strategy legitimizes adolescents' desires to discontinue medication, while also ensuring that adverse outcomes related to discontinuation can be caught early and explained to youth.

Early and continued psychoeducation on the important aspects of ADHD treatment, such as medication adherence, should be tailored to meet the unique developmental needs of an adolescent. This approach has not only been shown to improve one's likelihood of continuing care over time (as cited by Price et al., 2011), but has been requested by adolescents themselves (Sleath et al. 2017). Finally, it would also be helpful for professionals to develop a model of transition with clear stages, similar to those developed for cystic fibrosis and diabetes. Currently, the transition from pediatric to adult mental health care is largely unstructured. This allows many teens to drop out of treatment easily and quietly, often without their explicitly choosing to do so (Robb & Findling, 2013).

Biopsychological factors. The decades-old debate around whether natural factors or environmental influences are more impactful on human development is, according to many researchers, coming to an end (Ashiabi, O'neal, 2015; Nigg, 2013; Bronfenbrenner, 1977). Ontogenic development, a term coined by Hinshaw (2015), encapsulates this change by considering the ways environmental influences interact with the body and psyche of an individual and result in their observable behaviors. For adolescents, an already difficult developmental period is compounded by the neurobiological origins of their ADHD (Van Hulst et al., 2017) and how these neurobiological dysfunctions can distort their perceptions of reality (McQuade et al., 2011). These distortions are apparent in a phenomenon termed self-perception bias (formally known as positive illusory bias or PIB), as well as in the plethora of neurobiological dysfunctions that inhibit an adolescent's insight into their ADHD.

Self-perception bias is a particularly well-researched cognitive distortion often associated with ADHD. It is defined by Brinkman et al. (2011) as when a child or adolescent holds unrealistically high evaluations of their own skills relative to their academic, behavioral and

social impairments. Researchers suspect that it derives from cognitive deficits in executive processes regulated by the prefrontal cortex, as well as in working memory, broad attention, and cognitive fluency (Steward, Tan, Delgaty, Gonzales & Bunner, 2017; McQuade et al., 2011). On one hand, this mechanism is adaptive in its ability to protect an adolescent's self-esteem and sense of self from the consequences of failures in a variety of domains. On the other hand, it may prevent adolescents from understanding the problematic aspects of their ADHD and, therefore, recognizing a need for treatment or change. Brinkman and his team (2011) suggest that the most efficacious ADHD interventions are those that cultivate accurate self-appraisals by participants so that they can progress through their illness career.

Perhaps unsurprisingly, one set of researchers found that high levels of self-perception bias was predictive of low levels of adolescent's insight into their ADHD (Jia, Jiang, & Mikami, 2016). A compilation of various literature suggests that insight can be defined as a youth's ability to (1) challenge conclusions that may or may not be influenced by their ADHD symptomology and (2) flexibly alter beliefs and actions in response to new information (Beck et al., 2004; Frost and Steketee, 2013). While poor insight is closely linked to ADHD symptomology, it is also influenced by many adolescents' proclivity to conflate their ADHD and personality, and to have insufficient or inaccurate knowledge of ADHD (Eccleston, Williams, Knowles & Soulsby, 2019; Bussing et al., 2012). Bussing et al. (2012) found that low insight was linked with low expectations of treatment effectiveness and a high anticipation of negative side effects related to psychological and pharmacological therapies. Therefore, interventions that provide (1) ADHD psychoeducation and (2) skills to cope with negative feelings that might arise in therapy may be most beneficial to engaging adolescents in care. In order to ensure continued participation in

care, providers should continually assess patient engagement levels throughout the treatment process.

The discussed biological phenomena directly impact the environment. However, ontogenic development demands that we also consider how the environment can alter neurobiological and cognitive processes. For the purposes of this study, the most relevant environmental influences that act upon an adolescent's neurobiology are stigma and pharmacological treatments. Public and courtesy stigma collude to create "stereotype threats" – stigmatized situations – that, over time and repeated exposure, may manifest in an individual as self-stigma. Adolescents who exhibit self-stigmatization have internalized the negative beliefs of society, which results in feelings of rejection and may negatively affect their self-esteem and certain neurobiological capacities (Corrigan & Kleinlein, 2005). Stereotype threat has been associated with increased anxiety that tampers with one's working memory resources, as well as with the use of social and emotional neural networks (to cope with stress) at the expense of networks related to learning (Cadinu, Maass, Rosabianca & Kiesner, 2005; Krendl, Richeson, Kelley, & Heatherton, 2008). Both hinder short-term and long-term learning abilities, which may make it difficult for teens to recognize problems associated with their ADHD. Common behaviors related to self-stigma include being secretive, feeling shame, and limiting interactions with others (Kranke, Floersch, Townsend & Munson, 2010). These types of behaviors are indicative of a desire to avoid seeking care for fear of being "caught," and surely impairs their ability to comply with the first phases of treatment.

Medication use, on the other hand, has a much more direct impact upon an adolescent's physiology. Storebø et al. (2015) reported that up to 29% of children and adolescents experience non-serious side effects (those not including death, hospitalization, etc.) related to stimulant

medications. However, a qualitative study by Eccleston, Williams, Knowles and Soulsby (2019) suggests that this rate is likely much higher. In their thematic synthesis of 11 studies, almost all study participants reported negative pharmacological reactions. Physical side effects included loss of appetite, weight loss, dizziness, headaches, stomachaches, nausea, tiredness, and loss of energy. While adolescents did cite these as reasons to discontinue treatment, participants were more dissatisfied with emotional side effects. They mentioned feeling numbed, irritable, subdued, and losing motivation to socialize or engage in activities they previously enjoyed. Youth were especially upset that these responses resulted in them, “losing themselves.” These adverse side effects, paired with the perception of a medication as ineffectual, are highly related to adolescents discontinuing treatment. Fortunately, when medications are perceived as effective and generally side effect-free adherence remains relatively high (as cited in Emilsson, Gustafsson, Ohnstrom & Marteinsdottir, 2017). Medications are also incredibly effective facilitators to care when adolescents can connect their medications’ effects to improvements in their social communications and schoolwork (Brinkman et al., 2011).

Gaps in the Literature

Significant gaps in the literature around factors related to adolescent engagement in ADHD care exist. Very little research has been done on self-stigma in teens with ADHD (Bussing & Mehta, 2013); their reactions to receiving a diagnosis of ADHD and subsequent treatment engagement (Jones & Hesse, 2018); and how adolescents’ transition from pediatric to adult care (Robb & Findling, 2013). Furthermore, in comparison to a wealth of quantitative research, very few qualitative studies have investigated young people’s experiences with ADHD treatment in a variety of settings (Lynch, 2016; Singh et al., 2010). How technology and other ADHD information sources may be effectively utilized to increase engagement in care is also

scarcely mentioned. Lastly, research on racial differences around topics relevant to ADHD suffer from many methodological limitations (Stevens, Harman & Kelleher, 2004). The current study is intended to gather information from qualitative interviews with adolescents in disadvantaged and minority groups in order to contribute to these various areas of ongoing research.

Research Context

The analysis of the current study was informed by the larger study, *Assessing Preferences for and Barriers to ADHD Treatment Among Diverse Families*, conducted by the *REACH for ADHD* lab at Boston Medical Center. Although this study is in its preliminary states and currently unpublished, a large amount of data has been analyzed. The primary aim of the larger study is to investigate the impact of social determinants, stigma, and other barriers to care engagement on diverse and underrepresented families. Results are informing the development of a community-based, culturally appropriate intervention for ADHD. Data is being analyzed using a grounded theory approach. Narratives that participants elaborate upon or emphasize have been, to a large degree, identified in open coding. Codes have been consistently modified, collapsed or dropped. The next level of coding, axial coding, has entailed identifying and clarifying relationships between the codes identified in open coding.

Both parents and adolescents were recruited to participate in individual qualitative interviews; each adolescent interview can be matched with the interview of their own parent, in which the parents were asked similar questions. In addressing similar themes within both parents' and adolescents' interviews, analysis of parent-child dyads in the future might be efficacious and informative. In the present study, the ways in which parent and adolescent interviews were conducted and analyzed informed each other. An unexpected theme arose during initial analyses of parents' interviews. Parents shared that communication between them and

their children about ADHD could be difficult, confusing, and sometimes detrimental to treatment. They were especially likely to worry that talking to their child about ADHD could damage their self-esteem. Analysis in the current study was informed by parent concerns around communication and adolescents' self-esteem, and subsequently influenced study findings.

Methods

Data Source

This study has been approved by Tufts University Health Science Internal Review Board (IRB) and uses data from a larger mixed-methods study being conducted by the *REACH for ADHD* lab at Boston Medical Center (BMC) in Boston, Massachusetts. The larger study has been approved by the Boston University Medical Campus (BUMC) IRB. Eleven adolescents between the ages of 13 and 17 years old and with a current diagnosis of ADHD were recruited to participate as a part of the larger sample. Individuals were excluded from the study if they or their child had a history of intellectual disability or cognitive impairment, autism, psychosis, or could not understand informed consent procedures.

Participants

The interview transcriptions of all 11 adolescents were analyzed. Demographic information for this sample was collected from the parents of each participant using a questionnaire. Adolescents were between the age of 13 and 17 years old, and the median age of participants was 15 years old. Nine of the adolescents were male and two were female. Three adolescents were born outside of the United States, and two adolescents conducted their interviews in Spanish. Sixty-three percent (7) of the adolescents identified as African American, 18% (2) identified as White/Caucasian and 18% (2) identified as Native American. In addition, 45% (5) identified as being of Hispanic, Latino or Spanish origin. More than half of the sample

(six adolescents) were reported to be on Medicaid or receiving some form of government assistance for those with low incomes or a disability. Three parents reported being told by a medical professional that their adolescent has a comorbid mental health condition (i.e., anxiety, depression) and seven were told that their adolescent had some type of disability that impedes learning (i.e., developmental delay, speech disorder, learning disability). It is important to note that all adolescents interviewed in this study were actively engaged in ADHD care. During data collection, every adolescent was on at least one medication for ADHD and receiving supportive services from their schools (i.e., IEP, 504 Plan). All but one adolescent had reported ever trying a behavioral therapy. Refer to Table 1 for complete details.

Procedures

Participants came into the lab for a 90-minute study visit. Parents were asked to fill out a demographic questionnaire on behalf of their adolescent participant. The adolescents themselves filled out three brief surveys designed to capture their perceptions of ADHD stigma, the number of adverse childhood experiences (ACES) they have been exposed to, and their own symptom severity. However, the primary outcome measure was an in-depth qualitative interview that asked participants about their lived experiences with ADHD and with obtaining various types of treatment. Based on a participant's preference, measures were provided in English, Spanish or Haitian Creole. Participants received monetary compensation for their participation.

Measures

Background information. The demographic questionnaire could be provided in multiple languages and was always filled out by a parent on behalf of themselves or their adolescent. Information for parents included age, sex, language preference, nativity, marital status, the make-up of their households, employment status, insurance information and their perceived level of

financial hardship. Information collected for adolescents included age, sex, language preference, nativity, race, current treatment plans and insurance information.

Qualitative interview. The goal of each qualitative interview in the original study was to gain a deeper understanding of (1) the barriers to ADHD care a participant perceived to be present in their life and (2) how those barriers may have contributed to their own level of treatment engagement. Researchers utilized a semi-structured qualitative interview guide to conduct 60-minute sessions with participants. The interview guide (see Appendix A) consisted of open-ended meant to promote discussion about facilitators and barriers to ADHD treatment engagement and adherence; stigma and socioeconomic disadvantages as barriers; and care engagement intervention content and delivery preferences. Interviewers could not introduce new topics to the conversation but could prompt participants to elaborate on topics they introduced during the session. If a novel term, idea or theme emerged over multiple study sessions, the interview guide was modified to explore that topic further in future interviews. Based on a participant's preference, interviews could be conducted in English, Spanish or Haitian Creole. Interviews were audio-recorded and then transcribed verbatim and (if necessary) translated. The English translations were verified for accuracy by research assistants and used in this study's analysis. In regard to confidentiality, all participant information was collected under a unique ID with any identifying participant information (i.e., names, phone numbers) stored in a separate, password protected document. Any identifying information shared during sessions was removed from the audio recordings and transcriptions.

For the purposes of this study, the entirety of an adolescent's interview transcription – as opposed to a specific portion of a transcription – was analyzed. Participants often do not relay their experiences thematically or linearly (Creswell & Poth, 2018). Relevant information to the

research question may present itself at any point throughout the interview. However, each section of the interview guide proved informative in unique ways. The utility of each section as it pertains to this study's primary research question is discussed in the following paragraphs.

Section I: ADHD Experience. The interview guide was organized into five sections. The first section sought to understand the experience and knowledge adolescents had amassed about their own ADHD. Participant responses to some of these carefully crafted questions (e.g., *How did you learn you had ADHD? How did you feel about being told you have ADHD? What are some questions you still have about ADHD?*) provided insights into how positive versus negatives experiences with the diagnostic process impacted their views on engagement with treatment. Questions about the treatment process facilitated discussion around what types of treatment are engaging or disengaging (e.g., *What treatments and services have you received?* (Probe: *Medication; Therapy; School Services*)) and why (e.g., *Can you give me an example of something that was positive about getting help for your ADHD? How about something that was negative?*). Finally, in response to the questions, *"Do you feel you have input in your care decisions?"* and, *"What would you tell other adolescents with ADHD about getting care?"* adolescents disclosed personal feelings around their treatment experiences.

Section II: Barriers to care. The barriers to care section was also revealing. In response to the question, *"What has helped you overcome difficulties to getting your treatment?"* adolescents identified what barriers they perceived as important, as well as what facilitators they felt were successful in engaging them in treatment. Responses to the question, *"What would help you feel more involved in your treatment?"* solicited information related to their current role in treatment, as well as how much agency they do or do not feel over the treatment process.

Considering the importance of the emotional world of a teenager, special attention was paid to this question and the subsequent section on stigma.

Section III: Stigma. In this section on stigma, adolescents reacted to questions about self-stigma, such as, “*How do you feel about having ADHD? Does your ADHD affect how you feel about yourself?*” and “*How does your ADHD affect how your parents treat or discipline you?*” Similarly, adolescents’ experiences with public stigma were investigated by asking questions such as, “*How have you or your family been treated differently by others because of your ADHD?*” and, “*Describe any situations when you or your family have felt judged or blamed by others about your ADHD treatment (Probe: Medication).*”

Section IV: Environmental risk factors. The fourth section sought to examine how adolescents perceive the impact of their environments on the severity of their ADHD symptoms. Questions asked about how (1) their emotions and behaviors had been affected by their environment (e.g., *How has your emotions and behavior been affected by your family’s financial situation/stressful events/school or classroom environment?*) and (2) how after-school activities, specifically, impacted their focus and hyperactivity. If an adolescent was able to answer these types of questions with nuance and/or depth, a certain amount of insightfulness about their own ADHD could be inferred. The literature suggests that this is an important factor to adolescent engagement in treatment (Bussing et al., 2012).

Section V: Intervention input. The final section sought to gather adolescents’ advice on how health care providers can better support the families of children with ADHD, what could be done to reduce stigma, how access to treatment can be improved, and how they would prefer to receive more and/or new information about ADHD. As largely concrete thinkers with actively developing brains, questions requiring abstract or emotional answers about oneself can feel

overwhelming to an adolescent (Clark, MacGeorge & Robinson, 2008; Pitskel, Bolling, Kaiser, Crowley, & Pelphrey, 2011). Therefore, the ability of these questions to depersonalize the issues mentioned above seemed to result in the giving of advice – opinions appraised as favorable by the giver – that were cogent and reflected their own desires and needs related to engagement in treatment.

Validity

In order to ensure the internal and external validity of the current study, I adhered to the validity criteria for qualitative research developed by Whittemore et al. (2001). In order to ensure that my findings were grounded within the data – what Whittemore et al. (2001) call the integrity of a study – it is important that I am transparent about my previous work with ADHD. I have worked with children (ages 4 to 10) who have ADHD and their families in both clinical (as a behavior modification expert) and educational (as a first through fourth grade teacher) settings. It is possible that my own conceptualizations of ADHD, particularly in my roles as an “expert,” biased my interpretations of the data. In order to avoid this threat, I was mindful of my biases and discussed my interpretations with mentors who alerted me to instances of bias.

To ensure the credibility of this study, I needed to be confident that the themes that emerged accurately represented what participants intended to express to interviewers. To this end, I consistently compared my own interpretations of a participant’s experience against a similar experience relayed by a different participant; intentionally analyzed ‘negative cases’ in which participant messages and experiences disconfirmed my own interpretations; and had peers review my interpretations. To ensure that a wide range of perspectives were represented in this sample – what Whittemore et al. (2001) call authenticity – I reviewed and can confirm that the

transcriptions revealed heterogeneity in adolescents' temperaments, attitudes around ADHD, attitudes towards their families, socioeconomic backgrounds and cultural backgrounds.

Finally, criticality refers to having a critically appraised, systematic research design. In the current study, I and another researcher coded interviews together until reaching a Kappa coefficient percentage of 80%, thus indicating substantial intercoder agreement. Only upon reaching this level of agreement did we code interviews independently. While I was not present during the recruitment of participants or the administration of the qualitative interviews, I can attest to the *REACH for ADHD* lab's commendable efforts to ensure internal validity within the larger study. I trust that researchers involved in this process controlled for as much variability as possible by adhering to study protocols.

Data Analysis

Methodological Approach

This study is exploratory in nature and, to this end, sought to provide rich and previously unknown answers to the following research question: *What factors and experiences do adolescents in treatment for ADHD at an urban safety net hospital perceive as affecting their engagement in care?* This question was developed within Maxwell's (2011) critical realism framework. Critical realism combines a constructivist epistemology ("critical") with a realist ontology ("realism"). This interpretive approach argues that a single reality governed by mental and material processes exists and that, because humans construct understandings of the world from unique perspectives, there are an innumerable number of correct understandings of this single reality. As demonstrated in this paper's extensive literature review, the symptoms characteristic of ADHD were heavily studied and – in the current study – are presupposed to exist. Critical realism proposes that the perceptions of the adolescent transcriptions collected can

be studied in a systematic manner (Maxwell, 2011) and subsequently understood within the context of ADHD. They can also be understood within the context of being members of underserved and minority families that often face the reality of socioeconomic hardship.

Methods of analysis. To achieve these goals, a cross-case secondary analysis was conducted using thematic analysis as outlined by Braun and Clarke (2006). Cross-case analysis was preferred because a principal aim of this paper is to deliver reasonably generalizable clinical implications per study findings. Cross-case analysis requires the careful analysis of multiple participants' cases in order to come to informed and somewhat generalizable conclusions about a data set (Miles & Huberman, 1994). Thematic analysis involves the identification of patterns across participant narratives through familiarization and coding of data, followed by the development of themes meant to capture the broader meanings and implications of narratives shared across cases (Braun & Clarke, 2006).

Type of thematic analysis. This thematic analysis utilized a semantic approach to review participant transcriptions. A semantic approach consists of interpreting what a participant says matters to them about their experience without looking for meaning beyond what that individual has stated (Patton, 1990). This is contrary to how other interpretive frameworks encourage the inferences of underlying meanings from participants' words, conceptualizing their narratives as a reflection of their own socially constructed realities (Miles, Huberman & Saldana, 2014). Ideally, a semantic approach lends itself to the progression of an analysis from description and summary, where the data have been organized to highlight patterns, to interpretation, where the significance of those patterns and their broader meanings is theorized (Braun & Clarke, 2006).

Analysis was conducted using a combination of the theoretical and inductive approaches. Patterns within the data were identified using a primarily theoretical approach. In thematic

analysis, this approach is driven by a researcher's predetermined analytic interest in an area. In the current study, this interest refers to the construct of 'engagement in ADHD care.' Literature on the topic was extensively researched before analyses took place and this study's primary research question was developed using pre-existing information. Moreover, this secondary data analysis was informed by parent concerns around communication and adolescents' self-esteem shared within the larger study, subsequently setting these constructs up for further investigation within the adolescent interviews. In tandem with this theoretical foundation, an inductive approach was taken to coding the data set. The codebook was developed using ideas and narratives that arose from the data, rather than having been created based on previous research and then imposed upon the data. The ability to derive themes closely linked to messages delivered by the participants themselves was considered essential. Although I had conducted a significant literature review, I attempted to prevent these established studies from biasing my understanding of the data by coding with a colleague who had not done such extensive research.

Six steps to thematic analysis. Braun and Clarke (2006) explain that the method is often inappropriately conflated with content analysis or grounded theory. Content analysis tends to analyze micro level phenomenon, utilizes frequency counts and often quantifies qualitative data for quantitative analysis (Wilkinson, 2000). Meanwhile, grounded theory involves complicated procedures and 'subsumes' thematic analysis as a tool (Creswell & Poth, 2018). In order to enhance the credibility of this qualitative methodology, Braun and Clarke (2006) delineated a series of six phases that a thematic analysis should follow. These phases will be discussed in more detail, and in conjunction with how they were performed in the current study's analysis, in the sections below. These phases are (1) familiarizing oneself with the data; (2) generating initial

codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report.

Making the Data Familiar

I familiarized myself with the data by listening to the audio of each interview, and then editing and ensuring the accuracy of transcriptions. To retain participants' unique voices and the nuance of narratives in each interview, transcriptions included verbal data recorded verbatim and nonverbal utterances (Poland, 2002). In addition, audio was listened to multiple times throughout the analysis process to gauge the tone of participants in response to interview questions. In this preliminary phase, as suggested by Braun and Clarke (2006), I sought to gain a broad understanding of the data set before coding any data. I reviewed transcripts and gained an overall impression of what constructs and ideas the adolescents – individually and as a collective – were sharing with interviewers. Then, I read and re-read the transcriptions while jotting notes on paper copies of all 11 transcriptions. Throughout the remainder of this section, analytic materials for participant 'ADD002' will be shared in the Appendices. A xeroxed copy of an annotated transcription for this participant can be viewed in Appendix B. Notes, per recommendations by Miles, Huberman and Saldana (2014), included personal reactions, the identification of possible patterns and questions for further investigation and cross-referencing. Throughout this phase, this study's research question was developed based on ideas that emerged from the data and consistently evolved in response to my team's impressions about the data set.

Initial Coding

At this point in the analytic process, a sufficient amount of information had been collected to solidify the primary research question as it is currently posed and to begin initial coding. The purpose of initial coding in thematic analysis is to organize data into meaningful

groups (Tuckett, 2005). To do this, basic segments of text are identified as and grouped under a “code,” or label, meant to encapsulate an interesting and/or reoccurring feature of the data. Once the data is grouped based on some significant feature, patterns become easier to identify and the next phase – searching for themes amongst the codes – can begin (Braun & Clarke, 2006).

In the current study, initial coding began when I used the information collected from note jotting to create lists of interesting constructs and ideas per case (see a xeroxed copy of the initial code list, named “Thematic Worksheets,” in Appendix C). From these lists, I created the beginnings of a codebook – a master list of definitions for each code, in which smaller codes fall into larger ‘categories’ of codes – using the computer program, NVivo. The development of this codebook was influenced by the larger study. Its overall structure was set up to parallel the codebook used for parents’ interviews; in this way, future analysis of parent-adolescent dyads would be efficacious. Therefore, and as is appropriate for the theoretical approach of this study, the codes were often – though not exclusively – generated in an etic fashion. Words from the researcher’s perspective and that exist in the ADHD literature were used to label an initial code. For example, the code, *Worries about social life*, was applied to the quote, “And I feel like when I drink the medicine, I feel, like, I feel antisocial, like I don't talk to anybody.” To capture this adolescent’s concern around medication side effects, the description of this code is, “Adolescent expresses worry, concern or hesitation about the consequences of treatment (including medication) on their social life.” The essence of what the adolescent was trying to convey is preserved using etic language and in a comprehensive code description. An emic approach – in which a participant’s own words were used to generate a code – was taken when adolescent narratives were especially helpful and unambiguous, or when it assisted researchers in

understanding a broader code grounded in the etic approach. The finalized codebook, with supporting quotes for each code, is provided in Appendix D.

Once the basic structure of the codebook was established, I and another researcher built upon this structure in a highly systematic way. We coded three transcriptions by sitting beside one another and editing the same NVivo document. Coding followed the high standards expounded by Braun and Clarke (2006). We gave every data item our full and equal attention, looked for data items that were likely to form the basis of themes (i.e., repeated patterns) and coded for as many potential themes as possible. Individual extracts were coded in as many different categories – called “nodes” and conceptualized as codes at a broader level – as they might be relevant to, as well as coded inclusively to preserve the context of the item. Each code was generated through discussion and consensus until the codebook created through this collaboration was approved by all relevant researchers. Next, we independently coded the same transcription and then measured our inter-rater reliability using Cohen’s kappa coefficient (k) before moving on to code a new transcription. We only coded transcriptions independently and without this measurement once a kappa coefficient percentage of 80% was reached. This protocol ensured high internal validity of the coding paradigm.

Searching for Themes

The third phase of thematic analysis is collating codes from the codebook into potential themes. To accomplish this task, researchers must shift their analysis from individual codes to the relationships between codes. Analyzing these relationships and combining codes based upon their similarities is how a potential theme is identified (Braun & Clarke, 2006). At this phase, Braun and Clarke (2006) caution researchers against discarding any potential themes. Until embarking on the next and fourth phase, in which data extracts are scrutinized in relation to the

potential themes, it is impossible to know which potential themes should be kept as they are, subsumed within another theme, edited or removed.

In the current study, a ‘theme’ was operationalized as reoccurring patterns related to the personal, social or material barriers to care engagement that multiple adolescents shared with earnestness or clarity. Earnestness and clarity were considered indicators of a theme due to adolescents’ own developmentally appropriate difficulty with verbalizing feelings (Pitskel, Bolling, Kaiser, Crowley, & Pelphey, 2011). With these qualifications in mind, themes were then identified and organized using tables and figures like those recommended by Creswell and Poth (2018). A large table, titled “Theme Identification Worksheet,” was created for each case. This table, which can be viewed in Appendix E, was split into two columns: “Potential themes” and “How theme appeared in this interview.” Potential themes were identified during the initial coding of each case and given a row in the table. A mixture of descriptive statements and direct quotes were input into the adjacent column if it supported the potential theme. For example, supporting evidence for the potential theme, “Negative Feelings Towards Medication,” in the case of participant ‘ADD002’ included:

- Worries medication effects will lead him to losing friends (he won’t talk as much to his friends during class because he’s focused)
- Poor experience with trial-and-error treatment with meds (“I was always depressed, always inattentive”)
- Felt the psychologist helped him more than the medication
- Medication is expensive (he went off them to save money)
- Mom and son decide together whether to do medication holiday

- Poor understanding of medications (he goes off meds periodically to see if he makes “any improvement”)

These descriptions and quotes were derived from the transcriptions themselves and developed by collating codes within NVivo’s nodes. “Experiences with ADHD Medication,” and its sub-codes, “Helpful,” “Unhelpful,” and “Side effects” provided a foundation for this potential theme. “Attitudes Towards ADHD,” its sub-code, “Medication Attitudes,” and the more detailed codes within it such as “Ambivalence” and “Anger/Frustration” were also informative.

This table served as a visual representation of how the various codes related to each other and to an overarching theme within one case. However, because the current study aims to complete a cross case analysis, a broader level of analysis needed to be undertaken. A series of peer discussions were utilized to review transcriptions, their accompanying “Theme Identification Worksheet,” and NVivo codes generated across cases. During these discussions, potential themes introduced in multiple transcriptions and discernable across most transcriptions emerged. Notes were taken on these discussions and summarized in bolded, red text at the bottom of the “Theme Identification Worksheet.” For example, the summary for participant ADD002 in Appendix E includes the research team’s overall impression of his insight levels, familial relationships and concerns around stigma. At the end of this cross-case peer discussion process, the two overarching themes of insight and self-esteem were identified, and a comprehensive set of candidate sub-themes had been developed.

Reviewing Themes

In the fourth phase of thematic analysis, candidate themes are reviewed for their accurateness and appropriateness. Braun and Clarke (2006) elaborate upon the two critical steps that characterize this phase, which are (1) reviewing themes at the level of the coded data

extracts and (2) reviewing themes in relation to the entire data set. In the former, the researcher must read the collated extracts for each theme and decide whether a coherent pattern exists within the theme to support its current presentation. If one does not exist, the theme must be discarded or edited accordingly. In the latter, the researcher must reread the entire data set to ascertain whether the overall analysis accurately encapsulates the narratives within the data set. Once this phase is complete, the researcher should have a good understanding of what themes are acceptable and what “overall story” (Braun & Clarke, 2006, p. 92) the themes will tell.

As in the previous phase, transcriptions were analyzed at the case level and then at the cross-case level. The review process began when I utilized NVivo to compare the coded extracts within one case to an associated candidate theme. Quadrant-based figures dubbed, “Process Maps,” (see Appendix F) were created to assist with this analysis. The design of these figures was developed for this study without reference to previously existing models in the literature. The horizontal and vertical axis represent the presence or lack of the two overarching themes found in this study – insight and self-esteem. Data extracts were identified, summarized and placed along an axis when it seemed relevant to only that one theme or placed inside a quadrant when it alluded to both insight and self-esteem. Whether these summaries were representative of the presence (i.e., the (+) sign) or lack of (i.e., the (–) sign) a theme was indicated by arrows pointing in the appropriate direction. These summaries were no longer than a sentence and often included short quotes. They came to be known as factors that “pushed” or “pulled” a participant in the direction of having insight, lacking insight, having self-esteem or lacking self-esteem.

Factors that appear within a quadrant represent a factor that intersected with both themes and proved most relevant to engagement in ADHD care. For example, talk therapy appeared in the upper quadrants for participant ADD002, indicating that this factor contributed to the

presence of insight. However, participant ADD002 felt that talk therapy contributed to both low and high levels of self-esteem. Talk therapy was associated with self-conscious discussion around ADHD that lowered self-esteem, as well as with “venting” that alleviated stress and improved self-esteem. These sub-themes are what ultimately solidified the appropriateness of insight and self-esteem as major themes. Creating process maps for each case required reviewing themes at the level of coded data extracts and designing the figure accordingly. After this step, one “Combined Process Map” (see Appendix G) was developed based on the eleven case level maps, and after multiple iterations and stages of refinement. To finalize this map, a majority of the data extracts were re-read and the case level process maps were referred to.

Step two of reviewing themes, in which the appropriateness of themes in relation to the entire data set is evaluated, was satisfied using a large table, titled, “Thematic Analysis Construct Review” (see Appendix H). The left side of the table lists themes related to each quadrant of the process map; that is, themes that related to the presence or lack of insight and self-esteem. These themes were taken directly from the combined process map and color-coded to represent eight larger categories the themes could be subsumed under. These eight categories were collated further to create three broad “experiences” all adolescents undergo when interacting with ADHD care: treatment attitudes, symptom management and relationships. These can be seen in the “Care Experiences” key at the top of this document. The right side of the table listed relevant data extracts. During this stage, and using this tool, additional data that was supportive of a theme but that had been missed earlier in the coding process were coded. For instance, most categories were represented within a quadrant and where this was untrue, particular care was taken to review data extracts that may represent the missing category.

Defining and Naming Themes

Defining and naming themes is the second-to-last phase of analysis delineated by Braun and Clarke (2006). It is at this point that one creates a clear hierarchical structure for themes deemed viable during previous phases. Themes must be analyzed for internal consistency, given names that are concise and informative, and then reordered into overarching themes, themes and subthemes. Furthermore, one is called to reflect upon the ‘essence’ of each theme – what aspect of the data does this theme capture and does the definition and name of this theme convey that essence? A useful way to determine this is to begin writing a narrative that explains and connects the various themes, illuminating how they create one ‘overall story’ that reflects the data set. According to Braun and Clarke (2006), this reflection is necessary to ensure that overlap between themes is minimal and, therefore, each theme can be clearly and uniquely defined.

An ‘emerging narrative,’ or comprehensive story, about the themes that emerged from this data set was written to assist with this phase. A more refined version of this narrative has been elucidated in the results section of this paper. Moreover, a comprehensive qualitative analysis includes a visual representation of one’s findings. To this end, Figure 1, “The Role of Insight and Self-Esteem in Adolescent Engagement with ADHD Care” was created. This figure identifies the “push” and “pull” factors essential to the smallest subthemes (e.g., peer acceptance of ADHD, radical acceptance of self), larger subthemes (i.e., treatment attitudes, symptom management, relationships) and overarching themes (i.e., insight, self-esteem) around adolescent engagement in ADHD care, as well as organizes them in a hierarchical fashion.

Crafting the Report

Both tools mentioned above were essential to Braun and Clarke’s (2006) sixth and final phase in thematic analysis: crafting the report. Per their recommendations, the results section of this paper entails the identification of each theme within this data set’s hierarchy and a

compelling definition of each theme's 'essence.' Furthermore, explanations as to how a theme connects with other themes and how it connects to adolescents' engagement with ADHD are provided. As Creswell and Poth (2018) would suggest, the primary analytic figure finalized in the previous phase will be utilized often when describing a theme. The findings of this thematic analysis will be discussed using compelling narratives pulled from adolescent transcriptions. The use of impactful and relevant participant quotations in the following sections of this paper will convey, to the greatest degree possible, a transparent and authentic analysis grounded in qualitative interview data.

Results

Defining Engagement

Themes around the definition of engagement emerged early in this thematic analysis, and in ways that remain unaccounted for by current literature and unique to adolescence. Adolescents often did not perceive their engagement with care to be related to their access to care (i.e., scheduling appointments, purchasing medications). The implications of being unable to obtain a license, being too young to take public transportation alone or being financially dependent upon parents for care meant that parents determined when, how and to what extent treatment was accessible. Furthermore, being younger than a parent often resulted in providers placing more importance on parent opinions and adolescents themselves deferring to parents for final treatment decisions. Feelings related to lacking autonomy and having less decision-making power compared to their parents also contributed to adolescents feeling that they must participate in treatment (e.g., attend doctor's appointments, be present for IEP meetings). However, adolescents expressed a range of attitudes and emotions related to this participation that appeared to enable or prevent them from acting in accordance with medical advice. Therefore, the

engagement of our adolescents may be better conceptualized as the level of “psychological buy-in” they exhibited. This referred to the psychological willingness of adolescents to participate in the treatment process, including the development of treatment plans, treatment compliance and the continuation of their own care. How much an adolescent in our study wished to participate in their treatment ranged from being exceptionally committed to the process to actively rejecting its every facet. Most fell in the middle of this spectrum, seeing the value of treatment but expressing ambivalence towards particular aspects of care.

Adolescents shared a myriad of opinions about the suitability of their treatment with interviewers and why they did or did not buy-in to the process. Most evaluated the suitability of their treatments against personal goals meant to further their professional and academic aspirations and support their social-emotional wellbeing. Adolescents reported aspirations such as becoming an engineer or attending college. Many expressed a strong desire to develop greater autonomy from their families and feel as though they could independently and successfully manage their ADHD symptoms. The lessening of ADHD symptom severity was intertwined with adolescents’ social-emotional wellbeing. They wanted to feel “normal,” feel valued by others, and avoid interpersonal conflicts. In addition, some adolescents mentioned being able to play a sport as a strong motivator for participating in treatment.

Adolescents who felt treatment was currently meeting or able to meet their goals reported positive attitudes toward treatment. They were willing to work with providers and make decisions related to their own care. Conversely, adolescents who reported treatment as incompatible with their goals reported negative attitudes towards treatment. Considering these findings, treatment engagement has been operationalized as distinct from treatment access – this being largely determined by parents – and comparable to psychological buy-in. How willing

adolescents were to engage with care was deeply influenced by feeling that their own personal goals, which may or may not have been specific to ADHD, were met by treatment.

The Intersection of Illness Insight and Self-Esteem

Illness insight and self-esteem appeared across all eleven cases as inexorably linked to adolescent engagement. Illness insight, based on the literature and informed by this data set, was defined by two similar but distinct concepts. Firstly, it referred to how much formal ADHD-related knowledge adolescents sought out or already had. Secondly, it referred to how well an adolescent was able to reflect on the role and influence of ADHD in their lives. This definition was developed when, through the creation of “Theme Identification Worksheets” (see Appendix C) and subsequent peer discussions, it became clear that many themes could be categorized as highly insightful or less insightful. Highly insightful narratives tended to include adolescents’ expressed interests in knowing more about ADHD, as well as sophisticated appraisals of environmental factors, outcomes and personal feelings related to ADHD. For instance, the following statement was indicative of reasonably high insight:

“Sometimes I don’t like talking to people about my concerns and stuff like that, like psychologist talk to me about these things, and I don’t like that. But I need to vent so I do have to talk.”

This adolescent unpacked multiple concepts. He was knowledgeable about therapy and that, per this method of treatment, he was expected to talk about stressful subjects. At the same time, he acknowledged his own ambivalence towards this process by explaining the ways in which it was both unlikeable and helpful. Conversely, less insightful narratives were those in which adolescents denied knowledge of basic ADHD-related information, struggled to connect their symptoms with a life event, or were unable to articulate feelings related to ADHD.

Where illness insight captured adolescents' appraisal of experiences, self-esteem was indicative of the emotional wellbeing influenced by these experiences. It is important to note that self-esteem as a possibly relevant concept first appeared in the larger study that informed this current study. Parents expressed concerns around communicating with their children about ADHD. Many stressed the importance of building agency within their teenagers and worried that talking about the disorder would only lower their self-esteem. In reviewing transcriptions for this study, it became evident that the self-esteem of adolescents was linked to overall positive versus negative attitudes towards treatment. Self-esteem surfaced as the degree to which adolescents exhibited a sense of self-respect – wherein pride and satisfaction were evident; a sense of self-worth – wherein feeling worthy of love and attention was clear; and confidence in their own skills and abilities. For example, one adolescent exhibited high self-esteem in framing his treatment as something that makes him feel valuable and proud:

“You don't have to think different of yourself. Just because you have this thing doesn't mean you're not a person. You're still a person within you. It's just like you're special in a way. So, you don't have to think of it as a weakness or something wrong with you, just think about it as a good way. Like you're special in a way. So, like you get more options in life.”

Adolescents who did not perceive treatment to be a positive experience often exhibited low self-esteem. Narratives related to feeling stigmatized, grappling with trauma, being bullied or expressing hopelessness about the future were coded as low self-esteem. One adolescent described the negative effects of stigma on her self-esteem, stating, “What they do is, like, they make you feel that... you're less of a person than somebody else is without [ADHD].” When

asked what interventions might be helpful, a different adolescent replied, “I don't think there's any way to help me.”

The emphasis adolescents placed on wanting to feel normal arose in almost every interview and appeared to be related to self-esteem. To this group of adolescents, normal referred to feeling worthwhile or desirable to others and was a standard that they measured a variety of life experiences against. Some resented both their diagnosis and treatment because ADHD interventions were perceived as abnormal or stigmatizing. Others described normal as being able to complete schoolwork of at least average quality. Many expressed a desire to be accepted as normal for their inherent value as human beings, as opposed to being singled out as “different” due to their ADHD. When asked how to reduce the negative attitudes that exist around ADHD, one adolescent replied:

“If somebody has [ADHD], they're still normal. They're still human... It's, like, it's not really a bad thing, it's just... you can't control yourself or something else. But you could just tell people, like, ‘You're still the same as this person. Everybody's the same.’”

This adolescent underscored the importance of feeling likeness to other people. A final subtheme stressed a similar importance on sociability, with adolescents feeling that the ability to engage in positive social interactions was an expression of normality. When adolescents felt normal and demonstrated accurate knowledge about ADHD, their narratives appeared to imply both high self-esteem and high insight. Further investigation into the relationship between these two constructs informed this report’s final overarching theme – the presence of four styles of treatment engagement.

Four Engagement Styles

The intersection of insight and self-esteem lent itself to four distinct styles of adolescent treatment engagement. Figure 1 provides a clear depiction of this relationship. In this graph, the y-axis represents the expression of either high or low levels of insight and the x-axis represents the expression of either high or low levels of self-esteem. “High” and “low” in these instances are meant to relay both the quality (good vs. poor) and quantity (a lot vs. a little) of the expressed construct. Each engagement style is representative of a quadrant derived from these interactions and is comprised of three overarching treatment experiences that every adolescent in our sample encountered. These are the development of treatment attitudes (i.e., “Treatment Attitudes”), experiences appraising and managing ADHD symptoms (i.e., “Symptom Management”), and navigating the dynamics between personal relationships and treatment (i.e., “Relationships”). The development of treatment attitudes involved how adolescents perceived the physical, psychological and emotional effects of their treatment; their level of participation and control in treatment; and the level and quality of ADHD-related knowledge they held. Navigating the dynamics between personal relationships and treatment was characterized by how adolescents perceived their own identity with ADHD; their interactions with others’ expectations; their communications and relationships with peers; and their communications and relationship with parents. As is reflected in Figure 1, subthemes specific to an engagement style were found to exist within each type of treatment experience. These subthemes are meant to encompass the behaviors, attitudes, thoughts and experiences that “pushed” or “pulled” adolescents towards being proactive, anxious, apathetic or actively rejecting of treatment.

Proactive engagement. The proactive engagement style, depicted in the top-right quadrant of Figure 1, is characterized by both a high level of insight into ADHD and a high level of self-esteem. This collection of themes suggests that engagement with treatment is an overall

Figure 1. The Role of Insight and Self-Esteem in Adolescent Engagement with ADHD Care. This figure illustrates the relationship between high and low levels of insight and high and low levels of self-esteem in adolescents' engagement with ADHD care.

satisfying experience, and that engagement is likely to continue beyond adolescence due to ample opportunities for insight-building and positive identity development.

Treatment attitudes that constitute this style include the perception that treatment is effective, helpful and within the adolescent's control. Effective treatment was perceived to successfully lessen the severity of ADHD symptoms and assist the adolescent in reaching personal goals, such as earning better grades or having fewer altercations with peers. Helpful treatment was indicative of professionals – including doctors, therapists and teachers – who were perceived to be informative, supportive and communicative. Being provided with and able to utilize accurate information about ADHD is essential to this engagement style; some adolescents were especially interested in the biological model of ADHD and found the implications of brain-based dysfunction empowering. Supportive providers were receptive to adolescents' unique personal needs and actively listened to their concerns and opinions, altering the course of treatment if possible and appropriate. This perception of control over treatment options appeared paramount to the proactive engagement style. This sense of control was evident in adolescents' ability not only to embrace the beneficial aspects of treatment, but also question aspects of care they disagreed with. Most (although not all) adolescents who expressed appreciation for their medications also reported ambivalence towards continuing to take them. Reasons to terminate pharmacological treatment included having been on medication for a long time or suspicion that their medications were no longer as effective as they used to be.

Pharmacological treatments, per this engagement style, work in conjunction with an adolescent's ability to positively appraise and effectively manage their ADHD symptoms. Many reported utilizing effective coping skills such as deep breathing to lessen anxiety, avoiding triggering situations and taking breaks from lengthy activities. Furthermore, adolescents

appeared to take pride in strengths they associated with their ADHD. These included being able to hyper-focus on preferred activities and having ample energy. With these coping skills and strengths to support them, it is unsurprising that this style suggests proactive engagers feel like their future goals (i.e., attending college, obtaining a job) are attainable. A few adolescents who reported this sentiment attributed their optimism to successful treatment.

Positive appraisals were not limited to symptom management. They were also found to permeate the relationships characteristic of proactive engagement. Authority figures (e.g., teacher, parents) with ADHD became role models when they shared their diagnosis and ADHD-related struggles with adolescents, thereby normalizing ADHD. Adolescents felt valued and less alone, with one adolescent stating, “it’s very good to know people that [...] have it and that you can relate to having it.” Further normalization of ADHD was seen in adolescents’ radical acceptance of themselves. To practice radical self-acceptance is to fully acknowledge, without judgment, the positive and negative aspects of one’s self and one’s reality in order to flexibly adapt to life’s challenges (Williams & Lynn, 2010; Alic, 2019). This process required significant insight and facilitated positive self-esteem, appearing in statements such as, “if somebody has [ADHD], they’re still normal” and “[ADHD is] an advantage and a disadvantage sometimes. Most things are an advantage and a disadvantage.”

In accordance with the acceptance this style of engagement seems to encourage, adolescents freely disclosed their diagnosis to peers. They reported that friends helped them manage their ADHD through physical activities (i.e., card games, sports) and words of encouragement (i.e., emotional support). The final relationship dynamic that appeared important to this engagement style was adolescents’ relationships with one or more parents. Adolescents perceived their parents to be sensitive to their needs, helpful, caring, and accepting of their

ADHD. Adolescents discussed their treatment preferences with one or more parents and, although parents made the final treatment decisions in every case, they believed their parents did so in their best interest. Communications were perceived to be informative and direct. Parents not only delivered accurate information about ADHD to their child but did so clearly and in reference to the child's own symptomology. For example, one adolescent noted that, "I was, like, very hyper, and [my mom] was like, 'This is why you're doing this in school. This is why you got in trouble and everything.'" The entirety of this quote and further evidence for this engagement style is provided in Table 2.

Anxious engagement. The anxious engagement style, depicted in the top-left quadrant of Figure 1 and summarized in Table 3, is characterized by a high level of insight into ADHD and a low level of self-esteem. This collection of themes suggests that engagement with treatment is rife with complications and uncertainty. Disengagement from treatment may occur due to chronic worries about the negative psychosocial implications of treatment.

Within this style, treatment is perceived as ineffective or problematic. Ineffective treatment was regarded as having unsuccessfully lessened the severity of ADHD symptoms. Meanwhile, treatment could be problematic in several ways. Firstly, negative physical and emotional consequences of treatment were reported as significant and unwanted. Pharmacological side effects included lacking an appetite, having headaches or experiencing fatigue, as well as causing adolescents to feel antisocial. Terms used to explain antisocial tendencies included feeling, "emotionless," "shy," and as though they "don't like to talk to anybody." A consequence of school and therapeutic services, although unintended, was feeling stigmatized. Secondly, treatments were considered disruptive to adolescents' daily lives or misaligned with their priorities. Adolescents expressed concern that priorities such as socializing

or participating in sports were undermined by treatment. One adolescent feared that his increased focus in classes would cause him to ignore and then lose friends. Another expressed frustration that feeling subdued and unmotivated prevented him from playing soccer. A few mentioned the scheduling of one or more appointments during school hours as disruptive.

While treatment attitudes intrinsic to this style are generally grounded in the present, appraisals related to ADHD symptoms and their management are fixated on the past and future. Chronic and frequent worries related to conditions comorbid with ADHD, the consequences of current impairments, and the demands of adulthood were reported by adolescents. A few struggled to understand how their ADHD interacted with comorbid psychiatric conditions (i.e., anxiety, depression, nonverbal learning disability). They lamented the negative impact these interactions had on their life and self-esteem. Worry over the consequences of current impairments included the receipt of poor grades – frequently attributed to attention problems – and tension in interpersonal relationships – usually attributed to “anger” or impulsivity problems. The persistence of ADHD symptoms into adulthood appeared particularly troubling to adolescents, contributing to related fears of academic and professional failure as adults.

Anxiety-ridden appraisals were not limited to symptom management. They also pervaded the relationships characteristic of anxious engagement. Adolescents expressed being deeply concerned about failing to meet the academic and behavioral expectations of their teachers and parents, as well as feeling judged by society at large for their ADHD. Preoccupation with stigma – both public stigma and self-stigma – were informed by a myriad of negative experiences, such as being bullied or otherwise shamed for their ADHD. One adolescent shared his diagnosis with a friend who proceeded to reject him for his “issues” and then bully him. Another adolescent reported being told she was incapable of doing certain things (i.e., attending a camp, going to

certain colleges) because of her ADHD, and added that her status as an African American complicated the matter:

“I feel like being a person of color, it makes it ten times harder because I feel like they already think we're stupid enough. [...] Just being a person of color and having ADHD, it's more difficult because it's just, like, [...] you have a clear disability. Like, they'll just throw you away like, you know, like you're trash.”

A lack of feeling accepted by others, exemplified by this quote, was apparent in adolescents' peer relationships. Some expressed discomfort with disclosing their diagnosis to friends and others intentionally avoided making new friends. These feelings may contribute to the development of self-stigma that typifies this engagement style. Adolescents described feeling unintelligent or “ashamed” of their diagnosis. One adolescent frequently insisted that she felt “stupid,” stating that, “even people not calling me stupid, you can feel stupid.”

Lack of self-acceptance appeared intricately related to the development of self-stigma. Many adolescents cited feeling abnormal or being treated as “special” as reasons for disliking themselves, their situation, or their ADHD. A couple of adolescents were further isolated by their experiences with parentification. Chase (1999) described this phenomenon as an emotional and/or functional role reversal in which the child sacrifices his or her own needs to accommodate and care for the needs of the parents. In the current study, one adolescent explained wanting to manage his ADHD, not for his overall health, but so that he could stop taking medications that put a financial constraint on his family. Another mentioned the money her mother was looking to borrow in order to take care of her, as well as highly stressful experiences related to foster care and her parents' physical disabilities. Both adolescents appeared more prepared than other adolescents in this sample to put their health aside for the wellbeing of their parents. Parent-child

relationships examined across cases suggest that this engagement style indicates a relatively poor parent-child relationship. Adolescents were highly insightful of experiences with parents that lowered self-esteem. For instance, adolescents reported feeling distant from parents due to hyperactive symptoms or poor grades, as well as detailed an increase in the severity of their symptoms due to tension with or the absence of a parent.

Actively rejecting engagement. The actively rejecting engagement style, depicted in the bottom-left quadrant of Figure 1 and summarized in Table 4, is characterized by a low level of insight into ADHD and a low level of self-esteem. This collection of themes suggests that engagement with treatment is an overall unpleasant experience that adolescents resist. Disengagement from treatment may occur due to feeling frustrated towards and disempowered by treatment.

Treatment attitudes that constitute this style include the perception that treatment is unhelpful and harmful. Of note, adolescents made no explicit mention of how effective or ineffective they felt their treatment was. Harmful treatment was primarily discussed in terms of pharmacological treatment, with adolescents believing side effects caused serious and unacceptable physical and emotional problems (i.e., making it difficult to eat, feeling depressed), as well as caused damage to their relationships with parents (i.e., more frequent arguments). Unhelpful treatment was provided by dismissive and unsupportive professionals. Adolescents described providers who did not care to understand their needs and teachers who failed to follow through with school services (i.e., one-to-one support, taking breaks). In addition to feeling unimportant at best, and affronted at worst, active rejectors may lack general knowledge about ADHD. Two adolescents endorsed inaccurate and stigmatizing beliefs about the origin of ADHD, and many did not know or expressed little interest in learning fundamental information

about the disorder. Overall, adolescents felt that treatment was forced upon them by their providers and especially by their parents. One adolescent described trying to express his dissatisfaction with medication and said, “[My] mom ends up winning. So, like, it's not even worth it.” Another asked the interviewer, “What could I like, just, what could I say that would really change things, change something? I mean, mom said if I don't take my medication, I can't live in her house or something.”

Lacking control over treatment may undermine adolescents' self-esteem, contributing to a lack of confidence in managing ADHD symptoms intrinsic to this style. After expressing deep reservations in his ability to get started on and complete tasks, one adolescent admitted, “I don't think there is anything I can do.” Another feared that, without his mother to monitor him, he would forget to take his medications or to pick them up from the pharmacy. Feeling ineffectual was not limited to symptom management. This feeling permeated relationships characteristic of this style due to public and self-stigma. Adolescents appeared resigned to believe that they were unable to meet the academic and behavioral expectations of others. This impression was reinforced by communications with parents that made adolescents feel entirely at fault for their ADHD, rather than acknowledged for their struggle with a challenging psychiatric condition. A generally tense relationship with parents delineates this style and may be especially damaging to adolescents' self-esteem.

Apathetic engagement. The apathetic engagement style, depicted in the bottom-right quadrant of Figure 1 and summarized in Table 5, is characterized by a low level of insight into ADHD and a high level of self-esteem. This collection of themes suggests that engagement with treatment is perceived as an overall inconsequential experience, and that disengagement from treatment may occur due to feelings of indifference towards living with ADHD.

Treatment is generally perceived as unimportant. Adolescents, although receiving treatment at the time of this study, did not concern themselves with the complexities of ADHD or share particularly strong opinions about medications. One adolescent stated, “[My ADHD diagnosis] wasn't really a big deal when I found out because I was hyper. I was hyper? Just take pills to control myself.” Others expressed no inclination to prioritize treatment and no interest in doctor’s appointments. A general lack of communication with providers is indicative of this engagement style. Adolescents stated they did not want to speak to providers, that they were not spoken to by providers, or that they relied on their parents to speak to providers on their behalf. While explicit reasons for this dynamic did not appear in the data, a sense of disempowerment caused by insufficient ADHD-related knowledge was noted and may have contributed to tenuous provider appointments. One adolescent described how his deference to provider expertise was, at least in part, informed by a lack of trust in his own knowledge: “My mom just kind of does whatever the doctors say and I just kind of do the same because they know more about it than I do, so.”

Adolescents were also nonchalant about their management of ADHD symptoms. Low insight is definitive of this engagement style and may be due to the nature of ADHD itself. Symptomatic behaviors such as having difficulty waiting, being irritable, and being bored easily were mentioned as reasons to be dismissive of treatment but were never associated with ADHD. Furthermore, impairments such as receiving poor grades and exhibiting aggressive verbal and physical behaviors (i.e., bullying) were emphasized as unimportant to some adolescents. One adolescent explained, “It's like with school and my grades. If I fail a class, I fail. I just don't really think about it that much.” Interestingly, the adolescent whose insight was poorest and who aligned most closely with this engagement style was also the youngest adolescent in this study. It

is possible that this engagement style is most prevalent for younger adolescents and becomes less applicable to adolescents as they mature.

Not thinking about a problem too much may safeguard the high self-esteem characteristic of this style. Deemphasizing the importance of an ADHD diagnosis may serve a similar purpose. Adolescents accomplished this by deciding not to disclose their diagnosis to people outside of their treatment team, including their extended family and friends. It is unclear whether this choice was driven by indifference, as some adolescents claimed, or was influenced by stigma. Regardless, keeping their diagnoses private deprived them of opportunities for insight-building and establishing peer support for ADHD. Instead, emotional support manifested itself in generally warm parent-child relationships. At the same time, communications about ADHD within these dyads appeared to be infrequent or unclear. Some adolescents denied having spoken with their parents about their diagnosis or treatment at all while others shared instances in which one or more parent used vague or unhelpful language. These difficulties with communication appeared related to parents' own inadequate knowledge of or dismissive attitude towards ADHD. In one case, an adolescent whose parents had ADHD reported that ADHD was so commonplace in his family that it did not warrant any urgent discussion, stating, "[M]y dad's the same way too and so is my mom. So, a lot of people just kind of figured." This narrative, as well as every narrative salient to the engagement styles proposed, has provided the field with a deeper understanding of what 'engagement in care' means to this often-overlooked population.

Discussion

The following question was posed at the outset of this research study: *What factors and experiences do adolescents in treatment for ADHD at an urban safety net hospital perceive as affecting their engagement in care?* An unexpected finding in this study is that the assumed

Table 2

Themes Characteristic of Proactive Engagement

Exp. Type	Characteristic	Themes	Data Extract Sample
Treatment Attitudes	Treatment Effects	1. Appreciation for and ambivalence around medication	Without those pills, I don't even know. But they just help me a lot, like, concentrate and everything.
	Treatment Participation and Control	2. Treatments perceived as effective	You can tell [therapeutic mentors], like, what's wrong in your life, like what problems you have and like, like they give good advice too.
		3. Informative, supportive and communicative providers	Doctors always make sure to check on you, they are always tracking them, asking questions and making sure that you are well and that the medication is in check.
		4. Control over treatment options felt empowering	If one day I want to stop them, my doctor will recommend not to do so but she can't keep me from stopping. My only barrier here is myself.
	Knowledge About ADHD	5. Feeling empowered by ADHD-related knowledge (esp. biological model)	Just to tell them that you're no different than the person that doesn't have it. Like, your brain can work a little different from that other person's, but you're still a person.
Symptom Management	Appraisal and Management of Symptoms	6. Future goals feel possible with treatment	Now I'm taking medication, school is getting better. It used to be really bad, so it doesn't worry me that much anymore or my family anymore.
		7. Uses effective coping skills	I've never watched like long videos or movies in one sitting. I always watch five minutes at a time and then pause it and then go do something else and then come back.
		8. Reports strengths associated with ADHD	To me, ADHD, I feel like it's a good thing because it's like moving a lot keeps you from being lazy.
Relationships	Interactions with Others' Expectations	9. Support from role models with ADHD	Like, one of my teachers actually have ADHD, so he knows where I'm coming from.
	Personal Identity with ADHD	10. Radical acceptance of self with ADHD	Any person – like, there's some stuff that they can't do that you could do, and some stuff that you can do that they can't do, because they don't have it. And he said it's an advantage and a disadvantage sometimes.
	Peer Relationships and Communication	11. Disclosure to and support from peers	They try to help me. Like, even my friends, they give me advice, they're like, "Yo, come on. Get your grades up."
	Parent Relationships and Communication	12. Generally good/warm relationship with parent(s)	No, well she helps me so she should... It shows that she cares about me.
		13. Informed and collaborative communication with parent(s) about ADHD	I asked about the symptoms and all, to see if it would actually do me any good. My mom's the one who says if it's alright.

Note. "Exp. type" stands for "Experience type."

Table 3

Themes Characteristic of Anxious Engagement

Exp. Type	Characteristic	Themes	Data Extract Sample
Treatment Attitudes	Treatment Effects	1. Medications not effective or problematic (i.e., side effects)	I still feel the same. Like, [the medication] doesn't really do much.
	Treatment Participation and Control	2. Treatments disruptive and misaligned with priorities	I mean it'd be nice if they made the appointments not during school hours because I don't like missing school really.
Symptom Management	Appraisal and Management of Symptoms	3. Worry about future with ADHD	I'm scared of not being able to make it because of my lack of concentration. If I'm going to study Engineering, I need to focus on math.
		4. Worry about current struggles (e.g., academic, interpersonal)	You're not able to concentrate on one thing at a time and you're always moving around. If someone talks to you, you look the other way and not pay attention to what they're saying.
		5. Worry about comorbidities	[M]y grandpa died. From there I started having more attention deficit plus depression kicked in and I couldn't concentrate.
Relationships	Interactions with Others' Expectations	6. Worry about not meeting others' expectations	I just didn't like being in a bigger class. I'm going to tell you I'll be able to keep up, but I just feel like I'm not going to be able to keep up.
		7. Feeling judged due to public stigma	[I]f I am showing a lot of attention deficit signs, he'll think that I'll be like another special kid, I won't be normal.
	Personal Identity with ADHD	8. Development of self-stigma	He said it was nothing to be ashamed of, and it was like...but I feel ashamed sometimes...
		9. Lack of self-acceptance (doesn't see self as "normal")	I have to tell people about [my ADHD] too, as if it should help me or make me forget that I have attention deficit disorder.
	Peer Relationships and Communication	10. Worry about acceptance from peers	People look at you different, and it's kind of embarrassing but it's just like, I feel like because I have certain issues with my ADHD, I don't meet new people.
	Parent Relationships and Communication	11. Generally poor/tense relationship with parent(s)	Something I remember that really affected me in a sad way was when my dad left and stopped being there for us for a long time. [...] That affected my behavior a lot because I would get very angry, after this my temper got really strong for a while.
		12. Communication with parent(s) about ADHD that may result in parentification	Yeah, my mom talking about how she couldn't take care of me, but she was just...she was trying to borrow some little cash.

Note. "Exp. type" stands for "Experience type."

Table 4

Themes Characteristic of Actively Rejecting Engagement

Exp. Type	Characteristic	Themes	Data Extract Sample
Treatment Attitudes	Treatment Effects	1. Perceives treatment as unhelpful and harmful (i.e., side effects, family tension)	Because the medicine, it, like, sometimes makes me not even do anything. [...].My mom tries to, like, go out, but, anywhere... Or like, just talk to me or something, I'll just be like, "No, I don't want to, no." And sometimes she would just get mad, or just think that I don't wanna.
	Treatment Participation and Control	2. Feeling forced into treatments (esp. medication)	We would argue sometimes, like, I don't want to take the medicine, but she says I have to, like, and then she ends up...she ends up winning. So, like, it's not even worth it.
		3. Feeling unimportant to and/or dismissed by providers/teachers	Like, they would rather help this... Another student then help me but just like... They'd rather just spend their time on someone else or like, whatever they say to me is brief, or like they not really invested in me.
	Knowledge About ADHD	4. Unsure of how healthcare system/accessing ADHD care works	I'm not sure about that, could you tell me how the system works?
		5. Lacking general knowledge about ADHD	Yeah, I only know that ADHD is...is hyper. I don't know if it means anything else, but that's all I know for now.
Symptom Management	Appraisal and Management of Symptoms	6. Feeling unable to manage ADHD symptoms or ADHD care	[ADHD] makes me think I can't do stuff. Lower... Um, lower my standards. Um, like...like I'll never get something done. Makes it hard to get started on tasks. Whatever, and it just makes me put a lot of things aside.
Relationships	Interactions with Others' Expectations	7. Perceived inability to meet others' expectations	Because the ADHD makes me act like a concern, like a different way.
	Parent Relationships and Communication	8. Generally poor/tense relationship with parent(s)	[My ADHD] hasn't really made it good. The relationship could be better, I think.
		9. Misinformed or blaming communication with parent(s) about ADHD	Participant: Well, my parents used to tell me chocolate. Interviewer: Chocolate, the sugar? Participant: Yeah. Yeah, sugar. When I have sugar, I get very hyper.

Note. "Exp. type" stands for "Experience type."

Table 5

Themes Characteristic of Apathetic Engagement

Exp. Type	Characteristic	Themes	Data Extract Sample
Treatment Attitudes	Treatment Participation and Control	1. Lack of communication with providers	Interviewer: Did you have, like, a conversation with them? Or is it kind of just, like, "You got ADHD"? Participant: I don't... I mean, I don't remember having a conversation. I don't think they did.
		2. General lack of interest in treatment process or options	[My ADHD diagnosis] wasn't really a big deal when I found out because I was hyper. I was hyper? Just take pills to control myself.
	Knowledge About ADHD	3. Feeling disempowered by lack of ADHD-related knowledge	Like I said, the question you're asking me, like, I don't... Like, I only have one, like... Like I said, I don't even know what ADH... Only, like – that I move a lot. I don't really know...
Symptom Management	Appraisal and Management of Symptoms	4. Symptoms prevent engagement with care	I'm mostly talking about patience, this, that. Mostly when you have to be waiting. That's what I hate so much.
		5. Child unconcerned about impairments (e.g., poor academics, negative social interactions)	It's just one of those things where like, it's like with school and my grades. If I fail a class, I fail. I just don't really think about it that much.
Relationships	Peer Relationships and Communication	6. Nondisclosure of ADHD to those outside of treatment team	I like to talk about other things that are more important than that.
	Parent Relationships and Communication	7. Parental ADHD	And my dad's the same way too and so is my mom. So, a lot of people just kind of figured. Yes, it wasn't really any like bad feeling towards it. It was just like I had it, you know.
		8. Generally good/warm relationship with parent(s)	Interviewer: So, how does your ADHD, or how do you think it affects your relationship with, like, your parents? Participant: It affects it in a good way, because, you know, like, my mom, like, can know what I need, like, help and all. [...] We're good.
		9. Lack of communication with parent(s) about ADHD	Interviewer: Okay. Um, so you said the doctor told you first. And then did you talk about it with your parents more? Participant: Mm-mm (negative).

Note. "Exp. type" stands for "Experience type."

meaning of ‘engagement in care,’ as it was presented in this question and based on existing literature, did not accurately portray the engagement experiences of adolescents. The ensuing discussion proposes that the definition of engagement in care should be reconceptualized for the adolescent population. Special attention should be paid to illness insight and self-esteem as independent concepts and interconnecting factors. The four adolescent ‘engagement styles’ that emerged from this intersection provide useful direction for families and clinical implications for providers.

Redefining Engagement

‘Engagement in care’ is an ambiguous term in the literature that often conflates concepts such as access to care, treatment adherence and treatment retention (O'Donohue, Larry & Snipes, 2017). Higgins, Larson and Schnall (2017) responded to this dilemma by conducting a concept analysis of 96 studies, operationalizing engagement as, “the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care” (p. 30). In large part, this definition appeared consistent with the abundance of rich experiences and compelling narratives adolescents shared in this study. Yet, this definition is also incomplete. In accordance with Faraone and colleagues (2017), adolescence appeared in this study as a period of transition, maturation, intra- and interpersonal upheaval and identity development that is unaccounted for in Higgins, Larson and Schnall’s (2017) definition. This definition can be narrowed to more appropriately address adolescent needs.

Engagement that is “uniquely appropriate to the individual” must not only be appropriate for individual adolescents, but for the parents that safeguard their access to treatment. It was noted that parents used their access to transportation and finances – which adolescents may use

at parents' discretion – to determine the overall assembly of their child's treatment. Therefore, although adolescents may be present at doctors' appointments or IEP meetings and participate to appease parents and providers, behaviors typically indicative of participation may be superficial or meant to undermine treatment. Adolescents, unlike children, are known to question familial norms and challenge adult decisions while seeking to establish their self-identity, build autonomy and gain increasing amounts of control over their lives (Eccelston, Williams, Knowles & Soulsby, 2019). The findings of this study suggest that 'engagement' is highly moderated by adolescents' levels of 'psychological buy-in,' or psychological willingness to participate in the care they may or may not have a choice in receiving. Therefore, it is inappropriate to ask whether adolescents' engagement in care appears to be successful or unsuccessful; this may be misleading. Instead, we should ask how psychologically willing an adolescent is to participate in treatment and the impact this might have on their continuation of care into adulthood.

Adolescents, like most individuals, will choose to participate in treatment for "the purposes of maximizing outcomes or improving experiences of care" (Higgins, Larson & Schnall, 2017). However, adolescents, parents and treatment providers may all have different ideas of what maximizes outcomes or improves adolescents' treatment experiences (Mcwilliam, 2009). Our findings suggest that adolescents were more likely to hold positive attitudes towards treatment when it successfully met their personal goals, such as feeling valued by others, avoiding interpersonal conflicts and obtaining professional and academic goals (i.e., becoming an engineer, attending college). This suggests that adolescents' psychological buy-in to treatment may be intimately linked to how effective they perceive their treatment to be in meeting their personal goals. This dynamic is being acknowledged in recent literature; chronic care is moving from a model of provider authority over patients to a patient-provider alliance that, through

techniques such as active listening and motivational interviewing, supports shared goals and has been found to increase patient engagement (McWilliam, 2009; Higgins, Larson & Schnall, 2017)

The Value of Self-Esteem in Engagement

Whether an adolescent had the “desire” or “capability” to engage in treatment was, in many ways, dependent upon their level of self-esteem. Almost all adolescents hoped that treatment would help them feel “normal,” feel valued by others and avoid interpersonal conflicts. Sentiments such as these support previous studies that characterize self-esteem as one’s cognitive and emotional self-concept, mediated by judgments of self-worth, competence and achievement (Mazzone et al., 2013). The current study expands on this interpretation by elaborating upon what it might mean for an adolescent to feel “normal.” To this group of adolescents, normal referred to feeling worthwhile or desirable to others and was a standard that they measured a variety of life experiences against. If experiences can be evaluated as normal, then it follows that experiences can also be conceived as “abnormal.” In this study, feeling abnormal was associated with lower self-esteem. Abnormalities included feeling unable to complete schoolwork of at least average quality, experiencing poor social interactions and feeling resentful towards one’s ADHD diagnosis and treatment.

Societal expectations played a major role in whether an adolescent felt they qualified as normal. Although this study could not evaluate actual levels of treatment engagement, adolescents’ perceptions of treatment suggest that willingness to engage with care was discouraged by feeling unable to meet expectations around academic achievement and developmentally appropriate behaviors. Eccelston, Williams, Knowles and Soulsby (2019) cited these same factors as contributing to adolescents dropping out of treatment. An unexpected, less common, and perhaps family-specific expectation related to engagement emerged in this study.

Parentification refers to the personally or parentally imposed expectation that adolescents sacrifice their own functional and/or emotional needs to care for the needs of their parents or family (Chase, 1999). Having experiences with parentification was found to contribute to poor self-esteem and subsequent feelings of ambivalence towards treatment. Although this phenomenon is under researched in relation to engagement in care for chronic health conditions, this finding is not wholly surprising. Prior research suggests that poor parent-child boundaries are likely to result in children developing internalizing symptomology and feelings of learned helplessness (Vuchinich, Cassidy & Emery, 1988; Sheeber, Hops & Davis, 2001), and these features negatively impact adolescents' self-esteem and help-seeking behaviors (Kranke, Floersch, Townsend & Munson, 2010).

The final construct associated with self-esteem in the current study was stigma. Public stigma refers to prejudicial beliefs and discriminatory actions that are directed towards individuals; it engenders highly stigmatized situations called "stereotype threats" (Corrigan & Kleinlein, 2005). Stereotype threats specific to adolescent ADHD reported in this study are similar to those reported in previous studies, including being bullied, avoided by others or shamed for their disorder (Lebowitz, 2013; Bussing et al., 2012). Self-stigma develops in response to frequent encounters with stereotype threats and refers to one's internalization of negative societal beliefs (Corrigan & Kleinlein, 2005). This study proposes that adolescents who report self-stigmatizing beliefs and behaviors have poor self-esteem and are more likely than other adolescents to be ambivalent about or actively reject treatment. A study by Cadinu, Maass, Rosabianca and Kiesner (2005) illuminates how this process might work. Researchers evaluated female participants' performance under stereotype threat and found that they were less likely to perform well on a mathematics exam when reminded of the common stereotype that men are

naturally better at mathematics than women. Negative thinking distracted participants from the task and was associated with decreased feelings of competence. A similar process might distract adolescents with ADHD from their care or leave them feeling disempowered. Krendl, Richeson, Kelley, and Heatherton (2008) found that increased anxiety associated with self-stigma caused individuals to spend finite neurological energy coping with their anxiety instead of fully processing new information or attending to a task. This implies that adolescents who endorse self-stigma are primed to think negatively about or feel anxiety towards their ADHD and may be less able to process or attend to – and, therefore, proactively engage with – treatment.

Radical acceptance arose as an unexpected theme that contrasted greatly with the process above. Radical acceptance refers to an individual fully acknowledging, without judgment, the positive and negative aspects of one's self and one's reality in order to flexibly adapt to life's challenges (Williams & Lynn, 2010; Alic, 2019). This concept is central to Dialectical Behavioral Therapy (DBT), which seeks to help clients cope with stress by emphasizing unconditional acceptance of oneself and reality while simultaneously teaching skills for emotional regulation (Bass, van Nevel, & Swart, 2014). Mode Deactivation Therapy (MDT) has been successful in accomplishing these same goals using mindfulness techniques to reduce aggression in those with Conduct Disorder, which is often comorbid with ADHD (Apsche, 2010). Neither of these therapies have been sufficiently tested for their efficacy with adolescents who have ADHD, but the ways in which their emphasis on radical acceptance has proven to be successful for other populations (i.e., substance abuse and bipolar disorder in DBT, conduct disorder in MDT) are reflected in the data of this study. Adolescents who perceived their ADHD to be an acceptable and important part of their self-identity exhibited positive self-esteem and sophisticated illness insight. They were able to accurately appraise the reality of living with

ADHD, successfully manage their symptoms accordingly, and perceive themselves as valuable and deserving of their supports. Considering that DBT and MDT were developed to treat patients who perceived the edict of Cognitive Behavioral Therapy's (CBT) to challenge their thoughts as an overly judgmental rather than helpful practice, the power of radical self-acceptance should not be underestimated (Apsche, 2010).

The Value of Illness Insight in Engagement

The desire, and especially the “capability,” of an adolescent to actively participate in treatment is directly related to illness insight. This construct has almost exclusively been investigated in relation to psychosis and schizophrenia but is currently being applied to a plethora of other psychiatric disorders, including ADHD. Illness insight refers to one's ability to challenge conclusions that may or may not be influenced by their psychopathology and flexibly alter their beliefs and actions in response to new information (Beck et al., 2004; Frost and Steketee, 2013). A slightly different definition of illness insight was informed by the experiences of adolescents in the current study. Based on narratives shared with interviewers, illness insight came to be defined as adolescents' abilities to self-reflect on their disorder and take in new information, as well as how much formal ADHD-related knowledge they sought out or already had. Poor insight has been linked to moderate to severe ADHD symptomology, high levels of perception bias and inaccurate knowledge of ADHD (Eccleston, Williams, Knowles & Soulsby, 2019; Bussing et al., 2012; Jia, Jiang, & Mikami, 2016). The importance of this revised definition as it pertains to engagement is apparent in a study by Bussing (2012). This researcher found that low insight in adolescents with ADHD was associated with low expectations of treatment effectiveness and high expectations of negative side effects related to pharmacological and psychological therapies. Two of the four engagement styles that emerged in this study were

characteristic of low insight and provide additional support for this claim. Both the apathetic and actively rejecting engagement styles describe adolescents' inability to articulate whether they think their treatment is effective. While the apathetic engagement style posits that adolescents see treatment as inconsequential to their lives, the actively rejecting engagement style suggests that adolescents perceive treatment side effects as physically and psychologically harmful.

Poor insight may mediate more than just adolescents' appraisals and personal opinions of ADHD treatment. According to sentiments expressed by adolescents in this study, lacking accurate and fundamental information about ADHD contributed to feelings of disempowerment and self-stigma, which are both associated with poor engagement in care (Bussing et al., 2012; Davidson & Ford, 2001). One promising approach to combatting these poor outcomes is educating adolescents about the biomedical model of ADHD. Many adolescents in the current study expressed feeling empowered by this model and curious about its many constituents. Their interest, according to the literature, is not unfounded. Attribution theory posits that when someone is perceived to be in control of their actions, it is appropriate and fair for society to hold this person accountable for said actions. In line with this logic, if an adolescent exhibits stigmatized or disruptive behaviors that are then associated with a psychiatric condition outside of their control, it is – to a degree – inappropriate and unfair for society to blame or punish that adolescent. This reconceptualization of ADHD as a medical disorder like any other, as opposed to an individual failing, has been shown to illicit kinder reactions from others, such as sympathy and helping behaviors (Lebowitz & Appelbaum, 2019). It has also been shown to improve the wellbeing of adolescents with mental health disorders, in so far as they exhibit less self-stigma and improved medication adherence (Bai, Wang, Yang & Niu, 2015; Montoya, Colom & Ferrin, 2011). Interestingly, the lessening of self-stigma might also increase adolescents' ability to learn,

as neural networks previously occupied coping with stress may become available to process information related to building illness insight (Krendl, Richeson, Kelley & Heatherton, 2008).

It is important to individualize psychoeducation to address the self-perception biases some adolescents with ADHD might hold. Self-perception bias is a well-established phenomenon demarcated by cognitive deficits that prevent an adolescent from accurately evaluating the problematic aspects of their ADHD and is predictive of low levels of illness insight (Brinkman et al., 2011; McQuade et al., 2011; Jia, Jiang, & Mikami, 2016). This appeared most clearly in the apathetic engagement style. This style portrays an adolescent who may perceive treatment as unimportant, lack opinions about their diagnosis and treatment, be unconcerned with their impairments, and refrain from discussing ADHD with peers or parents in their daily life. In a sense, self-perception bias is adaptive in its ability to protect adolescents' self-esteem from the consequences of failures due to ADHD. At the same time, being unable to appreciate the problematic aspects of their ADHD prevents them from recognizing a need for treatment or change. Remaining uninterested in engaging with care is likely to result in poor and ultimately avoidable negative outcomes (Steward, Tan, Delgaty, Gonzales & Bunner, 2017). It is essential to consider this and other neurobiological dysfunctions characteristic of ADHD when formulating interventions for adolescents.

Implications for Families and Providers

While it is helpful to situate the major findings of this analysis within the literature, it is essential to narrow their scope so that they are useful to families and providers. Adolescents' behaviors, attitudes and thoughts towards treatment may indicate whether they favor proactive, anxious, actively rejecting or apathetic engagement. By identifying what engagement style an adolescent favors, their families and providers can determine whether and in what ways that

adolescent is at-risk for discontinuing treatment into adulthood. The sections below detail interventions pertinent to each style:

Proactive engagement. Proactive engagement appeared as the most “successful” style of engagement in care and embodied high levels of both insight and self-esteem. Narratives that describe ample opportunities for insight-building and positive identity development suggest proactively engaged adolescents are likely to continue treatment into adulthood. Targeted measures can be taken to cultivate adolescents’ preference for this style, as well as assist adolescents who endorse less favorable styles to see the value in and then adopt this approach.

These findings in this study, as well as the literature, are highly supportive of providers’ actively listening to adolescents’ opinions and concerns; providing individualized treatment; and working in partnership with adolescents to create treatment plans that they feel a sense of ownership over (Price et al., 2011; Eccelston, Williams, Knowles & Soulsby, 2019). Adolescent ambivalence around pharmacological and psychological treatments should not be eschewed by providers and families but embraced as opportunities to increase adolescents’ illness insight and sense of autonomy. Supervised medication trials, as proposed by Brinkman and his colleagues (2011), would be a useful clinical tool that satisfies adolescent needs while also ensuring their safety. This study also supports the psychoeducation of adolescents using the biomedical model of ADHD. In this way, adolescents can feel informed and empowered to participate in treatment (Lebowitz & Appelbaum, 2019). This knowledge also serves to lessen self-stigma and, when provided alongside the promotion of radical self-acceptance, may greatly increase adolescents’ confidence in their symptom management abilities. Interestingly, the importance of role models with ADHD emerged as consequential to the development of this engagement style. This suggests that increasing adolescents’ exposure to successful individuals may help to normalize

ADHD, as well as convey that being successful with ADHD is possible. Finally, the role of peer and parental support in the appearance of this engagement style cannot be understated.

Relationships characterized by warmth and sympathy, as well as parent-child communications that are informative and direct should be encouraged by providers and valued by families.

Anxious engagement. Adolescents who have mixed feelings towards treatment and tend to experience internalizing symptoms (i.e., anxiety, depression) may favor this style.

Disengagement from treatment may occur due to perceiving their current treatment is ineffective and being highly sensitive to the negative psychosocial implications of treatment. To prevent disengagement, families and providers should aim to increase adolescents' self-esteem by (1) considering alternatives to traditional ADHD treatments, (2) addressing underlying feelings of anxiety and (3) decreasing their exposure to public stigma and their endorsement of self-stigma.

A defining feature of this engagement style is the belief that treatment, especially pharmacological treatments, are ineffective. Therefore, it may be prudent for adolescents to engage in less conventional forms of treatment such as cognitive behavioral therapies or life management skills coaching. The efficacy of these interventions for ADHD in adolescents is under researched. However, their emphasis on increasing adolescent autonomy and assuaging adolescents' fears about the future directly address factors related to disengagement that are intrinsic to this style (Knouse & Safren, 2010; Antshel & Olszewski, 2014). Cognitive behavioral therapy, in particular, is highly effective in treating internalizing symptoms characteristic of anxiety and depression (Bass, van Nevel, & Swart, 2014).

Finally, decreasing the influence of stigma on anxious engagers would increase their self-esteem and allow them to be more proactively engaged with treatment. Anti-stigma campaigns can be introduced in schools and communities to help eliminate public stigma (Bai, Wang, Yang

& Niu, 2015; Montoya, Colom & Ferrin, 2011), while self-stigma can be addressed through psychoeducation of the biomedical model of ADHD, the encouragement of radical self-acceptance and increased exposure to role models who have ADHD. Furthermore, providers should look for evidence that the adolescent is experiencing parentification. If it appears that an adolescent's relationship with their family is tense or that the adolescent is willing to forgo vital aspects of their treatment to satisfy parental needs, a discussion with parents on the importance of parent-child boundaries or perhaps recommending parent trainings may be warranted.

Actively rejecting engagement. Actively rejecting engagement may present in adolescents who perceive treatment to be an overall unpleasant experience. They are likely to psychologically resist and then discontinue care due to feeling frustrated towards and disempowered by treatment. To prevent disengagement, families and providers should seek to increase adolescents' self-esteem and illness insight by (1) making the treatment process as collaborative as possible, (2) easing unrealistic expectations around behaviors and academic performance and (3) providing psychoeducation to both adolescents and their parents.

Adolescents that actively reject treatment require significantly more emotional support than adolescents that subscribe to other engagement styles. The style suggests that an adolescent may feel impaired by treatment and that treatment is forced upon them. Therefore, it is recommended that providers do what is necessary to include adolescents in the decision-making process. Providers should request to hear adolescents' concerns and opinions, be willing to conduct supervised medication trials and offer to discuss treatment options without parents in the room. Feelings of disempowerment appear in adolescents' perceived inability to control their ADHD symptoms and to meet the behavioral and academic expectations of others. Therefore, it might be prudent for providers and families to soften societal expectations for these adolescents

in order to, as research has suggested, increase their engagement with care (Gallichan & Curle, 2008). This may prove difficult for some families due to the criticism-rejection parenting style that appears intrinsic to this engagement style. Muñoz-silva, Lago-urbano and Sanchez-garcia (2017), found that this type of relationship – which is full of misinformed and blaming language about ADHD – worsens ADHD symptoms and promotes disengagement from care.

Psychoeducation for both the adolescent and child would not only increase each parties illness insight, but may also incite empathy and helping behaviors in parents and promote a healthier parent-child relationship.

Apathetic engagement. Adolescents who favor the apathetic engagement style neither dismiss nor endorse benefits related to ADHD and may be at risk for discontinuing treatment due to feelings of indifference towards living with ADHD. To prevent disengagement, families and providers should resolve to increase adolescents' illness insight by (1) explicitly connecting provider and parent treatment goals to the personal goals of adolescents and (2) increasing discourse about ADHD throughout multiple domains of their life.

When treatment is perceived as unimportant, it may be useful for providers and families to identify what is important to an adolescent that favors this style. To build illness insight, a creative provider or attentive parent may be able to help an adolescent identify immediate or long-term goals and then help them connect the feasibility of this goal to treatment.

Neurobiological and behavioral limitations should be considered when developing treatments that cultivate accurate self-appraisals – such as psychoeducation or life management skills coaching – as this strategy is known to be effective in improving engagement (Brinkman et al., 2011). This form of insight building is directly related to high-quality discourse about ADHD, which is notably absent from almost every aspect of this engagement style. While apathetic

engagers enjoy positive peer and parental relationships, they choose not to disclose their ADHD diagnosis to peers and are unlikely to communicate about ADHD with their parents. Providers should actively facilitate conversations about ADHD between parents and their children.

Limitations and Future Directions

This study has several limitations. Firstly, it is possible that the interviewer effects were influential in the current study. Interviewer effects refers to the myriad of ways an interviewer – through their gender, tone, questions, etc. – influences the answers of respondents. Highly valid answers are often associated with the minimization of interviewer effects (Lavrakas, 2008). Early in the data collection process, interviewers tended to utilize a relatively scripted question-and-answer format. As the data collection process unfolded, it became evident that adolescents were not overly receptive to the question-and-answer interview format. Interviewers responded by adopting a conversational style meant to elicit information in a relatively natural way. It would be beneficial for future research in this area to adopt a consistent interview style across cases. In this way, differences in adolescent responses can be attributed to what they shared of their own volition and not in response to this alteration in interview style.

Secondly, there was a stark difference in the quality and length of interview responses elicited from the two female participants in comparison to the nine males. The female participants' transcriptions averaged 27 pages, while the male participants' transcriptions averaged 11 pages. This created a dilemma in which only two female perspectives are represented in this sample, but these two perspectives may have had a disproportionately large influence on data analysis due to their relative verbosity. Their verbosity may be related to gender differences, or to interviewer effects in that all interviewers that participated in data collection were women. It may have been easier for the female adolescents to relate with and

trust female interviewers. In the future, it may be helpful to incorporate more female perspectives in the data set while also striving to elicit more information from individual male participants.

Lastly, this report consists of 11 adolescents from minority and disadvantaged families who receive ADHD treatment at an urban safety net hospital. It provides invaluable insights into the perspectives of an often-overlooked population at one point in time. However, this small sample size and relatively specific population parameters prevent these results from being generalizable to most adolescents with ADHD. In addition, although the engagement styles proposed in this report suggest a likelihood of continued engagement versus drop out, actual continued engagement versus dropout could not be determined without (1) provider and parent reports of engagement and (2) interviewing adolescents about their engagement experiences at multiple time points, as would be possible in a longitudinal study.

This study was a secondary data analysis using one primary measure that captured only adolescents' perspectives. Future research in this area would be enriched by adopting a multi-faceted approach to collecting data. For instance, utilizing youth-report and parent-report measures related to ADHD symptom severity would have allowed us to compare an adolescent's illness insight with the severity of their symptomology. Reports from adolescents' providers and parents on how they perceived adolescents to engage with treatment would have similarly enriched the data. In line with a multi-faceted approach, analysis of this data has laid the groundwork for future studies on parent-adolescent dyads in which the youth have ADHD. The transcriptions of adolescent interviews in this data set can be matched with the transcriptions of their parents (from the data corpus) discussing comparable topics. The similarities and inconsistencies that this dyad share about ADHD could illuminate underlying relationship and

communication dynamics between the adolescents with ADHD and their parents. The latter topic is almost completely absent from the literature.

Several topics discussed in this paper were absent, under researched or contentious in the literature. Illness insight should be further researched in relation to disorders other than psychosis and schizophrenia. The concept of radical self-acceptance should be explored for its potential to improve the self-concept and engagement levels of adolescents with ADHD. The role of parentification in adolescent's engagement with ADHD care would be an interesting, currently untouched, avenue for future research. Self-esteem, a hotly debated construct in and of itself, has not yet been compared with the idea of "normalcy" or thoroughly researched in relation to adolescents' engagement with care. Above and beyond these specific topics for future research, the stories, beliefs, concerns and hopes of adolescents with ADHD as they experience their own ADHD are largely absent in the psychological and psychiatric literature. Qualitative analyses of their experiences are even rarer. It is my hope that the findings in this paper provide researchers with a multitude of jumping off points to explore, from the adolescent point of view, what it means to live with ADHD.

Conclusion

The findings of this thesis suggest that successful engagement in ADHD care is analogous to whether an adolescent, who sometimes has no choice but to participate in parent-mandated treatment, psychologically buys-in to treatment. Illness insight and self-esteem emerged as essential to adolescents' willingness to engage in care, as well as the development of adolescent attitudes towards treatment, symptom management, and the way relationships in their lives interact with their ADHD. These attitudes manifested in whether an adolescent tended to proactively, anxiously, apathetically or actively reject engagement with care. Proactive

engagement appeared as more than just a positive attitude towards treatment; it was indicative of prosocial tendencies, confidence and self-acceptance during an otherwise tumultuous stage of life. With the hope of encouraging as many adolescents to proactively engage with ADHD care as possible, the findings in this report have the potential to inform pediatric, psychiatric, school and community interventions for ADHD.

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Care57

Tables

Table 1

Participant Demographics

Variables	Sample Characteristics (N=11)
Median age in years	15
Sex	
Male	9 (81%)
Female	2 (18%)
English proficient	11 (100%)
Languages spoken at home	
Exclusively English-speaking household	5 (45%)
Multilingual household	6 (57%)
Nativity	
Born within the U.S.	8 (73%)
Born outside of the U.S.	3 (27%)
Race	
African American	7 (63%)
White/Caucasian	2 (18%)
Native American	2 (18%)
Identified as being of Hispanic, Latino or Spanish origin	
Yes	5 (45%)
No	6 (57%)
Family experienced financial hardship at least “somewhat often”	7 (63%)
Adolescent diagnosed with a mental health condition (i.e., anxiety, depression)	3 (27%)
Adolescent diagnosed with a disability that impedes learning (i.e., developmental delay, speech disorder, learning disability)	7 (63%)
Treatment services received	
Currently on ADHD medications	11 (100%)
Currently receiving school services	11 (100%)
Ever received behavioral therapy	10 (90%)

Appendix A

Adolescent Qualitative Interview

Qualitative Interview Guide – Barriers to ADHD Treatment v.1.2 Adolescent Interviews

This interview guide is intended to help assist interviewers with navigating key content areas of data collection for the individual qualitative interviews, ensuring the same content is discussed in each interview. While the guide is used to assist with the discussion, it is not a rigid script that will be adhered to verbatim. This insures that interviewers have the ability to adapt and clarify questions that suit the needs of different patients. Similarly, questions need not be asked in this particular order. Rather, the interviewer will adapt the conversation as needed according to the narrative within each interview, pursuing a priori research topics as well as any emergent themes that evolve from the discussion.

All information and questions to read to participants are in *italics*. Information intended to guide the interviewer is non-italicized.

Interview Date: _____

Interviewer Initials: _____

Participant ID#: _____

We have invited you to participate in this study because you are a teen with ADHD. We are trying to learn how to better support children with ADHD and their parents. To do this, we are asking parents and teens to share their experiences

Experience and Knowledge

- I. *Tell me about the experience of learning you had ADHD.*
 - a. *How did you learn you had ADHD? How did you feel about being told you have ADHD? (Probe: Who told you?)*
 - b. *How did you learn about ADHD? (Probe: or from whom...?)*
 - c. *What do you wish you had learned about ADHD?*
 - d. *What are some questions you still have about ADHD?*
 - e. *How did your parents talk to you about your ADHD? How would you have liked them to talk to you about your ADHD? (Probe: How has how they talked to you about your ADHD affected how you feel about it?)*
- II. *Tell me about the experience of getting help for your ADHD.*
 - a. *What treatments and services have you received? (Probe: Medication; Therapy; School Services)*
 - b. *How have your parents/guardians make decisions about your care?*
 - c. *Do you feel you have an input in your care decisions?*
 - d. *Who has helped you to make treatment decisions? (Probe: or what has helped...?)*
 - e. *Can you give me an example of something that was positive about getting help for your ADHD?*
 - f. *How about something that was negative?*
 - g. *What would you tell other adolescents with ADHD about getting care? What would you tell parents of children with ADHD about getting care?*

- III. *If Applicable – Tell me about the experience of having a sibling with ADHD*
- How has having a sibling with ADHD helped you? (Probe: or made it harder?)*
 - How does your sibling feel about ADHD?*
 - How does having a sibling with ADHD affect how you feel about your own ADHD?*

Barriers to Care

- I. *Tell me about any difficulties you have had getting help for ADHD.*
- What makes it difficult for you and your family to get help for your ADHD? (Probe: e.g. Keeping appointments? Getting medication? Getting extra help at school?)*
 - How has your race affected how people treat you when you're having trouble with attention/hyperactivity?*
 - How has your ethnicity or culture affected how people treat you when you're having trouble with attention/hyperactivity?*
 - How has money affected how you're treated? How has money affected you getting help for your ADHD?*
 - What has helped you to overcome difficulties to getting your treatment?*
 - How could health care professionals help you overcome difficulties getting your treatment?*
 - What would help you to feel more involved in your treatment? (Probe:???)*

Stigma

- I. *Tell me about your feelings and attitudes toward ADHD.*
- How do you feel about having ADHD? Does your ADHD affect how you feel about yourself?*
 - How do you feel about ADHD treatment? (Probe: Medication, Therapy)*
 - How does your ADHD affect your relationship with your parents/guardians? (Probe: Are there times when you think it puts stress on the relationship? Fights, tension, etc.)*
 - How does your ADHD affect how your parents treat or discipline you? (Probe: compared to your siblings?)*
 - What fears and concerns do you have about your future with ADHD? (Probe: Are you concerned about it affecting your higher education, career, family, etc. and how?)*
 - How has your cultural background affected your opinions about ADHD? (Probe: Have you heard any family members talk about ADHD, either in a positive or negative way? Do you think this affected your thoughts about ADHD?)*
- II. *Tell me about the feelings and attitudes of the people around you about ADHD.*
- How have you or your family been treated differently by others because of your ADHD? (Probe: Have you ever felt judged? Have you ever noticed your family being treated differently because of your ADHD?)*
 - Describe any situations when you or your family have felt judged or blamed by others about your ADHD treatment. (Probe: Medication)*
 - How has worry about being judged by others affected you or your family's decisions about your treatment? (Probe: Fear of being judged by other family members, family friends, etc.)*

Environment

- I. *How has your emotions and behavior been affected by your environment? Specifically, how have you been affected by:*
 - a. *Your family's financial situation?*
 - b. *Your neighborhood?*
 - c. *Difficulty making ends meet or meeting your family's needs (e.g. for food, clothes, housing, etc)?*
 - d. *Stressful events in your life? (i.e. Parents divorce, separation from family, moving around a lot, etc.)*
 - e. *The health and well-being of adults in your household?*
 - f. *Your school or classroom environment? (I.e. friends in classroom, fear of being/being treated differently in school, etc.)*
 - g. *How do any of these factors affect your ability to concentrate or focus on school work?*
- II. *How have after-school activities (i.e. sports, teams, organizations) affected your focus and hyperactivity? (Probe: What are they?) How has your ADHD affected your after school activities? (Probe: Choice, experience compared to other kids)*

INTERVENTION QUESTIONS: We are designing a program for clinics to help doctors and other health care providers better support families whose children have ADHD. We would like your advice about this program.

- I. *What do you propose we do, as health care providers, to better support parents and families of children with ADHD?*
- II. *What could we do to reduce the stigma (or negative attitudes) associated with ADHD?*
- III. *How could we make it easier to get ADHD treatment for patients and families?*
- IV. *How would you want to receive more information about ADHD? (e.g. from your doctor, another health care provider, the internet, other parents with children who have ADHD, etc)*

Appendix B

Annotated Transcription for ADD002

15 pgs

Title: ADD002 Interview

Interviewer: Okay. You're going to notice me looking at this paper sometimes. This paper is to help me remember all the questions that I want to ask you, so that I don't forget. So, we invited you to participate in this study because you have attention deficit disorder. So, we're trying to learn how to better support children and teenagers with attention deficit as well as their parents. In order to do that, we've asked some teenagers and their parents to share their experiences with us. Okay? So this is an interview, but there are no right or wrong answers, I just want to know how your experience has been, okay? And if you have any questions, don't hesitate to interrupt me and I'll immediately clear it up for you, alright? Good. So tell me a little bit about your experience and how you found out you had attention deficit disorder.

Participant: When I realized it was very difficult for me to focus in school and started getting bad grades.

Interviewer: When was that?

Participant: About 5 years ago.

Interviewer: 5 years. You're currently in 9th grade, so that means you were in 4th or 5th grade when that happened. So what did you or your teachers notice?

Participant: That I couldn't concentrate, that I'd just look at my classmates and didn't do anything.

Interviewer: Alright. Who told you or your mom that you had attention deficit?

Participant: My teachers.

Interviewer: They were the ones who told you.

Participant: Yes.

Interviewer: Okay. And where... In your own words, how would you describe what attention deficit disorder is?

Participant: Not being able to focus and moving a lot, looking all around you but not concentrating on one thing at a time.

Interviewer: Okay, like not being able to focus on one thing at a time, you are saying that you are easily distracted.

Participant: Yes.

Title: ADD002 Interview

Interviewer: That's how you'd describe it. So you were around 9 years old when your teachers told you this, what would you have liked to have known before that?

Participant: How to manage my attention deficit.

Interviewer: What do you mean?

Participant: Like I want to be able to focus on one thing, not look at what's around me, only focus on the person, not move constantly...

Interviewer: Okay, but you can move, you know that, right? It's okay. You're telling me you would've liked to know how to manage it even before you were in 4th or 5th grade.

Participant: But when I got to 6th or 7th grade, my anxiety level kept increasing and all and I couldn't focus, I couldn't do anything, I was just moving constantly. When that happened, I got really bad grades, I got F's in all my classes, but it was because of that.

Interviewer: What do you think changed? Because you're saying that it all got worse when you got to 6th or 7th grade, the symptoms got worse but the grades as well.

Participant: At that time I already had attention deficit disorder but then my grandpa died. From there I started having more attention deficit plus depression kicked in and I couldn't concentrate.

Interviewer: I'm very sorry. So you were already having issues, it made it more difficult for you...

Participant: After that, when my grandpa died, that's when it all got so much worse.

Interviewer: Were you close to him?

Participant: I was.

Interviewer: So you were also suffering from depression and anxiety, you'd get sad and that would make you feel even more anxious.

Participant: Yes, it would really affect me because I remember my grandpa would always say "I'm going to go eat pasta", so whenever they served pasta at lunch in school, I'd get depressed.

Interviewer: You'd get sad thinking about him.

Participant: Yeah.

Title: ADD002 Interview

Interviewer: And still today, right? It seems like you still remember all of it.

Participant: You should see my arm...

Interviewer: What do you mean?

Participant: Look.

Interviewer: What's wrong with your arm? Did you do that? Tell me about it.

Participant: It happened yesterday. I was sleeping and I dreamt about him, he told me so many things. I woke up and started crying. Then I took something and I felt so depressed that I did this.

Interviewer: You cut yourself, is this the first time you do this?

Participant: Yes.

Interviewer: The first time. Okay.

Participant: Then my mom saw what I had done and took away the object I used to cut myself.

Interviewer: What did you use to use cut yourself?

Participant: In that moment, I had found something in the car, it was some kind of pocket knife, and I told my mom "I am going to throw it away". However, I wanted to do it discretely because I couldn't let my brothers see me do that and since they're always with me, I didn't get around to doing it.

Interviewer: The pocket knife.

Participant: Yes. I just hid it and when I dreamt about him, I remembered I still had that thing.

Interviewer: Okay, you had forgotten all about it until that sad moment. You just felt like you needed to do something.

Participant: Yes.

★ → AT THIS POINT, INT. PAUSED FOR EMERGENCY INT.
Interviewer: I'm so sorry, I had no idea. And what are some questions... You've mentioned like attention deficit, as well as depression, and anxiety; which are a lot, aren't they? Do you have any questions in regards to attention deficit disorder?

3

Title: ADD002 Interview

Participant: If I'm able to do sports to calm my anxiety down, like entertain myself to not have this.

Interviewer: Okay, you're wondering if doing any sport or any activity could help you manage your anxiety.

Participant: Yes, it's what I'm doing now; it helps me because I'm learning lots of new things.

Interviewer: It helps you, okay. But you're thinking of sports because you like them.

Participant: Yes.

Interviewer: Okay. Do you have any other questions about it?

Participant: Like overcoming it... like if I can have friends while managing my attention deficit but at the same time not focus too much on them, to keep going.

Interviewer: If you can make friends while paying attention? Is that what you mean?

Participant: Yeah. The thing is that, before, I used to always talk to my friends in class no matter if the teacher was talking. But then, like I said, I say hi to them and stuff but then I still have to continue paying attention.

Interviewer: Exactly, okay.

Participant: Exactly, but I used to get distracted while the teacher was talking.

Interviewer: You'd start talking to your friends.

Participant: Exactly.

Interviewer: Okay, and what are you worried about...?

Participant: I'm worried that if I ignore them, I will be alone.

Interviewer: Oh, I get it. You're afraid that, if you're able to focus in class, you won't be talking to them, then you'll lose your friends since you're not interrupting your classes anymore.

Participant: Yes.

Interviewer: I understand. So your question about attention deficit is basically if you'll be able to continue those friendships without getting distracted in class.

4

Sports as
a way to
cope w/ ADHD

★
Evidence of
Low self-
esteem?
Doesn't just be, w/ meds,
it's good enough
for his friends

T3
Worried
friends
won't
like his
↑ focus
in class

meds =
↑ focus =
↓ friends

maladaptive
coping

understanding of cars.
compassion for family/
concern for family wellness

struggles w/
poor grades
but likes
learning -
sports/hands on
learning may be
more his style!

Title: ADD002 Interview

Transitioning from PR to MA

Participant: Exactly.

Interviewer: I understand.

Participant: That's basically what I'm doing now; I say hi to them but then I pay attention to my teacher and do my work. When school's over is when I talk to them.

Interviewer: I understand, it was different before; but it's pretty different now as well since you just moved to Boston, how long have you been here?

Participant: 7 months.

Interviewer: So you're still in the friend-making process, aren't you?

Participant: Yeah.

Interviewer: Okay. You told me your teachers were the ones who told you you had attention deficit, but what kind of help did you receive back in Puerto Rico?

Participant: I had a psychologist with whom I used to talk. Then, they prescribed me some medicine for my anxiety but they didn't work, they had no effect on me. They proceeded to increase my dosage but it'd still be the same. I was always depressed, always inattentive. However, the psychologist helped me more than the medicine.

Interviewer: So you were taking medicine, and who would give them to you?

Participant: The psychiatrist.

Interviewer: And the psychologist would converse with you.

Participant: Yes.

Interviewer: Okay. What other help did you get in Puerto Rico or here in Boston as well?

Participant: Here I've talked to special teachers at school, like special education and stuff like that.

Interviewer: And you're also getting...

Participant: I never got that in Puerto Rico.

Interviewer: At school?

T2

combats sophisticated understanding of multiple tx. and identifies preference
↓
I wonder why this preference?

Title: ADD002 Interview

Participant: Because the hurricane came and it was impossible.

Interviewer: It was harder. And what was that like for you?

Participant: It was okay, the help was great. I trusted them. The medicine would have an effect on me every time they'd increase the dosage but I still felt the same way.

Interviewer: Who decides on which treatment you get?

Participant: My mom.

Interviewer: Do you have a say in the kind of treatment you get?

Participant: Yes, but I just have to ask how the medicine works.

Interviewer: What do you mean?

Participant: For example I'm taking Zoloft which is for my anxiety, but before being prescribed, I asked about the symptoms and all, to see if it would actually do me any good. My mom's the one who says if it's alright, but sometimes she'll say she doesn't think so, and she asks for another options.

Interviewer: So both of you ask the doctor about the symptoms and the side effects of the medicine.

Participant: Yes, the side effects.

Participant: Okay. I'd like you to tell me about a positive experience you've had with the treatment you're getting.

Participant: Zoloft.

Interviewer: ok, the medication has helped you.

Participant: Yeah.

Interviewer: What about a negative experience?

Participant: Sometimes I don't like talking to people about my concerns and stuff like that, like psychologist talk to me about these things, and I don't like that. But I need to vent so I do have to talk.

T7

TRAUMA
natural disaster as a barrier to engagement

P-C COMM

Shared decision making, adol. specific limits
↓
adol. stages informed about tx, mom has the final say

T5

T4 *meds have helped*

T6

↳ Even though "psychologist helped me more than meds"

- Because of stigma?
- Because he is not adept at verbalizing feelings? what makes that uncomfortable?

LATER IN INT.:

- Talking about it reminds him he has ADHD, feels abnormal...

Title: ADD002 Interview

Interviewer: So you don't like talking to psychologists.

Participant: No.

Interviewer: Okay so that's been your least favorite part of the treatment. But you do feel like the Zoloft has helped you.

Participant: Yes. **ADHD med? or only MDD/Anx.?** (T4)

Interviewer: Okay. What would you tell other kids who also have attention deficit disorder? What would you recommend them or their parents?

Participant: I'd tell them to just be normal. **? what does normal mean here?** to keep on going with their lives and to try to focus on things and not worry about their friends, to stay focus on one thing at a time.

Interviewer: That's a good piece of advice. Tell me, has it been difficult for you or your mom to get the help you need for the treatment?

Participant: Yes.

Interviewer: How so?

Participant: When we first moved here it was really hard to find the medications.

Interviewer: Okay.

Participant: As well as a psychiatrist.

Interviewer: How was it hard?

Participant: Finding the doctor or someone, finding the medicine.

Interviewer: It was hard.

Participant: Yeah.

Interviewer: Do you think the fact that you're Latin affected the getting-help process?

Participant: No.

Interviewer: What about finances, money? Did that affect the process?

T7.5

uncommon for adol in our sample to know these things

Does he know too much about family? Parentification?

T2

T8

T9

T6

Title: ADD002 Interview

Participant: Yes.

Interviewer: How so?

Participant: Like we have to pay for the medications. We don't have a lot of money and we have to pay about \$7 for each medicine because they're not covered by the insurance.

Interviewer: Oh okay, that's money that perhaps you don't have, right? How have you managed to overcome those barriers?Participant: Improve the situation in order to stop taking medication.

Interviewer: What do you mean?

Participant: Like if I am anxious, I try to be like "Okay, I have to focus on one thing at a time" and when I am able to manage the situation and forget about it, well I don't have to take medicine anymore and I don't have to buy them. **tries to use non-med coping skills**

Interviewer: Because of the money, I get it. So you get to handle your situation and what you're going through.

Participant: If I were to overcome my depression caused by my grandpa's death, I wouldn't have to take any more medicine for depression. It's been a while since I started feeling better, but I felt bad when I dreamt about him.

Interviewer: It's hard losing someone close to you. But what you're telling me shows that knowing that there are certain things you have control over helps you feel better and makes the rest of the process a bit easier.

Participant: Exactly.

Interviewer: What's your opinion on attention deficit disorder?Participant: That it's not a good thing; when you have attention deficit you're not able to concentrate on one thing at a time and you're always moving around. If someone talks to you, you look the other way and not pay attention to what they're saying. **focusing entirely on (-); ev. of low self-esteem causes**

Interviewer: Okay and how do you feel about having attention deficit disorder yourself? How does that make you feel?

Participant: Bad because on top of not being able to focus on things I have to tell people about it too as if it should help me or make me forget that I have attention deficit disorder. For

why he does not like talking → thinks the talking makes it worse. Has not yet accepted the dx, or have tools to manage it

Title: ADD002 Interview

Mom gives son autonomy (perhaps lacking guidance/ correct med. information)
 example, my mom always asks me: "Are you going to take your medication or do you feel like you don't need it?" to see if I can manage or not. And sometimes I just say: "Yes, I need the medication". Sometimes I feel normal and other times I feel like I have the attention deficit.

Interviewer: So, on occasions, your mom tells you to take them and in others she tells you otherwise.

Participant: Yes. What we try to do is take them during the week and stop them on the weekend, like I did this week, to see if I can manage without them.

Interviewer: So it seems like some weeks are worse than others, that's what you're trying to say.

Participant: Exactly.

Interviewer: So you sometimes say like "Well this week went well and I don't need it". Do you do that with all your medicine or just with...?

-in. Participant: I do that with my depression medicine as well since I sometimes feel sad but other times I feel normal.

→ poor understanding of mental illness here

Interviewer: Do you think your perception of yourself or your self-esteem have gotten affected by the fact that you have attention deficit disorder?

Participant: No.

Interviewer: Okay. How do you feel about your self-esteem, has it changed? Do you have any worries about your future?

Participant: I'm scared of not being able to make it because of my lack of concentration. If I'm going to study Engineering, I need to focus on math which is really difficult not only to look at the graphs, but also the equations if I can't even concentrate.

Interviewer: And you are worried that you won't be able to concentrate and fail.

Participant: Yeah.

Interviewer: Okay. In what way does your culture affect, influence or shape your opinions on attention deficit disorder? What I mean by this is that if the way you grew up, your culture and environment have anything to do with the way people think of this disorder. What I mean by this is how the way you grew up does or the way you were before, from your culture and environment, has anything to do with how people think about attention deficit?

stigmatization associated w/ medication

T10
 Having ADHD is NOT normal

MED TRIALS

but NOT to evaluate med effectiveness for management. For evaluation of whether meds can be stopped.

Poor self-esteem

Concern for future

Title: ADD002 Interview

Participant: They look at me and how I am. Let's say if I have a friend that have known for many years, he'll know how I behave myself, and then if I am showing a lot of attention deficit signs, he'll think that I'll be like another special kid, I won't be normal.

Interviewer: What friend? I didn't get that.

Participant: Like, I had a friend in Puerto Rico and...

Interviewer: Tell me about it.

Participant: We've been friends for a very long time, since primary school, and we used to study together. But after I told him, because I trusted him, I told him that I suffered from attention deficit and depression, he was like: "So it seems like you have problems". So I don't know, like from everything I told him he only kept that I have problems, like I am different, not normal. And stuff like that affects anybody. It really affected me.

Interviewer: I understand. Like obviously because you trusted him you told him "Look I have attention deficit and depression" and he started treating you differently.

Participant: Yes, he started treating me so differently. I'm a normal kid, I just have that problem.

Interviewer: But he didn't treat you as if you were normal.

Participant: Exactly.

Interviewer: As if you were a kid with special needs and it affected you. That must've affected you and your relationship with him as well.

Participant: We weren't even friends anymore; really, he treated me badly. He started hanging out with other people because he said I had "issues".

→ ADHD stigma = isolation (and bullying?)

Interviewer: Thank you so much for sharing that with me. And you shared this after I asked about how your culture influences because you believe that people actually think like that where you grew up?

Participant: Yes.

Interviewer: How so?

Reports effects (-)

T12

Cultural stigma in PR...

A friend started bullying him bc ADHD label

Title: ADD002 Interview

Participant: Here I can say I have attention deficit disorder and people take it well like "Okay, you can still be a normal kid". However, I sometimes get so anxious I start scratching my skin, and my friends are always there for me telling me "stop scratching yourself".

Interviewer: Here in Boston.

Participant: Yeah. On the contrary, in Puerto Rico, my friends wouldn't help me if I started scratching my skin because they wanted to see something.

Interviewer: Something like...?

Participant: For example, if I scratch myself too hard, I sometimes bleed and they wanted me to do that. Here, I scratch myself because of my anxiety, but my friends here help me and they tell me not to do that. And I can do stuff with them like playing cards or things like that.

Interviewer: Okay, you get distracted with them.

Participant: Exactly. My friends in Puerto Rico didn't really care.

Interviewer: They never helped you.

Participant: No.

Interviewer: It seems like people here are more understanding; they're less prone to treat you like a special kid.

Participant: Exactly.

Interviewer: That's really interesting; people are different in every country. Have you ever felt judged by anyone before? Like if you did something and then someone said "Oh, he did that because he has attention deficit?"

Participant: No.

Interviewer: Okay. Tell me how your environment has influenced your behavior. You've told me a little bit about this, like in the case of your grandpa when something happened and you got worse; but how do you think that your behavior, your environment affect you attention deficit? For example, do you feel like your family's financial situation affects your attention deficit?

Participant: Yes.

you
Boston!
♥

T12 Friends
in PR
would let
him anxiously
scratch
himself till
he bled
community
attitudes

T2
Talks about
it in terms of
MDD, not
ADHD

Title: ADD002 Interview

Interviewer: In what way?

Participant: The fact that I can't see them. I have family members in Puerto Rico and I'm here in Boston and that affects my depression greatly because I don't know if they're okay or not. I can call them, yes, but it's not the same as seeing them in person and that affects me a lot. My grandma is very sick right now, she can't see and she's making the effort to come here to see me, and that hurts me because she can't see, how is she going to make it here? She called me the other day and asked me what color I was going to wear so she could distinguish me from everyone else.

Interviewer: She can't distinguish colors anymore.

Participant: No.

Interviewer: I get it. She wanted to know what color of clothes you were going to wear so she could focus on you.

Participant: Exactly, so I told her: "I'll be wearing blue and red", and she said "Okay, that's how I'll see you", because if I chose to wear black...

Interviewer: She wouldn't know it's you.

Participant: Exactly because everyone dresses in black here.

Interviewer: I know. Well, you're helping your grandma in some way, it's really nice. So you're saying that's connected to your family's financial situation because if you had money, you would be able to visit them. Not being able to see them makes you feel worse and sad.

Participant: Yes.

Interviewer: Okay. What about your neighborhood, do you think it affects your attention deficit?

Participant: Yes.

Interviewer: How so?

Participant: There was so much violence in it; people would get killed all the time.

Interviewer: [REDACTED]

Participant: Eh...

Full
de-identified
in NWFO

T2

T8
Can't
afford to
visit his
family in
PR

in PR

Title: ADD002 Interview

Interviewer: Oh, you mean in Puerto Rico.

Participant: Yes, back there people would get killed every 5 seconds. One day they kill one person and then the next they kill 20.

Interviewer: Ah, ok. I know you told me the name of the city you're from, but we weren't recording so would you mind tell me again?

Participant: I'm from [Name Omitted]. A lot of shootings go on there.

Interviewer: A lot of violence, okay. Would they kill a lot of people from your neighborhood?

Participant: Yes.

Interviewer: How did that affect you...?

Participant: Every time someone told me "Ay, someone got killed" I'd get worried it's someone I knew and that would upset me. I'd think "Wow, who did they kill?" and then since they don't know who it is, I think it's someone I personally know and it affected me.

Interviewer: You'd overthink it.

Participant: Yeah.

Interviewer: I get it. Let me check my phone in case your mom's calling me. Now, I have a question: is it difficult for your family to cover the monthly expenses?

Participant: It is.

Interviewer: Is it? I'm talking about food, clothes, rent...

Participant: Yes.

Interviewer: Do you think that affects your behavior?

Participant: No, it affects them.

Interviewer: But it doesn't affect you.

Participant: No because I could make a huge effort to help but I can't do much; I can't work, I'm a

minor...

young age might be keeping him in the - he can't work instead of go to tx!

13

Title: ADD002 Interview

Interviewer: Even though you look 21!

Participant: Exactly.

Interviewer: So it affects them but it doesn't affect your attention deficit as much. What about...? Oh! Your mom's calling.

(Non-interview chatter)

Interviewer: We're about to be done, okay? We were talking about how your surroundings affect your behavior and disorder. You told me that there are times when a lot of things are going on and that affects your attention deficit, but that sometimes things are a bit calmer and you feel better. Now, what kinds of stressful events go on around you that make you feel worse momentarily?

Participant: Walking by myself, for example. Something could happen to me and it scares me like someone could kidnap me or something like that. It stresses me out a lot and gives me major anxiety.

Interviewer: That worsens your condition, then. What about school, does it have a positive or a negative effect on you?

Participant: Positive because now that I've managed to control my anxiety a little bit, I'm able to focus more; and if I am distracted or stuck on something, I don't scratch myself anymore, I just don't do anything.

Interviewer: That's good, so it's seems like school is a big help for you. Focusing on your school work seems to help you with your anxiety, depression and attention as well, doesn't it? Is there any other thing you'd like to comment on?

Participant: No.

Interviewer: The first question I asked you was if you knew what attention deficit disorder really was. You told me it was difficult for you to concentrate and that you tend to move a lot; but in your opinion, what is the cause for it?

Participant: It's like a societal thing; it has a lot to do with who you're with. You sometimes have to pay a lot of attention to something you care about, but if you think school's boring and you hate studying, you start thinking of other stuff.

↳ promotes SELF BLAME (self stigma?)

Interviewer: Do you think that could be the cause? Do you think your surroundings could cause it? Like you said, if something is boring or ...

14

* misinformation! may be exacerbated by env., but is a neurobiological dx.
* what might he think if he knew bio?

TRAUMA

TRAUMA & CO-MORBIDITIES
ADHD ex. amplified?

catastrophizing
invasive thoughts

T2

T2

ID

↳ anxiety = bad ADHD sx

poor self esteem via misinformation

T9

T13

T10

Self stigma bc belief is child can control the ADHD

Title: ADD002 Interview

Participant: Yeah, exactly.

Interviewer: Why do some kids suffer from attention deficit disorder unlike others?

Participant: Maybe because they can't focus on the things they're interested in.

Interviewer: Okay. It's easier for some children to focus on what they're interested in.

Participant: I have friends who focus on their interests really quickly but sometimes they have something they're interested in but they still get distracted.

Interviewer: Okay, but do they have attention deficit disorder too?

Participant: Some of my friends do. → Has people he can relate to!

Interviewer: Alright. Let me see if I'm missing something... If any of your friends here in Boston think that they have attention deficit disorder, what would you tell them or which recommendations would you give to them to get help for it? Where would you tell them to go?

Participant: I'd tell them to do something active so they don't feel the need to focus on the problem.

Interviewer: Like a sport?

Participant: Like a sport, or playing cards with their friends; like they do with me, a way to distract themselves and not think about it.

Interviewer: What games do you like to play?

Participant: Uno.

Interviewer: Really? So do I, but I always lose. Thank you so much, it was a great pleasure to talk to you about your experiences, they really are unique. Thanks for participating, especially since you told me you don't like talking about these kinds of things. I'm going to turn off the recording now.

T6

↳ Prefers distraction
over confronting
various comorbidities
↳ maladaptive if
taken too far

coping
preference/
advice to other
kids

Appendix C

Thematic Worksheet for ADD002

1/12/20 ADD002

THEMES		COPING METHODS
T1	↑ knowledge of ADHD as helpful and/or damaging	• Uses sports to calm anxiety, p. 4
T2	Comorbidities considered influential in life	• Utilizes talk therapy
T3	Concern that tx. will impact friendships	• Tries to focus on one thing at a time, p. 7
T4	Appreciative of medication	• Tries to control the situation when possible, and tries to let go of control of situations when it can't be controlled
T5	Semi-active role in treatment	• Utilizes peer social support
T6	Dislike (but uses) talk therapy	• Distracts himself w/ friends to avoid thinking (-> things)
T7	Trauma as a barrier to tx.	• Self harm
T7.5	Navigating healthcare system as barrier to tx.	
T8	Finances as a barrier to tx.	
T9	Poor self esteem due to ADHD / Felt abnormal	
T10	Self stigma present (via meds and symptoms)	
T11	Concern/Worry about the future	
T12	Cultural stigma against ADHD	Turned into / Presented as bullying
T13	Attributes ADHD to environmental causes, NOT the biological model (4th, 5th grade)	
AGE: 15 AGE @ DX: ~10 AGE @ TX:		
GENDER: Male LANGUAGE: Spanish		
WHO DX? WHO SPOKE W/ ADOL? Teachers (and mom?)		
WHO NOTICED SX? Teachers		
SERVICES: IN PUERTO RICO: psychologist, psychiatrist / meds		
IN BOSTON: special ed., meds		
PC COMM IMPRESSION: Mom and son go to appts together and adol participates but mom has the final say. Doesn't mention comm much, but knows a lot about family finances and hardships, suggesting that they talk about these barriers (if not ADHD).		
INSIGHT IMPRESSION: Connected making (-> ex of ADHD and comorbidities to grandpa's death. Seems very aware of the problem's ADHD causes, but even more aware of the role of depression and anxiety in his life and how the environment affects them. Is concerned about ADHD ex and his future job prospects.		
AUDIO IMPRESSION: Seemed to take interview seriously		

Adolescent Care Engagement Qualitative Interview Codebook

Last updated by NZ on 2/24/2020

Code	Description	Example from data, optional
ADHD Diagnosis	Adolescent describes the ADHD diagnostic process.	
Barriers to diagnosis	Adolescent describes perceived barriers/issues they experienced in obtaining their diagnosis.	
Dismissive family	Adolescent describes how unsupportive or dismissive their family was about (1) the process of being diagnosed with ADHD or (2) their ADHD diagnosis.	<p>Participant: I've known I had ADHD and I've been telling them for quite a while. They never believed it but I knew I had it. So, like, I didn't care because I didn't think it was nothing serious.</p> <p>Interviewer: So, what did they say when you told them that you had ADHD?</p> <p>Participant: They were like, "I don't think so," or something like that.</p>
Diagnostic process	Adolescent describes how they were diagnosed.	
Age of diagnosis	Adolescent relays to the interviewer the (1) age they were when diagnosed with ADHD or (2) that they do not remember at what age they were diagnosed.	<p>Interviewer: All right. So how old were you when you were diagnosed with ADHD?</p> <p>Participant: Um... I was in uh, kindergarten I think.</p>
Paediatrician Evaluation	Adolescent describes being evaluated by their paediatrician to obtain a diagnosis.	<p>Participant: Yes, I was in the doctor's office and she walked in and she just told me. I mean it didn't really change anything.</p> <p>Interviewer: Do you remember why you were there in the first place?</p> <p>Participant: No. I think it was just a regular physical. I don't really remember. I might have been recommended for one of the checkups to see if I had it or not.</p>
Specialist Evaluation	Adolescent describes seeing a specialist (e.g. psychiatry, psychology, neurology, developmental paediatrician) to obtain a diagnosis.	I think it was my psychologist the first person to tell me, but the person I actually remember telling me is my mom. She was straight forward and told me what I had, and I just said "Okay". That's how it happened. I don't remember any names or anyone in particular, though.
Unspecified provider	Adolescent reports being diagnosed by a provider but does not specify what kind of provider.	<p>Interviewer: Yeah, um... So, like, to start off, who told you?</p> <p>Participant: The doctors.</p>
Emotions related to diagnosis	Adolescent describes how they felt about receiving their diagnosis or currently feel about their diagnosis.	
Undisturbed, Untroubled	Adolescent describes feeling undisturbed, untroubled or at ease by their diagnosis. This may sound like, "I didn't think it was nothing serious," or "it was no big deal."	I wasn't confused or scared. I was like okay. It was not a big deal for me.

Facilitators to diagnosis	Adolescent describes the perceived facilitators/facts that they feel helped them obtain their ADHD diagnosis.	
Adolescent noticing symptoms	Adolescent reports noticing their own symptoms before diagnosis.	I've been known I ADHD and I've been telling them for quite a while, they never believed it but I knew I had it. So, like, I didn't care because I didn't think it was nothing serious.
Family members noticing symptoms	Adolescent describes family members noticing their symptoms as a facilitator to treatment.	Interviewer: Like, who could tell that maybe you might have ADHD? Participant: My sister, yeah. My sister or my Aunt [name].
Parent(s) noticing symptoms	Adolescent reports parent(s) noticing their symptoms.	Interviewer: And it was your parents that noticed that your leg was really shaking or was it like a teacher at school? Participant: It was my parents.
Teacher feedback	Adolescent describes how feedback and communication between (1) themselves and a teacher or (2) their parents and a teacher facilitated a diagnosis.	Interviewer: 5 years. You're currently in 9th grade, so that means you were in 4th or 5th grade when that happened. So, what did you or your teachers notice? Participant: That I couldn't concentrate, that I'd just look at my classmates and didn't do anything. Interviewer: Alright. Who told you or your mom that you had attention deficit? Participant: My teachers. Interviewer: They were the ones who told you. Participant: Yes.
ADHD Effects on Relationships	Adolescent describes how their ADHD has affected relationships in their lives.	
Adolescent reports no connection between ADHD and relationships	Adolescent reports no connection between ADHD and parent, family or peer relationships.	Interviewer: Oh. How is your relationship with your sister and your brother and stuff? Participant: Not that good. Interviewer: Has your ADHD affected that do you think? Participant: No.
Adolescent-parent(s) relationship	Adolescent describes how their relationship with their parent or parents is positively and/or negatively affected by their ADHD.	It affects [the relationship with my parents] in a good way, because, you know, like, my mom, like, can know what I need, like, help and all. And she... Like, whenever we go to the doctors, she can explain to them, like, what I do...what I do at home. And, I dunno. It's just... We're good.
Overall family dynamic	Adolescent describes how their overall family dynamics are positively and/or negatively affected by their ADHD.	
Adolescent reports no connection between ADHD and family dynamics	Adolescent reports no connection between ADHD and family dynamics.	Interviewer: When you go to your doctor, you say that you go in and talk. What do you usually talk about? Participant: How my day is, things that I need help with, problems with my family, stuff like that. Interviewer: Okay. Do you feel any of those problems that you talk about are usually related to you having ADHD or are they separate? Participant: They're separate.
Causes tension	Adolescent describes how their ADHD symptoms has caused tension in the family.	Interviewer: So how does your ADHD affect your relationship with your family, like your parents?

		Participant: Um... sometimes I like... mean... I can't... I mean I'm less um, not as respectful at times, like I just say the first thing that comes in my mind. Like I just say like the wrong stuff sometimes. [...] The relationship could be better, I think.
Peer relationships	Adolescent describes how their relationship with peers is positively and/or negatively affected by their ADHD.	
Bullying	Adolescent describes being bullied by peers.	We weren't even friends anymore; really, he treated me badly. He started hanging out with other people because he said I had "issues".
Difficulty making friends	Adolescent expresses difficulty in creating new relationships because of their ADHD.	People look at you different, and it's kind of embarrassing but it's just like, I feel like because I have certain issues with my ADHD, I don't meet new people.
Emotional reactivity	Adolescent describes being emotionally reactive to provocation due to their ADHD.	And the fact that I have a strong character and a problem with my anger, I get angry very easily, [the medication] also helped me with that. It wasn't easy to bother me anymore so I never got to a point where I would react inappropriately. I was paying more attention in school, keeping calm, not giving in to provocation.
Losing friends	Adolescent describes (1) actually losing friends or (2) worrying about losing friends due to ADHD diagnosis, treatment or symptomology.	The thing is that, before, I used to always talk to my friends in class no matter if the teacher was talking. But then, like I said, I say hi to them and stuff but then I still have to continue paying attention. [...] I'm worried that if I ignore them, I will be alone.
Positive relationships	Adolescent describes their experience of ADHD as having a positive impact on a peer relationship(s).	I tell my friends that I have it but they just don't say anything because, like, they know that, like... Because I tell them, like, "Oh, I take pills, like, to control myself. That's why sometimes I'm not like guys...those guys." Like, loud or whatever. And some days I'm, like, just quiet. And they're just like, "Oh, then just keep doing that so you can focus." He said it was nothing to be ashamed of, and it was like...but I feel ashamed sometimes, and then when people that don't even have it... He said, "Do you feel ashamed being around me?" I said, "No, because you talk to me like I could actually get you," and I'm still friends with him to this day.
Sibling relationships	Adolescent describes how their relationship with siblings is positively and/or negatively affected by their ADHD.	Interviewer: How do you feel about [your brother] having ADHD? Participant: I don't know.
ADHD Functional Impairment	Adolescent describes impact of ADHD on their own behaviour, emotional, cognitive and social functioning.	
Adolescent stress from ADHD	Adolescent describes how ADHD symptoms/treatment cause them stress.	Yes. I talk really fast, so because I talk really fast, I get misunderstood a lot; or when they'll be like, "What'd you say?" I'm like, "Never mind. I don't want to say it no more." I was like... I would say, "Never mind. I don't want to say it." Like, "Never mind," because I'm already mad about it—not really mad. I'm just aggravated,

Effects of ADHD symptoms on learning	Adolescent describes their symptoms interrupting or affecting their academic learning.	When I realized it was very difficult for me to focus in school and started getting bad grades.
ADHD Knowledge	Adolescent describes the extent or source of their knowledge about ADHD.	
Wish for ADHD information earlier	Adolescent describes wishing they had known about ADHD or specific aspects of having ADHD (symptoms, treatment) earlier	I would've... I learned that apparently some people with ADHD like me can do this thing called "hyperfocus". I'd like to know if there are things we can do that other people can't or things that we need to do that others can't. I definitely would've loved to know that beforehand in order to know that I was able to do something different, but since I didn't know, well, I didn't do anything about it.
Knowledge about ADHD origin	Adolescent describes mostly accurate beliefs about what causes ADHD.	<p>Interviewer: ... in your opinion, what is the cause for [ADHD]?</p> <p>Participant: It's like a societal thing; it has a lot to do with who you're with. You sometimes have to pay a lot of attention to something you care about, but if you think school's boring and you hate studying, you start thinking of other stuff.</p> <p>I asked questions, um, and researched it — about how my brain works and stuff like that. I basically asked ques... like, just like, researching it, asking my mom, like, "What's wrong with my brain?" Or, "What's different with my brain? What's different from a regular person's brain and from, like, not...being not like a regular person?" Well, it's different from the ADHD brain. It's that a person, like, does not have ADHD. Like, different in spots. It's like...not like...not my communication, but you see how I learn and how I think is different. So, I think, like, I'm a little faster, and most people would not think it's, like...it's fast. They think you're just a little, like, slow or something.</p>
Knowledge acquisition preference	Adolescent describes where they like to get information about ADHD.	Doctors tend to give flyers no one ever reads. It's true; no one will read them unless they're very bored and have nothing else to do. I feel like sending emails or texts are better for people with ADHD, and it's a better way because people will feel interested in checking them out, they'd be like "Who is this person texting me? I don't have their number on my phone" or "Whose email is this?" It's a great way to spread awareness about ADHD.
Misinformation or misconceptions about ADHD	Adolescent describes things they have learned about ADHD that are known not to be true. They may also provide the source of this information.	When I have sugar, I get very hyper. Yeah, so, yeah. I think that's another thing too. Like, if...if, like, if I have sugar, I'm gonna be very hyper.
Sources of knowledge	Adolescent describes how, where and/or from whom they learned about ADHD.	
Family previous experience with ADHD	Adolescent describes how their family's experience with ADHD served as a source of knowledge.	Well, the way I remember it going was most of the people in my family had an idea that there was something wrong with my attention because it was bad. And my dad's the same way too and so is my mum. So, a lot of people just kind of figured.

Family to adolescent knowledge	Adolescent describes receiving information from their parents or family members.	Interviewer: Okay. So, who has helped you make treatment decisions? Participant: My doctor and my mom
Internet	Adolescent describes learning about ADHD through the internet.	I had to look it up on Google. My mom told me it was maybe the meds. I grabbed the meds fast and looked up on Google to see the side-effects. The first thing that popped up was major headache. That's why I don't like side effects meds.
Lived experience	Adolescent describes acquiring knowledge about ADHD and symptoms by living through or reflecting upon their experiences.	Not really. I mean I kind of knew a little bit about it because you just hear about it. You kind of know what it is basically and I had lived it.
Other people (unspecified)	Adolescent describes learning about ADHD from a person, otherwise unspecified in this codebook.	No. Like, I heard... I heard other people talk about, like, how they... they used to have it when they were younger, and then they were saying, like, how now they don't have it anymore. So I'm just like, well, we'll see if that happens to me as well.
Peer to peer knowledge	Adolescent describes receiving information from other adolescents with ADHD.	Well, it's not even that. It's just because I hear from all my friends who have ADHD and they said the same thing and that happened to me too.
Professionally provided information	Adolescent describes receiving information about ADHD from a professional i.e. psychiatrist, PCP, therapist, etc.	Interviewer: Who told you, the doctor? Participant: Yes. Interviewer: What kind of things did she tell you? Participant: She told me what was related to it. So, she told me that this happened because of this. Like not being able to pay attention, she said that was because of ADHD. I always had problems focusing. I could focus but I had a short attention span and she told me that was. Well, what she thought was ADHD.
School, community learning	Adolescent describes receiving information from others in school (classes, informal conversations, teachers, lectures) or in the community, support groups, people in the community without ADHD.	They taught it in our school, like about it. So, a lot of people kind of knew what it was. A lot of kids in my school. So, the thing was too, there probably is if I found that I had ADHD when I was younger. Because by the time I found out, everyone was older and plenty of plenty of people had already found out they had ADHD.
Self-taught knowledge	Adolescent describes learning about ADHD on their own using resources such as books.	Interviewer: Where did you hear about it from, like what kind of sources? Participant: Friends, some books or school. I don't really remember exactly but I remember that I've had the information before.
ADHD Treatment	Adolescent describes feelings/facts surrounding their own ADHD treatment.	
Adolescent unsure of treatment specifics	Adolescent describes a form of treatment but does not have the vocabulary to describe treatment in an explicit manner.	Interviewer: Okay. Do you know what other treatments that you've been having, like the therapy, the medication, any extra help at school? Are you taking anything for the ADHD, the medication the Ritalin, the Adderall, any of that? Participant: I can't really tell. I don't know.
Age treatment began	Adolescent describes at what age they began treatment.	I had a IEP since...well, I remember since fourth grade.
Barriers to treatment	Adolescent describes perceived barriers/issues they experienced in obtaining or maintaining treatment.	

Accepting ADHD as immutable	Adolescent describes accepting their ADHD as part of them in such a way that the nature of ADHD and the symptoms are unlikely to change.	I take it for school and I have friends who take it all the time but I don't... I mean not focusing is just like a part of me.
Feeling forced	Adolescent describes feeling forced into getting treatment and how it demotivates them from it.	I mean... I've argued, that... We would argue sometimes, like, I don't want to take the medicine, but she says I have to, like, and then she ends up...she ends up winning. So, like, it's not even worth it.
Financial barriers	Adolescent describes financial struggles as a barrier to care.	Like less money for like, transportation or, like, food where we're going.
Getting prescriptions	Adolescent describes issues obtaining their ADHD medication.	Like we have to pay for the medications. We don't have a lot of money and we have to pay about \$7 for each medicine because they're not covered by the insurance.
Inconvenience of appointments	Adolescent describes how going to appointments for their ADHD is a hassle or inconvenient.	I mean, today I have four appointments total. That's so I can go to school. I just had one with [psychiatrist name omitted] and then, like yeah, I don't even know where I have to go next, but if I didn't have, like, ADHD or anything I wouldn't have to come here, and I would have had just a normal day, but, like, always it's going to these appointments, you know...
Scheduling appointments	Adolescent describes issues scheduling appointments for their ADHD care.	When we first moved here it was really hard to find the medications. [...] As well as a psychiatrist.
Transportation issues	Adolescent describes how problems around transportation prevent them from engaging in treatment.	Right now, it's really cold. Like, me and my mom, we waited a long time for the bus. And, like, we were about to go home, but...but we still waited.
Waiting	Adolescent describes how having to wait demotivates them from treatment.	I'm mostly talking about patience, this, that. Mostly when you have to be waiting. That's what I hate so much.
Worries about social life	Adolescent expresses worry, concern or hesitation about the consequences of treatment (including medication) on their social life.	And I feel like when I drink the medicine, I feel, like, I feel antisocial, like I don't talk to anybody. That's it.
Facilitators to treatment	Adolescent describes the perceived facilitators/facts that they feel helped them obtain and/or maintain treatment.	
Child cooperation in treatment	Adolescent describes appreciating their treatments.	Yes, yes. The medication definitely helps. School, I mean LC is just extra time almost. It's just like a "Help." It's like a room with just a bunch of teachers and they help you with your homework and your classrooms and studying. Yes, it's helped.
Parent introduction of treatment	Adolescent describes parent introducing teen to a form of treatment, whether the parent explains treatment explicitly or not.	My dad told me that someone was going to come pick me up and take me places to go eat and talk. I was like, "Okay," and then it started. Then I went with him and we started going places and talking and buying food and eating.
Provider support and guidance	Adolescent describes how support and guidance from their providers facilitate treatment and care.	Well, when I got treated, I don't know if this is common or not, but we didn't stay on one medication the whole time. We tried different things and we would meet every month or like three weeks. Like we met pretty frequently and we would talk about it. Then we would try new stuff and see what worked and what didn't work. That really helps because I feel like I got medication that was perfect.

Reporting no barriers to care	Adolescent reports no barriers to care.	Interviewer: That's awesome. Do you think there's been any difficulties getting care, treatment or it's been affected by anything? Participant: No. No difficulties, it's been pretty easy.
Shared decision making	Adolescent describes making treatment decisions together with their parents and providers.	For example, I'm taking Zoloft which is for my anxiety, but before being prescribed, I asked about the symptoms and all, to see if it would actually do me any good. My mom's the one who says if it's alright, but sometimes she'll say she doesn't think so, and she asks for another options.
Sibling's ADHD	Adolescent describes having a sibling with ADHD facilitated their own access to treatment.	Interviewer: So do you feel like since your brother has ADHD, you know, your mom already had to help... Get help training him and everything like that, do you feel like it helped you or made it harder for you? Participant: No. Interviewer: Which one? Participant: It made it... It didn't make it harder, it made it easier.
Transportation	Adolescent describes having transportation as a facilitator to treatment.	I take kind of like an Uber for free. Just for appointment, though.
Methods of treatment		
Medication	Adolescent describes using medication as a treatment method.	Once they found that out, they said... Um, like, I got put on medicine, but then they had me on a lot [emphasis] of medicine, so I'm... Now, this is great, they have me on this medicine, but that made me gain weight. So, the medicine made me gain weight, but now that it's in me, I don't really...because I can get diabetes from it, like, it balanced out a little bit.
School services	Adolescent describes types of treatments and accommodations that they receive at school.	Like, we have a plan. I have a IEP, and then, um... Just, like, I have, like, tutors and everything that they just...I just started working with. And I have...I have a school bus from, like... It drop drops me off home, like, in front of my door.
Therapy	Adolescent describes using therapy as a treatment method.	Sometimes I don't like talking to people about my concerns and stuff like that, like psychologist talk to me about these things, and I don't like that. But I need to vent so I do have to talk.
Motivations to participate in treatment	Adolescent describes their motivations for participating in treatment.	Interviewer: Can you give me an example of something that was positive about the process of you getting care? Participant: Positive? Interviewer: Yeah. Participant: Um, focused and more mature.
Trial and Error Treatment	Adolescent describes the process of trial and error when using different services to find the right fit.	Well, when I got treated, I don't know if this is common or not, but we didn't stay on one medication the whole time. We tried different things and we would meet every month or like three weeks. Like we met pretty frequently and we would talk about it. Then we would try new stuff and see what worked and what didn't work. That really helps because I feel like I got medication that was perfect.
Treatment decisions	Adolescent describes how treatment decisions were made and ultimately who made them.	The doctor was the one who recommended medication. We didn't really need any convincing. My mum just kind of does whatever

		the doctors say and I just kind of do the same because they know more about it than I do, so.
Adolescent Insight	Adolescent describes various experience related to ADHD with the presence of, building of or lack of cognitive insight.	
Adolescent not curious	Adolescent lacks desire or curiosity to learn new or more information about ADHD.	I mostly don't care about ADHD, to be honest.
Building insight	Adolescent describes various experiences in which their insight into their ADHD increased or improved.	For example, when I came here, people started talking to me about it; they'd tell me that some people are very smart but sometimes they need a bit of help. Depends on the person's level of ADHD or how long they've suffered from it. But I mean, honestly, ever since I was 8 or 10 years old, I didn't pay much attention to these things because I feel like they always repeat the same things. However, no matter the hospital I go to, whether I change hospital or not, they always give me information if I want to know more about it and try to answer my questions.
Autonomy seeking	Adolescent describes their experience building insight through autonomy-building and autonomy-seeking behaviors or thoughts that are related to/impact their ADHD.	For example, in class I always concentrate and try to pay a lot of attention. I like participating in class even without the medicine, because I deliberately stopped taking the medicine for like 2 days [...] to see how if I functioned the same without it and yes, I still felt normal, calm, I participated in class, took notes and all, so I do feel like I don't really need the medication.
Lack of insight	Adolescent describes various experiences related to ADHD with the lack of cognitive insight.	
Presence of insight	Adolescent describes various experiences related to ADHD with the presence of cognitive insight.	
Detailed understanding of treatments	Adolescent describes details of their treatment that show deep understanding	Methadone for the night and the morning. Clonidine and that little pink and white med for sleeping. Mostly at night. The one I take in the afternoon I think, is Clonidine. And the one I take in the morning is those two gigantic pills, and methadone, I think. The 20 or 30mg.
Evidence of reflection on effective treatment	Adolescent reflects on the effectiveness of treatments on their ADHD symptoms.	Yes, yes. The medication definitely helps. School, I mean LC is just extra time almost. It's just like a "Help." It's like a room with just a bunch of teachers and they help you with your homework and your classrooms and studying. Yes, it's helped.
Evidence of treatment preference	Adolescent describes preference for a type of treatment (i.e. sports, therapy, music, etc.).	I had a psychologist with whom I used to talk. Then, they prescribed me some medicine for my anxiety but they didn't work, they had no effect on me. [...] The psychologist helped me more than the medicine.
Recognition of environment effect on ADHD symptoms	Adolescent recognizes and connects the impacts of environment effects on the presentation of their ADHD symptoms.	Interviewer: Is there anything that might happen in particular that stops you from focusing or makes it really hard for you to focus? Participant: When something else is going on. Like something else funny, distracting, stuff like that.
Recognition of symptoms	Adolescent describes and/or recognizes their own ADHD symptoms.	That it's not a good thing; when you have attention deficit you're not able to concentrate on one thing at a time and you're always

		moving around. If someone talks to you, you look the other way and not pay attention to what they're saying.
Understanding how others may experience mental illness	Adolescent describes describe how others might be processing and/or experiencing a mental illness (i.e., ADHD, depression, PTSD).	And then, a lot of people do not know what they have, because they're never able to talk about...they never even got the chance to talk about it. Nobody ever asked them how their day is going or how are you doing, and that could be a really important thing for somebody that has ADHD.
Understanding how their symptoms impact their own life and others	Adolescent describes how their ADHD symptoms (1) impact their own life and (2) might make other people feel.	Interviewer: Do you feel like your closer to your mom because you have ADHD or do you feel more distant from your mom because you have ADHD? Participant: [...] Distance because of the ADHD. Interviewer: Okay. What makes you feel distant about it? Participant: Because the ADHD makes me act like a concern, like a different way.
Understanding of ADHD as lifelong disorder	Adolescent recognizes that ADHD symptomology may persist and/or change over their lifetime.	Interviewer: Is there anything that you feel would help you more that you're not currently getting? Participant: For now, I'm good. Interviewer: Okay. Well, you said, "For now." Is there something that you think might happen? Participant: I dunno. Some days, just... Because I still have three years left of high school, so I don't know what's gonna happen later on,
Adolescent Response, I don't know	Adolescent replies to an interviewer's question with, 'I don't know.' This may represent that they genuinely do not know information, or are unwilling to share the requested information.	Interviewer: What would help you feel more involved in your treatment? Participant: I don't know.
Adolescent Symptom Management	Adolescent describes their process and strategies of managing/coping with their own ADHD symptoms (excluding the taking of their medications).	
Having and prioritizing goals	Adolescent describes managing their ADHD by prioritizing larger goals in their life.	It's like I don't care about things that are not important for me. For example, I don't think that this matters as much as school, or graduating or having a house, things like that. Now I know how to separate what's important from what isn't and what I should care about and what I shouldn't.
Hobbies, preferred interests	Adolescent describes engaging in a hobby or utilizing preferred interest to manage their ADHD	Interviewer: Do you take anything that helps you focus? Participant: No. I mostly just be focused on the phone, or YouTube seeing more beats on the piano I could do. I'm into music; and science, and crafting.
Identifying triggers	Adolescent describes identifying situations that trigger ADHD symptoms	When they mocked me, sometimes it bothered me, other times not that much. That's why earlier I said I encountered some problems because sometimes it bothered me and sometimes it didn't. In 5th grade, I managed to stop caring about them and I learned how to ignore them. I am grateful for my medication because it really helps me there

Mindfulness	Adolescent describes being conscious and aware of their symptoms and practicing mindfulness (mindful breathing, focusing on sensations, meditation, redirecting their attention).	Like if I am anxious, I try to be like “Okay, I have to focus on one thing at a time”
Perspective taking	Adolescent's describe how their ability to take or consider the perspective of someone else help them manage their ADHD symptoms.	ADHD is just, for me it's normal. Like, like, if it was, like, something, like, more worse, then yeah I'd be more worried and more scared, but it's just hyper, that's it. [...] Like, if they said I had Autism or something.
Physical activity	Adolescent describes how sports and other types of physical activity (i.e. hiking, camping) function as a type of symptom management.	Being active is always a good thing to do as well. Like me I'm hyperactive so I keep active by doing sports, like tracks or athletic things. So yeah, I feel good.
Reframing negative aspects of ADHD as positive	Adolescent exhibits using the coping skill of reframing negative aspects or thoughts their ADHD as, at least in part, something positive.	No. To me, ADHD, I feel like it's a good thing because it's like moving a lot keeps you from being lazy.
Separating self from ADHD symptoms	Adolescent describes separating their self/self-worth/self-identity from an ADHD symptom in order to manage their ADHD or personal frustrations.	I'm just aggravated, so I tend to say, “Never mind. Whatever. It's whatever, because you don't hear me because I talk too fast. That's not my fault. I can't help that.”
Taking breaks	Adolescent describes how taking breaks help them manage their symptoms.	I still have like, the stuff I'm interested in, I also have a short attention span with that. So, I've never watched like long videos or movies in one sitting. I always watch five minutes at a time and then pause it and then go do something else and then come back.
Utilizing social support	Adolescent describes how social support (via family members, peers etc.) has help them manage their ADHD.	Like a sport or playing cards with their friends; like they do with me, a way to distract themselves and not think about it. Everybody in my school, like, I know them, they know me. They try to help me. Like, even my friends, they give me advice, they're like, "Yo, come on. Get your grades up."
Valuing strengths	Adolescent describes activities and skills that they're good at as a way to cope with their ADHD.	In fifth grade I was picking so much fights. And a little bit in sixth grade. Then I changed since I went to [school name omitted]. And since I found out I was good at science; math, and crafting. Mostly, I'm good at everything.
Adolescent Symptoms	Adolescent describes their own symptoms, which might be related to ADHD.	
Anger	Adolescent describes an experience of anger that may be related to ADHD.	And the fact that I have a strong character and a problem with my anger, I get angry very easily, [the medication] also helped me with that.
Difficulty sitting still	Adolescent describes having difficulty staying in one place.	Because the only thing I know that I have ADHD is just can't stand still.
Distractibility	Adolescent describes being easily distracted.	And school, because like that's where I most get distracted.
Fidgeting	Adolescent describes a constant need to fidget.	Like, why my leg kept twitching?
Forgetful	Adolescent describes being forgetful or forgetting things as one of ADHD's symptoms.	It's hard to focus. Easy to forget stuff.
Hyperactivity	Adolescent describes being more active than is average	I was just, like, all hyper and everything.
Hyperfocus	Adolescent describes their preference to focus intensely on preferred tasks.	At school, it's weird because it's something I'm really not interested in. So, I just don't focus. So, I get sleepy when I'm not into anything and it's like first thing in the morning too.

Inattention	Adolescent describes not being able to concentrate or pay attention to their surroundings.	It's like, in class, I can pay attention for a good, like, five minutes before I just stop paying attention.
Increased energy	Adolescent describes having increased energy.	It's like I have a lot of energy, and sometime, like, that energy keeps me from focusing and remembering stuff.
Lack of focus	Adolescent describes lacking an ability to focus.	I've always had trouble in school. Trouble focusing, just generic stuff.
Non-Psychiatric Comorbidity	Adolescent describes non-psychiatric, physical conditions (i.e. asthma, diabetes) that they have in addition to ADHD.	I was a premature baby, so I was, like... my development was very, very slow, but then I used to be like, just running up, just up and down the stairs, like, just, like, acting kind of crazy because of my ADHD.
Psychiatric Comorbidity	Adolescent describes psychiatric conditions that they have in addition to ADHD.	
Anxiety	Adolescent describes experiencing symptoms of an anxiety disorder.	For example, if I scratch myself too hard, I sometimes bleed and they wanted me to do that. Here, I scratch myself because of my anxiety, but my friends here help me and they tell me not to do that. And I can do stuff with them like playing cards or things like that.
Depression	Adolescent describes experiencing symptoms of a depressive disorder.	At that time, I already had attention deficit disorder but then my grandpa died. From there I started having more attention deficit plus depression kicked in and I couldn't concentrate.
Talking fast	Adolescent describes talking very fast as a symptom of ADHD.	I talk really fast, so because I talk really fast, I get misunderstood a lot.
Violence	Adolescent describes an experience of violence that may be related to ADHD.	I used to fight almost every day because they used to enjoy bullying me a lot, especially in that school.
Adolescent Wellness	Adolescent describes various emotions and feelings towards their ADHD that impact their health and wellbeing.	
Acceptance of self	Adolescent describes accepting who they are with ADHD.	<p>Interviewer: Does having a diagnosis of ADHD affect the perception of yourself in any way?</p> <p>Participant: No. I was always this way, so it just kind of gives it a word for me to describe or call it.</p> <p>If somebody has it, they're still normal. They're still human. [...] ADHD is just something that people...some people have. It's, like, it's not really a bad thing, it's just... Just wanna, like, I... you can't control yourself or... or something else. But you could just tell people, like, "They're still... You're still the same as this person. Everybody's the same."</p> <p>Any person – like, there's some stuff that they can't do that you could do, and some stuff that you can do that they can't do, because they don't have it. And he said it's an advantage and a disadvantage sometimes. He said most things are an advantage and a disadvantage.</p>

Adolescent advocacy, empowerment	Adolescent describes (1) advocating for himself/herself as it relates to ADHD or (2) expressing feelings of empowerment related to advocacy.	<p>I'm fine. When I knew often, when I had ADHD, I started like thinking about it and solving my own questions. And like I solved it all for myself?</p> <p>No, I've never encountered any difficulties that kept me from getting my medicine. Only myself. Yes me, like I told you, I forgot twice when I wanted to... I was my only barrier. If one day I want to stop them, my doctor will recommend not to do so but she can't keep me from stopping. My only barrier here is myself.</p>
Aloneness	Adolescent describes feeling alone or isolated because of their ADHD.	<p>It's just like, people—they think you're stupid. They think you're just... I don't know. Like, I don't want to say they are but I think it's true; just people think, like, you can't do anything for yourself, just 'cause... And it's like, "You're just so hyper. You're just being...and that's all that is," and see, it's like, "You can't sit still," and just because you can't sit still, they treat you like you're crazy or that you're a psychopath. [...] What they do is, like, they make you feel that you're lesser...you're less of a person than somebody else is without it.</p>
Blame-shifting	Adolescent blames others for something wrong or inappropriate that they did.	<p>One of my friends, my brother's friend's mom, she thinks I was bullying her autistic son just because I'm big. I'm not mostly that bad. I'm just bored.</p>
Evidence of low self-esteem	Adolescent exhibits, either within a narrative they share or through thoughts/feelings they express, low or lack of self-esteem.	<p>Makes me think I can't do stuff. Lower... Um, lower my standards. Um, like...like I'll never get something done. Makes it hard to get started on tasks. Whatever, and it just makes me put a lot of things aside. [...] I don't think there's any way to help me.</p> <p>What they do is, like, they make you feel that you're lesser...you're less of a person than somebody else is without it.</p> <p>I'm in the higher one right now, because I...when I was little, too...but just being put in with that...that problem that I had, I felt stupid. Even people not calling me stupid, you can feel stupid.</p>
Evidence of self-esteem	Adolescent exhibits, either within a narrative they share or through thoughts/feelings they express, the presence self-esteem.	<p>Yes. You don't have to think different of yourself. Just because you have this thing doesn't mean you're not a person. You're still a person within you. It's just like you're special in a way. So, you don't have to think of it as a weakness or something wrong with you, just think about it as a good way. Like you're special in a way. So like you get more options in life.</p> <p>When I found out I had... that I was hyper or that I had or needed special education, it didn't really bother me, I just thought... I can say I felt somewhat special because I felt a bit different but not too different at the same time. I couldn't really tell very much, it's not like I felt like I didn't fit in or anything like that. I mean it's always been easy for me to talk to people and make friends, or connect and talk to other people pretty quickly, or even at school.</p>

		So, it never made me feel different or stressed or bad about myself.
Feeling heard, feeling related to	Adolescent describes others being able to relate to their struggle with (1) ADHD or (2) as a teenager as helpful in their ability to manage their own ADHD.	It was difficult. Like, one of my teachers actually have ADHD, so he knows where I'm coming from. He still has it though and he's my vocational teacher, and he actually understands what I'm going through and how it's affecting me. So, some people actually can relate...is a...very good to know people that you can, like...that have it and that you can relate to having it.
Frustration with parent(s)	Adolescent describes being frustrated or annoyed with their parent(s).	What could I say that would really change things, change something? I mean, mom said if I don't take my medication, I can't live in her house or something. Or like, because she doesn't, because I guess... I'm not well behaved or something.
Frustration with school	Adolescent describes being frustrated or annoyed with their school or school official (e.g., principal, teacher)	Participant: In school I'm not getting the help that I'm asking for. Makes me frustrated. Interviewer: And what usually happens when you ask for help. Participant: Um, teachers tend to ignore me.
Frustration with treatment	Adolescent describes frustrated or annoyed with treatment.	I mean, today I have four appointments total. That's so I can go to school. I just had one with [psychiatrist name] and then, like yeah, I don't even know where I have to go next, but if I didn't have, like, ADHD or anything I wouldn't have to come here. I would have had just a normal day. But, like, always it's going to these appointments
Parentification	Adolescents describes wanting to sacrifice things for themselves in order to help their family.	Participant: Like we have to pay for the medications. We don't have a lot of money and we have to pay about \$7 for each medicine because they're not covered by the insurance. [...] Like if I am anxious, I try to be like "Okay, I have to focus on one thing at a time" and when I am able to manage the situation and forget about it, well I don't have to take medicine anymore and I don't have to buy them. Interviewer: Because of the money, I get it. So you get to handle your situation and what you're going through.
Perceived strengths	Adolescent describes aspects of themselves that they perceive as strengths.	I mean it's always been easy for me to talk to people and make friends, or connect and talk to other people pretty quickly, or even at school. So it never made me feel different or stressed or bad about myself
Perceived weaknesses	Adolescent describes aspects of themselves that they perceive as weaknesses.	Interviewer: Can you talk a little bit more about that, about what worries you? Participant: Like, if I'm gonna take [the medications], like, forever, and like, what if I'm, like, living by myself or something, and then I still have to take those. I'd probably be, like, just not responsible with them.
Adolescent's Future	Adolescent expresses hope or concern for their own future as it relates to their ADHD.	
Concern for future	Adolescent expresses or describes concerns about their future as it relates to their ADHD.	

Academic future	Adolescent expresses or describes concerns about their academic proficiency and success in the near or distance future.	So, if you have ADHD...say if you're ADHD, right? You be like, "Oh, you're..." Like, "Oh, you're stupid," or, "You just can't really have that," or, "You can't do that," or, like... I don't know. [...] I want to say college won't cover you because you have... I won't say colleges won't accept you because you have ADHD, but some college probably don't have the help that you need to succeed in college with ADHD. [...] Like, it stops you from going what you want to go after.
Professional future	Adolescent expresses or describes concerns about their future career prospects.	I'm scared of not being able to make it because of my lack of concentration. If I'm going to study Engineering, I need to focus on math which is really difficult not only to look at the graphs, but also the equations if I can't even concentrate.
Worry around needing medication as an adult	Adolescent expresses their concern or worry around having to continue the use of medication into adulthood.	Interviewer: And how did you feel when she told you that you'd have to take some pills for it? Participant: I was kinda, like, not sad, but I was like... Just, not...I was just worried, like, I was just asking myself if I was going to take it forever. I don't know.
Worry around persistence of ADHD	Adolescents describe worry or concern around the persistence of their ADHD symptoms into adulthood.	No. Like, I heard... I heard other people talk about, like, how they...they used to have it when they were younger, and then they were saying, like, how now they don't have it anymore. So, I'm just like, well, we'll see if that happens to me as well. I don't know. That's the only concern.
Hope for future	Adolescent expresses or describes hopes about their future as it relates to their ADHD.	
Education	Adolescent expresses having hope for their academic future.	Well, it concerned me because up until like the 7th grade, I never really had good grades in any class. Until I started taking the medication, was like the first time I've ever had good grades. So, it's definitely helped me when I think about my future because now I can see myself going all the way through high school, and after that whatever I decide to do.
Advice for Reducing Stigma	Adolescent describes suggestions for reducing the stigma around ADHD.	Just to tell them that you're no different than the person that doesn't have it. Like, your brain can work a little different from that other person's, but you're still a person. You might have disabilities that might affect you, but you're still a person. You're not lower than them; you're not above them. You're the same person. They can be above you at learning. Okay, yeah, that's about it, but you're the same person. You are who you are and that's not going to change.
Advice to Clinicians, Hospitals	Adolescent describes suggestions to clinicians, providers, etc. to improve treatment for ADHD.	Well talking to someone about personal, intimate stuff and not have their parent in the room because I feel like we, as teenagers and kids, sometimes feel uncomfortable talking about personal things when our parents are around. For example, when I was little it didn't bother me that much

		because my mom always had my back, but I've seen people—I know there are certain people who feel very uncomfortable with this. I think it'd be great to talk about that, like "What's bothering you?", "What can I do to help you?" or "We're here to help in case you want to talk to anyone about what's bothering you." Things like that that can make someone feel more comfortable to open up, feel relieved and trust you in order to help them feel better and less upset, less negative.
Advice to Other Kids and Parents	Adolescent describe suggestions to help other children/adolescent with ADHD and their families.	<p>You don't have to think different of yourself. Just because you have this thing doesn't mean you're not a person. You're still a person within you. It's just like you're special in a way. So, you don't have to think of it as a weakness or something wrong with you, just think about it as a good way. Like you're special in a way. So like you get more options in life.</p> <p>But, like, if you just tell him, like, "No, you're good. Like, you know... Like, just do you. Like, it might be hard sometimes to control yourself, but, you know, you've got your family, you've got teachers that can help you. So, really, don't really stress...don't stress about it at all."</p>
Attitudes Towards ADHD	Adolescent describes their own attitude towards ADHD (or the symptoms) or their experience facing others' attitudes towards ADHD.	
Adolescent Attitudes	Adolescent describes their own attitudes about ADHD.	
Anger, Frustration	Adolescent describes feeling angry or frustrated towards ADHD.	<p>Interviewer: Okay. How do you feel about having ADHD at all? Like, at school or at home?</p> <p>Participant: Like, frustrated.</p> <p>Interviewer: Can you talk to me about an experience that made you frustrated?</p> <p>Participant: Like, school, home, and... like, I just get, like, time to do homework 'cause I don't really know how to do it. 'Cause it be hard.</p>
Desire to overcome symptoms	Adolescent describes a desire to overcome their ADHD symptoms.	<p>Interviewer: Got it. Is there a reason that you recently started trying harder in school?</p> <p>Participant: Um, um, because, like... Um, because, like, there's only, um, one chance. And I'm trying to, like, learn everything and not go back and try to learn it, just learn it while I'm there.</p>
Disdain	Adolescent describes feeling disdain towards ADHD.	<p>Interviewer: What's your opinion on attention deficit disorder?</p> <p>Participant: That it's not a good thing; when you have attention deficit you're not able to concentrate on one thing at a time and</p>

		you're always moving around. If someone talks to you, you look the other way and not pay attention to what they're saying.
Dismissiveness	Adolescent describes feeling indifferent or dismissive towards ADHD.	It's just one of those things where like, it's like with school and my grades. If I fail a class, I fail. I just don't really think about it that much.
Feeling special	Adolescent describes how they perceive having ADHD as something that makes them "special" in a positive way.	I can say I felt somewhat special because I felt a bit different but not too different at the same time.
Unconcerned, indifference	Adolescent describes feeling unconcerned or indifferent towards ADHD.	Interviewer: Do you like having that word [ADHD] to describe it or it doesn't really matter to you? Participant: Yes, it doesn't really change much. I mean it's just like learning a new word. I mean if you go to your friends and you're just like, "I have ADHD," no one's really going to care because it's not a big deal.
Family and community attitudes	Adolescent describes family and community beliefs and attitudes towards (1) ADHD in general and (2) their own ADHD.	
Acceptance	Adolescent describes their family or community's acceptance of their ADHD.	Well, the way I remember it going was most of the people in my family had an idea that there was something wrong with my attention because it was bad. And my dad's the same way too and so is my mum. So, a lot of people just kind of figured. Yes, it wasn't really any like bad feeling towards it. It was just like I had it, you know. Being pulled after class, being told, like, "We can talk about it." People that don't have ADHD understanding where you're coming from, and just being somebody to come to I think, when people need to brighten up somebody's day. Not just about my day, but just being able to talk about it—that kind of brightens up my day, that...make sure that she'll looking out for me, but somebody has my back,
Medication Attitudes	Adolescent describes their feelings towards ADHD medication.	
Ambivalence	Adolescent expresses ambivalence towards medication.	Interviewer: And how did you feel when she told you that you'd have to take some pills for it? Participant: I was kinda, like, not sad, but I was like... Just, not...I was just worried, like, I was just asking myself if I was going to take it forever. I don't know. I mean, the thing I want to improve is the medicine. I mean, I've been on medicines for a long time, so... Medicines help me to stay focused in school...
Anger, Frustration	Adolescent describes feeling angry or frustrated towards their ADHD medication.	Interviewer: Tell me about your feelings towards ADHD. Participant: I get mad. Interviewer: What makes you mad about it? Participant: That I have to take medicine.
Gratitude	Adolescents express feeling grateful for ADHD medication	In 5th grade, I managed to stop caring about [bullies] and I learned how to ignore them. I am grateful for my medication because it

		<p>really helps me there... The medicine sometimes helps decrease my energy to make me less active than I usually am. And so, I was able to ignore them and be there as much as I can for my brother because he was getting bullied a lot since he couldn't stand up for himself.</p> <p>Without those pills, I don't even know. But they just help me a lot, like, concentrate and everything.</p>
Parent attitudes	Adolescent describes how they perceive their parents' attitudes towards (1) ADHD in general and (2) their own ADHD.	<p>Interviewer: And what do they usually say?</p> <p>Participant: They said, like, they could if I, like, if I work hard or just be a little more responsible, which is, I dunno, just stupid.</p> <p>I've been known I have ADHD and I've been telling [my parents] for quite a while, they never believed it but I knew I had it. So, like, I didn't care because I didn't think it was nothing serious.</p> <p>Interviewer: And how about, um, your mom, do you know how she feels about you having ADHD?</p> <p>Participant: No, well she helps me so she should... It shows that she cares about me.</p>
Peer attitudes	Adolescent describes how they perceive their peers' attitudes towards (1) ADHD in general and (2) their own ADHD.	<p>Interviewer: Tell me about feelings or attitudes of people around you about ADHD. So, what do you think other people feel about ADHD?</p> <p>Participant: Like they don't care.</p> <p>Interviewer: What makes you think that they don't care?</p> <p>Participant: 'Cause they still my friends. They really don't care.</p>
Stigma	Adolescent describes stigma they have personally faced or seen towards other people (kids, teens, adults) with ADHD and their families.	
Adolescent reports no connection between ADHD and stigma	Adolescent reports no connection between ADHD and stigma.	<p>Interviewer: Have you seen someone being treated badly because they have ADHD?</p> <p>Participant: No. People don't care too much about ADHD.</p> <p>Interviewer: Why do you think that is?</p> <p>Participant: Because they're young.</p>
Cultural stigma	Adolescent describes cultural stigma related to their ADHD that they have experienced.	For example, if I scratch myself too hard, I sometimes bleed and [my friends in Puerto Rico] wanted me to do that. [In Boston], I scratch myself because of my anxiety, but my friends here help me and they tell me not to do that. And I can do stuff with them like playing cards or things like that.
Medication stigma	Adolescent describes medication stigma related to their ADHD that they have experienced or endorse.	<p>Like, sometimes, people call you stupid because you take certain medicines—that's why I want to get off the medicine now, because I've been on them for a long time.</p> <p>Participant: If they are like 17 or 18. It's crazy. They on drugs then.</p> <p>Interviewer: What kind of drugs?</p>

		<p>Participant: Crazy drugs. It's a metaphor I use. When I see crazy people. I say they're on drugs.</p> <p>Interviewer: Are those people with ADHD that are on the crazy drugs?</p> <p>Participant: I don't know. I just call them crazy.</p>
Public self-stigma (internalized), negative self-image	Adolescent expresses acceptance of or agreement with the prejudices around them.	<p>Bad because on top of not being able to focus on things I have to tell people about [my ADHD] too, as if it should help me or make me forget that I have attention deficit disorder.</p> <p>He said it was nothing to be ashamed of, and it was like...but I feel ashamed sometimes...</p> <p>Probably being in special ed class, not like a... I'm in the higher one right now, because I...when I was little, too...but just being put in with that...that problem that I had, I felt stupid. Even people not calling me stupid, you can feel stupid.</p>
Public stigma (externalized), concern with public attitudes	Adolescent describes stigma expressed as prejudice or discrimination.	<p>They look at me and how I am. Let's say if I have a friend that have known for many years, he'll know how I behave myself, and then if I am showing a lot of attention deficit signs, he'll think that I'll be like another special kid, I won't be normal.</p> <p>I've had a few problems here and there also because of that "special" label that I have, attention deficit or special education.</p> <p>Interviewer: Like people that might like judge you, or blame you or, you know, treat...treat you differently at all because you have ADHD or because you take ADHD medication?</p> <p>Participant: I think the teachers might.</p> <p>Interviewer: How so?</p> <p>Participant: Like, they would rather help this... Another student then help me but just like... They'd rather just spend their time on someone else or like, whatever they say to me is brief, or like they not really invested in me.</p>
Treatment (other than medication) attitudes	Adolescent describes their attitudes towards treatments (other than medication).	<p>Interviewer: Okay. How do you feel about ADHD treatment? Do you like the ADHD treatment or do you not like your ADHD treatment?</p> <p>Participant: No, I don't like it.</p> <p>Interviewer: Why don't you like it?</p> <p>Participant: Because it makes me not feel like I'm a regular person.</p> <p>Sometimes I don't like talking to people about my concerns and stuff like that, like psychologist talk to me about these things, and I don't like that. But I need to vent so I do have to talk.</p>

Comparing ADHD to Other Conditions	Adolescent compares ADHD care to other conditions. These comparisons can include treatment plans, awareness, resources, and stigma.	They have more, other things which might be more severe than others, and it might cause them to have a little bit more trauma or pain than they do with me, and not only have ADHD.
Environmental Influences on ADHD Symptoms	Adolescent describes how factors in the environment affect (1) their ADHD symptoms and (2) their ability to manage their ADHD symptoms. This excludes the school environment; use 'Experience with School.'	
Absent Parent	Adolescent describes not having a parent around (could be both) due to different reasons that include divorce/separation, abandonment, incarceration, death.	Something I remember that really affected me in a sad way was when my dad left and stopped being there for us for a long time. Although, he was with us when we were little but when we started growing up it was as if he didn't care about us anymore and I felt like he didn't love us until I came to Boston. When I came here, that's when he started calling more and wanting our attention, but it's not like I needed it anymore, you know? That affected my behavior a lot because I would get very angry, after this my temper got really strong for a while.
Adolescent reports no environmental effects on ADHD	Adolescent reports no environment factors impact his/her ADHD.	Interviewer: Okay. Um, how has money, or, like, you know, your family's finances, like, affected how you're treated? Participant: I mean, I don't really know about finances and all that, but I know, um, my mom...they raised the rent. So, my mom works more.
DCF involvement	Adolescent describes how DCF involvement in their family's lives impacted their ADHD.	Interviewer: Okay. So you spent, like, two, three years having to deal with foster care? Is that like right? Participant: Not foster care, no. Like, different people that...not to diagnose me, but to see what my...what, like, was the problem or why I was...why it was happening, or like...but [Inaudible 00:53:19] people switching them and switching them and switching them.
Difference between settings	Adolescent describes their behaviour/symptoms variance between settings. For example, how they experience their symptoms at home versus at school.	And school, because like that's where I most get distracted. I mean, when I'm in the house, I'm more, like, calm.
Financial Issues	Adolescent describes how financial factors impact their ADHD.	Like do I have any money issues? Not really money issues, but maybe just getting the help that I need now. It's just, um, kind of affecting me a little more. Yeah, my mom talking about how she couldn't take care of me, but she was just...she was trying to borrow some little cash.
Lack of a stimulating environment	Adolescent describes how the lack of a stimulating environment impacts (usually exacerbates) their ADHD.	Interviewer: Do you think it's worse at school when you're not? Participant: Definitely, just because it's something I'm really not interested in.
Large classrooms	Adolescent describes how classrooms with many students inhibits their own learning needs (needs that are due to ADHD).	I just didn't like being in a bigger class. I'm going to tell you I'll be able to keep up, but I just feel like I'm not going to be able to keep up

Neighbourhood	Adolescent describes how the neighbourhood they live/lived in impacts their symptoms.	<p>Interviewer: Has there ever been anything that happened in your house or your neighborhood that's gotten in the way of you going to the doctors?</p> <p>Participant: Shootings; accidents, police outside, crazy people, traffic, a lot of stuff.</p> <p>Interviewer: How has that affected your mood, or any anger issues you have?</p> <p>Participant: It doesn't trigger the anger issue. It mostly triggers just tired. Sleeping.</p>
Parenting effect on ADHD	Adolescent describes how parenting styles affect their ADHD symptoms.	<p>Participant: Just the anger because she be lying too much. First, she says I'm going to get you a phone or a PS4. On the first, lie. On the third, lie. On the second, lie. That's why I don't believe it until I see it with my own eyes.</p> <p>Interviewer: And you feel like that makes the anger a lot worse for you?</p> <p>Participant: Yeah, I mostly hate lies the most.</p>
Parents with disabilities	Adolescent describes how having one or more parents with a disability impacts their ADHD.	It's very hard but people don't understand, like, if you have two parents that are disabled.
Separation from family	Adolescent describes how being separated from loved ones impacts their ADHD.	Something I remember that really affected me in a sad way was when my dad left and stopped being there for us for a long time. Although, he was with us when we were little but when we started growing up it was as if he didn't care about us anymore and I felt like he didn't love us until I came to Boston. When I came here, that's when he started calling more and wanting our attention, but it's not like I needed it anymore, you know? That affected my behavior a lot because I would get very angry, after this my temper got really strong for a while.
Transitions	Adolescent describes how changing situations impact their ADHD.	Um, I...I don't know because I...I just... I switched last year, so I don't... I wasn't really focusing on my [Inaudible 00:05:15]. It was, like, it had to take some getting used to.
Trauma, PTSD	Adolescent draws a connection between their experience with trauma/PTSD and impact on their ADHD symptoms. This code includes the death of a family member.	At that time, I already had attention deficit disorder but then my grandpa died. From there I started having more attention deficit plus depression kicked in and I couldn't concentrate.
Experiences with ADHD Medication	Adolescent describes both their positive and negative experiences with ADHD medication.	
Helpful	Adolescent describes how ADHD medication helps them and their symptoms.	Well, it concerned me because up until like the 7th grade, I never really had good grades in any class. Until I started taking the medication, was like the first time I've ever had good grades. So, it's definitely helped me when I think about my future because now I can see myself going all the way through high school, and after that whatever I decide to do.
Side effects	Adolescent describes side effects resulting from ADHD medication.	<p>Interviewer: And how do you feel about medication for ADHD?</p> <p>Participant: I don't really like it.</p> <p>Interviewer: Why don't you like it?</p> <p>Participant: Because it like, makes it hard to eat. It um, like brings my mood down. Um, it kinda just makes me emotionless.</p>

Unhelpful	Adolescent describes how ADHD medication does not help them and their symptoms.	I still feel the same. Like, it doesn't really do much. Like, it doesn't... Like, if you raise it, I mean, it's supposed to make me feel more, like... I dunno, they said, like, it makes me feel tired. Like, sometimes I feel tired, but sometimes I just, like, I don't talk or anything. I still feel the same way. Like, I don't really... I don't really feel different.
Using medication as needed, Medication holidays	Adolescent describes taking medication only when they need it most and/or taking breaks from medication on weekends or school vacations	What we try to do is take them during the week and stop them on the weekend, like I did this week, to see if I can manage without them. For example, in class I always concentrate and try to pay a lot of attention. I like participating in class even without the medicine, because I deliberately stopped taking the medicine for like 2 days in [INAUDIBLE] to see how if I functioned the same without it and yes, I still felt normal, calm. I participated in class, took notes and all, so I do feel like I don't really need the medication.
Experiences with Healthcare	Adolescent describes the role and/or influence of a health-care provider in the diagnosis, treatment or management of their ADHD.	
Dissatisfaction with healthcare	Adolescent describes being dissatisfied with their healthcare experience.	Interviewer: And what do they usually say? Participant: They said, like, they could if I, like, if I work hard or just be a little more responsible, which is, I dunno, just stupid.
Poor communication about Dx. or Tx. with provider	Adolescent reports not receiving explicit information about ADHD diagnosis and/or ADHD treatment from their providers.	Interviewer: Did the doctor talk with you about that, that might happen? That you might feel? Participant: No. I had to look it up on Google. My mom told me it was maybe the meds. I grabbed the meds fast and looked up on Google to see the side-effects. The first thing that popped up was major headache. That's why I don't like side effects meds. Interviewer: The doctor told you? Okay. Um, and did they, like, explain what it is? Did you have, like, a conversation with them? Or is it kind of just, like, "You got ADHD"? Participant: I don't... I mean, I don't remember having a conversation. I don't think they did.
Satisfaction with healthcare supports	Adolescent describes being satisfied with healthcare supports i.e. positive communication experiences, provider support, receiving information, feeling heard by providers, etc.	Doctors always make sure to check on you, they are always tracking them, asking questions and making sure that you are well and that the medication is in check. And well they are... How do you say that? "They take good care of you." They would tell me what to get and they talk to me.
Trust in provider	Adolescent describes their trust in providers i.e. Doctors, therapists, social worker as an influence in their decisions about care.	The doctor was the one who recommended medication. We didn't really need any convincing. My mum just kind of does whatever the doctors say and I just kind of do the same because they know more about it than I do, so.

Experiences with School	Adolescents describe the role and/or influence of both (1) the school as an institution and (2) specifics of the school environment in the presentation, diagnosis or treatment of their ADHD.	
Dissatisfaction with school support	Adolescent describes school supports as unhelpful or inadequate.	Because I'm in disabilities class, so, like, they act out. So, like, when I want help, it distracts the teacher to come and help me because they focus on the other kids that's doing what they're not supposed to be doing.
Satisfaction with school supports	Adolescent describes school supports as helpful or satisfactory.	Interviewer: Well, tell me a little bit about that. Have they been helpful, what if they've been working on with you? Participant: Whenever I'm like stuck on a problem or I need help, they give me help me with it or they usually ask a student to help me with it. Like that.
School as a positive environment for adolescent	Adolescent describes how the school environment positively impacts their ADHD.	Interviewer: So, you feel like if you're, um, if you get in trouble that your teachers are still nice to you? Participant: They...they help me, but... Interviewer: They help you? Participant: Yeah, they try to help me. Interviewer: That's good, how do they do that? Participant: Talking to me and finding out things to prevent it.
School symptom management	Adolescent describes how the school manages their ADHD symptoms.	Interviewer: You said you have someone that sits with you and works with you when you don't understand a question. Do they also help you when you get distracted? Participant: They help me get back on track. Interviewer: What do they do? Participant: They like tell me to focus or tell the kid was distracting to stop it or stuff like that.
Supportive teacher or school official	Adolescent describes how a specific teacher or school official was very helpful to them in managing their ADHD.	Like, one of my teachers actually have ADHD, so he knows where I'm coming from. He still has it though and he's my vocational teacher, and he actually understands what I'm going through and how it's affecting me. So, some people actually can relate...is a...very good to know people that you can, like...that have it and that you can relate to having it.
Parent Symptom Management	Adolescent describes the process and strategies their parents use to help them manage/cope with their ADHD symptoms.	
Parent reminds child to take medication	Adolescent describes their parent(s) reminding them to take their medication(s).	So, she, like, tries to, like, make sure I drink the medicine every day.
Reward System	Adolescent describes how their parents use a reward system to help them with their symptoms.	Participant: After school, we would go to the store and she will get me something, like a snack that I like. Interviewer: Did you have to be good for that? Participant: Yeah.
Parent-Child Communication	Adolescent describes their experiences communicating with their parents.	

Communication about diagnosis	Adolescent describes communicating with their parents about their diagnosis.	I think it was my psychologist the first person to tell me, but the person I actually remember telling me is my mom. She was straight forward and told me what I had, and I just said "Okay". That's how it happened. I don't remember any names or anyone in particular, though.
Communication about race	Adolescent describes communicating with their parents about their race.	That's why I don't like Boston: because it's a very racist state. Even though it's up North, it's still a very racist state. Even though I'm okay... And my mom told me this. She told me when she came here, when she was 16, and even when she came here, she told me that she couldn't go to certain beaches because of her skin color. And then I came here; they do the same thing to me, basically.
Communication about ADHD treatment	Adolescents describe communicating with their parents about their ADHD medication or treatment.	<p>Interviewer: Or, like, if you wanted to switch off of anything, were you able to tell someone, like, "Hey, I don't..." – really? Okay. Can you talk to me about that?</p> <p>Participant: I mean, I tell my mom.</p> <p>Interviewer: What do you tell your mom?</p> <p>Participant: That... 'Cause she gave me like two pills but I said like, "Can I take one?" And she said yeah, maybe a lower dose.</p> <p>I mean... I've argued, that... We would argue sometimes, like, I don't want to take the medicine, but she says I have to, like, and then she ends up...she ends up winning. So, like, it's not even worth it.</p>
Communication about ADHD symptoms	Adolescents describe communications with their parents that adolescents perceive to be about or related to their ADHD symptoms.	<p>Interviewer: And that makes you feel distant from your mom?</p> <p>Participant: Yeah 'cause, like, hyper. So... She doesn't like when I act like hyper.</p> <p>Interviewer: Okay. And since finding out about it in about second grade, like, you know, how did you learn more about ADHD? From the internet, from your mom, from your doctor?</p> <p>Participant: Mostly from my mom. She explained to me more.</p> <p>Interviewer: And what has she told you about it?</p> <p>Participant: It was just like, um, I was, like, a lot... I was, like, very hyper, and she was like, "This is why you're doing this in school. This is why you got in trouble and everything."</p>
Deceitful communication with parents	Adolescent describes an experience of being deceitful or dishonest with their parents about things related or unrelated to ADHD (i.e. depression, school).	In that moment, I had found something in the car, it was some kind of pocket knife, and I told my mom "I am going to throw it away". However, I wanted to do it discretely because I couldn't let my brothers see me do that and since they're always with me, I didn't get around to doing it.
Lack of communication	Adolescent reports not communicating with parents about ADHD.	<p>Interviewer: Mm-hmm (understanding). Okay. And like, how did your parents talk to you about your ADHD?</p> <p>Participant: They talk to me sometimes, but I don't really ask, so they don't really talk to me that much. I don't really ask them. I'm</p>

		not afraid to ask, but I just, like, do research on my own, but if I do ask them then they tell me, so yeah.
Personality traits vs. ADHD	Adolescent describes an experience that coders believe could be related to either their personality or their ADHD.	Well, I think there were times when I've encountered some problems but I think that it was mostly because of me and my difficult character. I think it was my mom. It was in second grade, but I didn't really know what it was until she told me, and, eh. It wasn't really a big deal when I found out because I was hyper. I was hyper? Just take pills to control myself.
Quote	Adolescent quotes that stand out to the researchers for their detail, clarity or insightfulness.	
Racial and Ethnic Discrimination	Adolescent describes how discrimination impacts ADHD diagnosis and treatment and/or their experience of ADHD.	Just being a person of color and having ADHD – it's more difficult because it's just like, either you [Inaudible 00:34:16] like you have a clear disability... Like, they'll just throw you away like...you know, like you're trash.
Technology Utilization	Adolescent describes using technology as it relates to their ADHD	Interviewer: How have you learned about ADHD? Participant: Um... the internet.
Unanswered Questions	Adolescent describes questions they still have about ADHD in regard to the disorder itself, diagnosis, treatment, prognosis, etc.	Interviewer: That's great. How do you think we could better the access to ADHD treatment? Participant: I'm not sure about that, could you tell me how the system works? I know how it works for me, but not for other people. Um does it go away? Um...um does it give you anxiety? Um... Is there any ways to like deal with it besides taking medication? Like, if I can have friends while managing my attention deficit but... at the same time not focus too much on them, to keep going. Um, well, how my brain works. I already know a part of it, but not all of it.
Adolescent reports no unanswered questions about ADHD	Adolescent reports no unanswered questions about ADHD.	Interviewer: Do you have any questions still about ADHD? Participant: No.

Appendix E

Theme Identification Worksheet for ADD002

Theme Identification Worksheet

Interview: ADD002 (Spanish) years old (10 th grade)		Male, 15
Age at diagnosis: 10 Age adolescent “knew” they had ADHD: 4 th /5 th grade when school began to get difficult Age learned about ADHD: —		
TREATMENTS ACCORDING TO DEMO: Are they currently on meds? Yes Have they ever received bx. therapy? Yes Do they have school services? Yes		TREATMENTS MENTIONED IN INTERVIEW: Medications: ADHD, Anxiety, Depression (Does med. trials) Therapies: “Psychologist” (but doesn’t like it) School: Special Ed. Other: “Sports”
Sources of ADHD knowledge: None discussed Knowledge Preferences: None discussed Who noticed ADHD first: Teachers Who diagnosed ADHD: Doctor in Puerto Rico (“unspecified”)		

Potential themes	How theme appeared in this interview
Importance About Not Feeling “Different” Or Alone	Wanted to feel “normal” Worry about inability to keep friends due to ADHD sx. = low self esteem Worry about inability to keep friends due to both positive and negative med side effects Utilizes social supports who him to stop scratching bc of anxiety – likes this better than friends in past (from PR) who treated him abnormally
The Negative Effects of Bullying	People in PR did not treat him like he was “normal” Friends in PR would watch him scratch himself until he bleeds
Barriers to Care	Difficulty finding psychiatrist Awareness of financial barriers (will sacrifice meds) Trauma as possible barrier to care
The Role of Co-Morbidities	Grandpa died – youth acknowledged this increased severity of his depression and ADHD sx. He appears to conflate the influence of the two. Youth related his self-harm activities and crying to depression Comorbidities appear in many of his stories (esp. depression) Sometimes, a comorbidity seemed to amplify the effects of ADHD (esp. inattention)
Insight	Can name his symptoms Can connect symptoms (ADHD and depression) to their impact on his school work Can connect symptoms (ADHD, depression, anxiety) to many life events Very informed on the details of his medications Will speak with doctor about meds – makes decisions <u>with</u> mom Went off medications to help family save money Poor understanding of how medications work

Environmental Triggers	<p>Grandpa died – youth acknowledged this increased severity of his ADHD sx.</p> <p>Only moved to Boston 7 months ago (discussed in light of fearing loss of friends, social supports may be rocky due to recent transition)</p> <p>Moved to Boston from Puerto Rico due to hurricane</p> <p>A lot of family in PR – he worries about them, grandma is sick</p> <p>Thought anxiety symptoms may be related to violence in PR</p> <p>Acknowledge that when school bores him or studying is hard, his ADHD gets worse</p>
Liking Learning Outside of School/Academics	<p>Cites sports as a positive learning exp. – this contrasts to difficulties with school</p> <p>Cites sports to help with anxiety and “clear his mind”</p> <p>Cites sports as a positive learning experience (“it helps me because I’m learning”)</p>
Disliking Therapy	<p>Know he “has to vent” but does not like talking to psychologist</p>
Negative Feelings Towards Medication	<p>Worries medication effects will lead him to losing friends (he won’t talk as much to his friends during class because he’s focused)</p> <p>Poor experience with trial-and-error treatment with meds (“I was always depressed, always inattentive”)</p> <p>Felt the psychologist helped him more than the medication</p> <p>Medication is expensive (he went off them to save money)</p> <p>Mom and son decide together whether to do medication holiday</p> <p>Poor understanding of medications (he goes off meds periodically to see if he makes “any improvement”)</p>
Puerto Rican vs. US Culture	<p>ADHD much more stigmatized in Puerto Rico</p> <p>Youth lost friends in PR after disclosure of his illnesses (says his friend stated: “it seems like you have a lot of problems”)</p> <p>People in PR did not treat him like he was “normal”</p> <p>Friends in PR would watch him scratch himself until he bleeds</p> <p>In PR they treat you like a “special kid” but in US they’re “more understanding”</p> <p>He connects neighborhood violence in PR with his anxiety</p>
Adolescent Desire for Autonomy	<p>Helps his mom make treatment decisions</p> <p>Is very informed about his medications</p>
Concern/Worry About the Future	<p>Worries about getting a job in engineering (because he’s bad at math in school)</p> <p>Worries about how other people will perceive his ADHD treatments</p>
Coping Mechanisms/Symptom Management	<p>What types did this adolescent utilize:</p> <ul style="list-style-type: none"> • Utilizes sports as a positive outlet (it is “something active”) • Utilizes school as a place to focus and prevent anxiety sx. (scratching) • Appreciates/Utilizes social supports • Utilizes distractions (via sports, friends) • Self-harming activities (possibly in relation to comorbidities) • Choosing to “focus on one thing at a time” • Utilizing medications (though he does so inconsistently)

Insight – This one has good insight on symptoms (describes symptoms), that he has ADHD, that he helps mother to make treatment decisions although she drives the decisions, that he wants to be accepted and social supports for his symptoms. Positive experience with treatment and included in treatment.

Parent-Child Communication – Mom and son go to appointments together. Adolescent participates by giving

Group Discussion:

his opinion but admits that, ultimately, his mother makes final treatment decisions. Adolescent does not mention communication with mother very often. However, it is clear that they speak about intimate family problems (not necessarily ADHD) because he knows a lot about the family’s financial hardships – he even sacrifices getting medications when they need money for other things.

Good insight into symptoms and diagnosis and medications too. Good communication with parent about symptoms and with doctor with mother making ultimate decisions. Some concerns about self-esteem related to stigma, in particular (e.g., wanting to be normal, wanting more peer support, not wanting to be “special” etc.). Knowing “too much” about family finances may hinder engagement. Adolescent feels he has an opinion in treatment but mom gets the final word.

What helps? (for well-being)

- Sports (positive learning experience, clearing mind, reduced anxiety)
- Social supports (prefers kids who try to help him stop scratching)
- Being aware of his symptoms and trying to manage them (e.g. consciously choosing to focus on one thing at a time)
- Meds work well for focusing
- Medication helping
- Being in US – more stigma in PR and they treat you more like a “special kid”
- Normalization – likes this in the sense of wanting people to accept him with his symptoms (not in the sense of dismissing symptoms or wishing he wasn’t in treatment)
- “The help was great. I trusted them.”

What doesn’t help?

- Meds help but then he doesn’t talk to his friends as much and then he worries he won’t be as social and will lose his friends
- Experiences with psychotherapy vs. medication vs. school services vs. parent relationship?
- Perception of ADHD as not important

Appendix F

Process Map for ADD002

CASE: ADD002

DEMO: Male, 15 years old **TOE OF INTERVIEW:** Sincere desire to participate & answer questions

DEFINITION OF NORMAL: Defines normal as being able to “focus on one thing at a time,” not having to talk with a therapist (“I have to tell people about [ADHD] too as if it should help me”), not having to take medication, not feeling sad (“I sometimes feel sad but other times I feel normal”), and not fitting in because of his ADHD – “if I am showing a lot of attention deficit signs, he’ll think that I’ll be like another special kid, I won’t be normal.” He seems to appreciate and trust his providers and wishes that people would accept him and his symptoms.

TREATMENT MOTIVATIONS: Become an engineer; Take financial burden off family; to “vent” frustrations

Appendix G

Combined Process Map

FOUR DEFINITIONS OF NORMAL IDENTIFIED: Not having or requiring treatment for ADHD; being of equal value and worth as other human beings; being able to complete at least average quality of schoolwork; being prosocially involved with others

SIX TREATMENT MOTIVATIONS IDENTIFIED: Manage ADHD symptoms; Play sports; Stay out of trouble/Avoid interpersonal conflicts; Achieve future goals (i.e., job, graduation); Feel "normal"; Feel valued

Appendix H

Thematic Analysis Construct Review

#	Themes Related to (+) Insight, (–) Self-Esteem	Quotes
<u>Engagement style: Anxious engagement with treatment</u>		
Anxious engagement style may be due to feeling the treatment process is (a) disruptive to their daily life, (b) misaligned with their priorities, (c) ineffective or (d) problematic (i.e. medication side effects); being consistently worried about the negative impact of their ADHD and other comorbid symptoms on their daily life and future goals; feeling they do not meet expectations set by teacher, parents or peers; feeling judged due to public stigma; developing self-stigma that causes them to frame their ADHD as an “abnormal” part of their identity; being concerned their peers will not be accepting of them due to ADHD symptoms; and having (a) a tense relationship with their parents and/or (b) parents who may inadvertently contribute to the parentifications of their child when communicating to them about their ADHD.		
<i>Adolescents with this engagement style seem to have very mixed feelings towards treatment and tend to experience internalizing symptoms. They may be at risk for disengagement upon entering the adult healthcare system.</i>		
		I still feel the same. Like, [the medication] doesn't really do much.
1	Medications not effective or problematic (i.e., side effects)	<p>The thing is that, before, I used to always talk to my friends in class no matter if the teacher was talking. But then, like I said, I say hi to them and stuff but then I still have to continue paying attention. [...] I'm worried that if I ignore them, I will be alone.</p> <p>Sometimes I don't like talking to people about my concerns and stuff like that, like psychologist talk to me about these things, and I don't like that. But I need to vent so I do have to talk.</p> <p>I mean, today I have four appointments total. That's so I can go to school. I just had one with [psychiatrist name omitted] and then, like yeah, I don't even know where I have to go next, but if I didn't have, like, ADHD or anything I wouldn't have to come here, and I would have had just a normal day, but, like, always it's going to these appointments, you know...</p>
2	Treatments disruptive and misaligned with priorities	<p>I mean it'd be nice if they made the appointments not during school hours because I don't like missing school really.</p> <p>Like, soccer season was, like, earlier. [...] And there was, like, times where I wouldn't take the medicine so I would feel, like, really good. Like, I would just feel active and just go there and then run there. Sometimes I'd take [the medicine], like, I would ask coach if I...if I...like, if I... I would tell him, like, that I don't want to go to practice or something because I feel tired or I just don't want to go.</p>

I'm scared of not being able to make it because of my lack of concentration. If I'm going to study Engineering, I need to focus on math which is really difficult not only to look at the graphs, but also the equations if I can't even concentrate.

3 Worry about future with ADHD

So, if you have ADHD...say if you're ADHD, right? You be like, "Oh, you're..." Like, "Oh, you're stupid," or, "You just can't really have that," or, "You can't do that," or, like... I don't know. [...] I want to say college won't cover you because you have... I won't say colleges won't accept you because you have ADHD, but some college probably don't have the help that you need to succeed in college with ADHD. [...] Like, it stops you from going what you want to go after.

4 Worry about current struggles (e.g., academic, interpersonal)

That it's not a good thing; when you have attention deficit, you're not able to concentrate on one thing at a time and you're always moving around. If someone talks to you, you look the other way and not pay attention to what they're saying.

The ADHD and nonverbal disability that comes into play with ADHD, and I'm...I don't... Just, I don't really understand that I have a disability, so that's kind of hard for me [...]. Nonverbal disability and ADHD—they both come together.

5 Worry about comorbidities

At that time, I already had attention deficit disorder but then my grandpa died. From there I started having more attention deficit plus depression kicked in and I couldn't concentrate.

I just didn't like being in a bigger class. I'm going to tell you I'll be able to keep up, but I just feel like I'm not going to be able to keep up

6 Worry about not meeting others' expectations

Interviewer: And then your mom tells you that, like, if you keep on the medicine and the treatment that [ADHD symptoms going away] could happen.

Participant: Yeah. Like, if I do... If I just do what I'm supposed to do.

Interviewer: And how do you feel about that, just, you know, doing what you're supposed to do?

Participant: I mean, it's kinda tough. Because she's basically talking about school, and right now I'm not doing good in school. They look at me and how I am. Let's say if I have a friend that have known for many years, he'll know how I behave myself, and then if I am showing a lot of attention deficit signs, he'll think that I'll be like another special kid, I won't be normal.

7 Feeling judged due to public stigma

Just being a person of color and having ADHD – it's more difficult because it's just like, either you [Inaudible 00:34:16] like you have a clear disability... Like, they'll just throw you away like...you know, like you're trash.

Let's say if I have a friend that have known for many years, he'll know how I behave myself, and then if I am showing a lot of attention deficit signs, he'll think that I'll be like another special kid, I won't be normal.

8 Development of self-stigma

He said it was nothing to be ashamed of, and it was like...but I feel ashamed sometimes...

Probably being in special ed class, not like a... I'm in the higher one right now, because I...when I was little, too...but just being put in with that...that problem that I had, I felt stupid. Even people not calling me stupid, you can feel stupid.

Bad because on top of not being able to focus on things I have to tell people about [my ADHD] too, as if it should help me or make me forget that I have attention deficit disorder.

9 Lack of self-acceptance (does not see self as "normal")

I've had a few problems here and there also because of that "special" label that I have, attention deficit or special education.

Let's say if I have a friend that have known for many years, he'll know how I behave myself, and then if I am showing a lot of attention deficit signs, he'll think that I'll be like another special kid, I won't be normal.

10 Worry about acceptance from peers

People look at you different, and it's kind of embarrassing but it's just like, I feel like because I have certain issues with my ADHD, I don't meet new people. Only because it's like you have to open up to them—and I'm not a person to talk...like, I don't want to open up at all.

[The medication] just makes me feel like a robot. Like, shy and stuff.

11 **Generally poor/tense relationship with parent(s)**

Something I remember that really affected me in a sad way was when my dad left and stopped being there for us for a long time. Although, he was with us when we were little... but when we started growing up it was as if he didn't care about us anymore and I felt like he didn't love us until I came to Boston. When I came here, that's when he started calling more and wanting our attention, but it's not like I needed it anymore, you know? That affected my behavior a lot because I would get very angry, after this my temper got really strong for a while.

Interviewer: So how does your ADHD affect your relationship with your family, like your parents?

Participant: Um... sometimes I like... mean... I can't... I mean I'm less um, not as respectful at times, like I just say the first thing that comes in my mind. Like I just say like the wrong stuff sometimes. [...] I mean this...this obviously hasn't had a positive effect on my family.

Like do I have any money issues? Not really money issues, but maybe just getting the help that I need now. It's just, um, kind of affecting me a little more. Yeah, my mom talking about how she couldn't take care of me, but she was just...she was trying to borrow some little cash.

12 **Communication with parent(s) about ADHD that might result in parentification.**

Participant: Like we have to pay for the medications. We don't have a lot of money and we have to pay about \$7 for each medicine because they're not covered by the insurance.

Interviewer: Oh okay, that's money that perhaps you don't have, right? How have you managed to overcome those barriers?

Participant: Improve the situation in order to stop taking medication.

Interviewer: What do you mean?

Participant: Like if I am anxious, I try to be like "Okay, I have to focus on one thing at a time" and when I am able to manage the situation and forget about it, well I don't have to take medicine anymore and I don't have to buy them.

(+) Insight, (+) Self-Esteem

Quotes

Engagement style: Proactive engagement with treatment

Proactive engagement style may be due having a plethora of accurate knowledge about ADHD (especially the biological model); feeling the treatment process is effective; feeling a sense of control over the treatment process; feeling supported, valued and listened to by teachers and providers; being confident in their ability to independently manage ADHD symptoms in their daily life and to accomplish future goals; embracing strengths they have that they associate with ADHD; connecting with and receiving support from role models who have ADHD; framing their ADHD – it's positive and negative aspects – as an acceptable and "normal" part of their identity; disclosing their struggles related to ADHD to peers who help them manage their illness; and having (a) a good relationship with their parents and/or (b) parents that use age-appropriate and direct language about ADHD.

Adolescents with this engagement style feel appreciative of and in control of their treatment options. They may be more likely than others to continue engaging with the adult healthcare system.

1 **Appreciation for and ambivalence around medication**

I mean, the thing I want to improve is the medicine. I mean, I've been on medicines for a long time, so... Medicines help me to stay focused in school...

Kind of. Ever since I turned 14 or 15, I've been feeling like the effects aren't the same as they were before. I don't feel their effect in general, and I feel like I don't need more medication. Although the doctor said it's normal for me to feel this way however the medication is still necessary and we haven't continued to [Inaudible].

Without those pills, I don't even know. But they just help me a lot, like, concentrate and everything.

Interviewer: Did you notice any change when you started taking your medication?

Participant: Yeah. [...] I was... I didn't get in trouble as much. [...] I felt normal.

Interviewer: What do you mean by normal?

- Participant:** Like, I don't know, like the other kids.
In 5th grade, I managed to stop caring about [bullies] and I learned how to ignore them. I am grateful for my medication because it really helps me there... The medicine sometimes helps decrease my energy to make me less active than I usually am. And so, I was able to ignore them and be there as much as I can for my brother because he was getting bullied a lot since he couldn't stand up for himself.
- 2 Treatments perceived as effective**
- You can tell [mentors], like, what's wrong in your life, like what problems you have and like, like they give good advice too.
- Yes, yes. The medication definitely helps. School, I mean LC is just extra time almost. It's just like a "Help." It's like a room with just a bunch of teachers and they help you with your homework and your classrooms and studying. Yes, its helped.
Doctors always make sure to check on you, they are always tracking them, asking questions and making sure that you are well and that the medication is in check. And well they are... How do you say that? "They take good care of you."
- 3 Supportive, informative and communicative providers**
- They would tell me what to get and they talk to me.
No, I've never encountered any difficulties that kept me from getting my medicine. Only myself. Yes me, like I told you, I forgot twice when I wanted to... I was my only barrier. If one day I want to stop them, my doctor will recommend not to do so but she can't keep me from stopping. My only barrier here is myself.
- 4 Control over treatment options felt empowering**
- Well, when I got treated, I don't know if this is common or not, but we didn't stay on one medication the whole time. We tried different things and we would meet every month or like three weeks. Like we met pretty frequently and we would talk about it. Then we would try new stuff and see what worked and what didn't work. That really helps because I feel like I got medication that was perfect. Just to tell them that you're no different than the person that doesn't have it. Like, your brain can work a little different from that other person's, but you're still a person.
- I'm fine. When I knew often, when I had ADHD, I started like thinking about it and solving my own questions. And like I solved it all for myself?
- 5 Feeling empowered by ADHD-related knowledge (esp. biological model)**
- Um, I asked questions, um, and researched it — about how my brain works and stuff like that. I basically asked ques... like, just like, researching it, asking my mom, like, "What's wrong with my brain?" Or, "What's different with my brain? What's different from a regular person's brain and from, like, not...being not like a regular person?" Well, it's different from the ADHD brain. It's that a person, like, does not have ADHD. Like, different in spots. It's like...not like...not my communication, but you see how I learn and how I think is different. So, I think, like, I'm a little faster, and most people would not think it's, like...it's fast. They think you're just a little, like, slow or something.
Well, it concerned me because up until like the 7th grade, I never really had good grades in any class. Until I started taking the medication, was like the first time I've ever had good grades. So, it's definitely helped me when I think about my future because now I can see myself going all the way through high school, and after that whatever I decide to do.
- 6 Future goals feel possible with treatment**
- Interviewer:** Do you have any concerns about it affecting your future?
Participant: Not really anymore. Now I'm taking medication, school is getting better. It used to be really bad, so it doesn't worry me that much anymore or my family anymore.
I still have like, the stuff I'm interested in, I also have a short attention span with that. So, I've never watched like long videos or movies in one sitting. I always watch five minutes at a time and then pause it and then go do something else and then come back.
- 7 Uses effective coping skills**
- Like if I am anxious, I try to be like "Okay, I have to focus on one thing at a time"
No. To me, ADHD, I feel like it's a good thing because it's like moving a lot keeps you from being lazy.
- 8 Reports strengths associated with ADHD**
- For example, it can help you concentrate more in moments you think it's necessary

It was difficult. Like, one of my teachers actually have ADHD, so he knows where I'm coming from. He still has it though and he's my vocational teacher, and he actually understands what I'm going through and how it's affecting me. So, some people actually can relate...is a...very good to know people that you can, like...that have it and that you can relate to having it.

9 Support from role models with ADHD

For example, I had a teacher here in Boston and me being from Puerto Rico, you would think we have "different ADHD", because how do you say this? We were born in different places. However, talking to her especially about our ADHD, made me realize that we are exactly the same.

Interviewer: Does having a diagnosis of ADHD affect the perception of yourself in any way?

Participant: No. I was always this way, so it just kind of gives it a word for me to describe or call it.

10 Radical acceptance of self with ADHD

If somebody has it, they're still normal. They're still human. [...] ADHD is just something that people...some people have. It's, like, it's not really a bad thing, it's just... Just wanna, like, I... you can't control yourself or... or something else. But you could just tell people, like, "They're still...You're still the same as this person. Everybody's the same."

Any person – like, there's some stuff that they can't do that you could do, and some stuff that you can do that they can't do, because they don't have it. And he said it's an advantage and a disadvantage sometimes. He said most things are an advantage and a disadvantage.

"I don't want to tell you I have ADHD," but [my friend] told me, because I told him. [...] I was like, "I know." He's like, "Well, you know..." He's like, "that's not a big deal." [...] And he said it's an advantage and a disadvantage sometimes. He said most things are an advantage and a disadvantage.

11 Disclosure to and support from peers

Like a sport or playing cards with their friends; like they do with me, a way to distract themselves and not think about it.

Everybody in my school, like, I know them, they know me. They try to help me. Like, even my friends, they give me advice, they're like, "Yo, come on. Get your grades up."

It affects [the relationship with my parents] in a good way, because, you know, like, my mom, like, can know what I need, like, help and all. And she... Like, whenever we go to the doctors, she can explain to them, like, what I do...what I do at home. And, I dunno. It's just... We're good.

12 Generally good/warm relationship with parent(s)

Interviewer: And how about, um, your mom, do you know how she feels about you having ADHD?

Participant: No, well she helps me so she should... It shows that she cares about me.

For example, my mom always asks me: "Are you going to take your medication or do you feel like you don't need it?" to see if I can manage or not. And sometimes I just say: "Yes, I need the medication".

13 Informed and collaborative communication with parent(s) about ADHD

For example, I'm taking Zoloft which is for my anxiety, but before being prescribed, I asked about the symptoms and all, to see if it would actually do me any good. My mom's the one who says if it's alright, but sometimes she'll say she doesn't think so, and she asks for another options.

Participant: Mostly from my mom. She explained to me more.

Interviewer: And what has she told you about it?

Participant: It was just like, um, I was, like, a lot... I was, like, very hyper, and she was like, "This is why you're doing this in school. This is why you got in trouble and everything."

(-) Insight, (-) Self-Esteem

Quotes

Engagement style: Active rejection of treatment

Active rejection of treatment may be due lacking accurate knowledge about ADHD (they may endorse myths) and the healthcare system; feeling the treatment process is unhelpful and harmful (e.g., medication side effects, causing family tension); lacking a sense of control over and feeling “forced” into treatments, perhaps creating resentment towards the treatment process; feeling unimportant to and dismissed by teachers and providers; feeling as though they are unable to manage their ADHD symptoms or ADHD care independently or in the long-term; feeling that they are unable to meet the academic and behavioral expectations of others; and having (a) a tense relationship with their parents and/or (b) parents who use misinformed or blaming language about ADHD.

Adolescents with this engagement style appear frustrated towards and disempowered by treatment. They are at risk for disengagement upon entering the adult healthcare system.

1 Perceives treatment as unhelpful and harmful (i.e., side effects, family tension)

Because the medicine, it, like, sometimes, it, like, makes me, like...like, not even do anything, like, just fall asleep or just not do anything. My mom tries to, like, go out, but, anywhere... Or like, just talk to me or something, I'll just be like, "No, I don't want to, no." And sometimes she would just get mad, or just think that I don't wanna.

Interviewer: And how do you feel about medication for ADHD?

Participant: I don't really like it.

Interviewer: Why don't you like it?

Participant: Because it like, makes it hard to eat. It um, like brings my mood down. Um, it kinda just makes me emotionless.

I mean... I've argued, that... We would argue sometimes, like, I don't want to take the medicine, but she says I have to, like, and then she ends up...she ends up winning. So, like, it's not even worth it.

2 Feeling forced into treatments (esp. medication)

What could I say that would really change things, change something? I mean, mom said if I don't take my medication, I can't live in her house or something. Or like, because she doesn't, because I guess... I'm not well behaved or something.

The school, like, they make plans for me and everything, but, like, when they say, like, "Oh, you're gonna start doing this, like, next week," and everything, like, next week happens and nothing happens. Like, I'm just, the same like always. Like...like, a plan, and then, the teachers are not there, for, like, to do what the plan says.

3 Feeling unimportant to and/or dismissed by providers/teachers

Interviewer: Like people that might like judge you, or blame you or, you know, treat... treat you differently at all because you have ADHD or because you take ADHD medication?

Participant: I think the teachers might.

Interviewer: How so?

Participant: Like, they would rather help this... Another student then help me but just like... They'd rather just spend their time on someone else or like, whatever they say to me is brief, or like they not really invested in me.

4 Unsure of how healthcare system/accessing ADHD works

NOTE: Combine with 'Lacking general knowledge about ADHD?')

Interviewer: That's great. How do you think we could better the access to ADHD treatment?

Participant: I'm not sure about that, could you tell me how the system works?

Yeah, I only know that ADHD is...is hyper. I don't know if it means anything else, but that's all I know for now.

5 Lacking general knowledge about ADHD

[ADHD is] like a societal thing; it has a lot to do with who you're with. You sometimes have to pay a lot of attention to something you care about, but if you think school's boring and you hate studying, you start thinking of other stuff.

Is it, like... I'm still asking, like, if it's... Is it something I have to, like, is it...can it go away, or no?

Interviewer: Can you talk a little bit more about that, about what worries you?

Participant: Like, if I'm gonna take them, like, forever, and like, what if I'm, like, living by myself or something, and then I still have to take those. I'd probably be, like, just not responsible with them.

Interviewer: Not responsible enough to, like, take them on your own?

Participant: To take them, or, like, to go pick them up at the pharmacy or something.

6 Feeling unable to manage ADHD symptoms or ADHD care

- Participant:** [ADHD] makes me think I can't do stuff. Lower... Um, lower my standards. Um, like...like I'll never get something done. Makes it hard to get started on tasks. Whatever, and it just makes me put a lot of things aside.
- Interviewer:** [...] What do you think would help you?
- Participant:** Like... I don't really know. I don't think there is anything I can.
- Interviewer:** And what do [your mom and your doctor] usually say?
- Participant:** They said, like, they could if I, like, if I work hard or just be a little more responsible, which is, I dunno, just stupid.
- Interviewer:** Can you talk to me about an experience that made you frustrated?
- Participant:** Like, school, home, and... like, I just get, like, time to do homework 'cause I don't really know how to do it. 'Cause it be hard.
- Interviewer:** Do you feel like your closer to your mom because you have ADHD or do you feel more distant from your mom because you have ADHD?
- Participant:** [...] Distance because of the ADHD.
- Interviewer:** Okay. What makes you feel distant about it?
- Participant:** Because the ADHD makes me act like a concern, like a different way.
- Participant:** Like... Like people wanna probably blame me or what is it... Um, I don't know. I can't really say... I mean... How has that affected the relationship with my family you said. [...] It hasn't really made it good. The relationship could be better, I think.
- Interviewer:** And that makes you feel distant from your mom?
- Participant:** Yeah 'cause, like, hyper. So... She doesn't like when I act like hyper.
- Participant:** Well, my parents used to tell me chocolate.
- Interviewer:** Chocolate, the sugar?
- Participant:** Yeah. Yeah, sugar. When I have sugar, I get very hyper. Yeah, so, yeah. I think that's another thing too. Like, if...if, like, if I have sugar, I'm gonna be very hyper. I think that's probably when I'm at my house too.
- Interviewer:** And what happens when you tell your mom or your doctor that you don't like taking the medicine?
- Participant:** They just tell me, they say, they just say, "Keep drinking it, and some day you're not gonna take it."

(-) Insight, (+) Self-Esteem

Quotes

Engagement style: Apathetic to engagement with treatment

Apathetic engagement style might be due to lacking knowledge about ADHD; lacking communication with providers; a general lack of interest in the treatment process or treatment options; feeling unconcerned about impairments that may be related to ADHD (i.e., poor school performance, negative social interactions); the presentation of their own ADHD symptoms that prevent engagement with care (e.g., being unable to wait for appointments, irritated easily, bored easily); deciding not to disclose their ADHD to those outside of the treatment team, thereby losing crucial opportunities for insight-building or the culmination of peer support for ADHD; and having (a) a good relationship with their parents and/or (b) lacking communication with parents about ADHD. This lack of communication may be due to parents feeling inadequate about their own knowledge of ADHD, having a desire to shield their child from the "realities" or ADHD, or feeling that ADHD is not a prioritized topic for discussion (in one case, this appeared related to parental ADHD).

Adolescents with this engagement style do not seem to either dismiss or endorse benefits related to ADHD treatment. They may be at risk for disengagement upon entering the adult healthcare system.

- Interviewer:** Okay. It sounds like when you're sitting with your mom and doctor in the appointment, your mom and doctor are talking, but you're not really involved in the conversation. How do you feel about that?
- Participant:** Kind of glad because I don't like answering too many questions.

1 Lack of communication with providers

Interviewer: The doctor told you? Okay. Um, and did they, like, explain what it is? Did you have, like, a conversation with them? Or is it kind of just, like, “You got ADHD”?

Participant: I don’t... I mean, I don’t remember having a conversation. I don’t think they did.

Participant: I mean, they ask me questions and they give me time to talk, but they do the most talking. But my mom... Like, I get it, like, my mom, like, knows me more. I’m with her every day. Every day, so...

Interviewer: So, it sounds like you... Do you...do you...would you want to be able to talk more, to give... In the doctor's appointment?

Participant: No.

[My ADHD diagnosis] wasn't really a big deal when I found out because I was hyper. I was hyper? Just take pills to control myself.

2 General lack of interest in treatment process or options

Interviewer: Do you wish the doctor talked with you directly about what goes on?

Participant: No. I mostly don't like talking. I mostly just text. Or, do something just to keep me company.

The doctor was the one who recommended medication. We didn't really need any convincing. My mum just kind of does whatever the doctors say and I just kind of do the same because they know more about it than I do, so.

3 Feeling disempowered by lack of ADHD-related knowledge

Like I said, the question you're asking me, like, I don't... Like, I only have one, like... Like I said, I don't even know what ADH... Only, like – that I move a lot. I don't really know...

At school, it's weird because it's something I'm really not interested in. So, I just don't focus. So, I get sleepy when I'm not into anything and it's like first thing in the morning too.

4 Symptoms prevent engagement with care

Interviewer: What about anything negative [about treatment]? Anything you don't like?

Participant: Phone calls. I hate people forcing me. I hate phone calls. I hate waiting the most. I got a lot of things I hate. I think there's like 105. I keep records of how many I hate.

Interviewer: Anything you really don't like about going to the doctors? Or, talking with doctors? Or, talking with counselors? Or, talking with people that work with you?

Participant: I'm mostly talking about patience, this, that. Mostly when you have to be waiting. That's what I hate so much.

It's just one of those things where like, it's like with school and my grades. If I fail a class, I fail. I just don't really think about it that much.

5 Child unconcerned about impairments (e.g., poor academics, negative social interactions)

One of my friends, my brother's friend's mom, she thinks I was bullying her autistic son just because I'm big. I'm not mostly that bad. I'm just bored.

I mean, everyone pretty much has disability, so... And ADHD is really, uh, nothing to me. I mean, it's not... To me, it's not serious, but I don't know how other people will take it.

6 Nondisclosure of ADHD to those outside of treatment team

Interviewer: Do [your friends] know that you have [ADHD]?

Participant: No.

Interviewer: Is there a reason that they don't?

Participant: Because I don't need to tell him things like that. [...] I like to talk about other things that are more important than that.

Well, the way I remember it going was most of the people in my family had an idea that there was something wrong with my attention because it was bad. And my dad's the same way too and so is my mum. So, a lot of people just kind of figured. Yes, it wasn't really any like bad feeling towards it. It was just like I had it, you know.

Interviewer: So, how does your ADHD, or how do you think it affects your relationship with, like, your parents?

Participant: It affects it in a good way, because, you know, like, my mom, like, can know what I need, like, help and all. And she...

Like, whenever we go to the doctors, she can explain to them, like, what I do...what I do at home. And, I dunno. It's just... We're good.

7 Parental ADHD

8 Generally good/warm relationship with parent(s)

Interviewer: So, what would you tell kids that they're going through the same thing, their parents aren't listening to them, what would you tell their kids that were like you?

9 **Lack of communication with parent(s)
about ADHD**

Participant: In time they will find out but, like, every parents notice things with their kids and stuff. They talk to me sometimes, but I don't really ask, so they don't really talk to me that much. I don't really ask them.

Interviewer: Okay. Um, so you said the doctor told you first. And then did you talk about it with your parents more? Not really?

Participant: Mm-mm (negative).

My dad told me that someone was going to come pick me up and take me places to go eat and talk. I was like, "Okay," and then it started. Then I went with him and we started going places and talking and buying food and eating.