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Malcolm B. Miller
The Retrospective Narratives of
Young Adults with ADHD: How
Self-Concept Development Impacts
Psychosocial Functioning

ABSTRACT

This study explores how young adults with ADHD construct self-concept, and how their self-concept impacts psychosocial functioning. Research shows that those with ADHD are more likely to experience significant setbacks across the lifespan due to impairments that negatively impact functioning in multiple life domains. Several studies note high comorbidity between ADHD and internalizing symptoms such as anxiety, depression, and low self-esteem. Although existing research suggests neurobiological correlations, there has been little investigation into other causal relationships. This researcher interviewed eight young adults with ADHD hoping to illuminate other possible pathways between ADHD and the presentation of comorbid internalizing symptoms and behaviors. Findings of this study suggest that young adults with ADHD are subject to recurrent misattuned and negative feedback from the relational environment in response to ADHD impairments. Such experiences appear to have a detrimental impact on an individual's self-concept and psychosocial functioning, thus exacerbating the burden of the condition.

The Retrospective Narratives of Young Adults with ADHD: How Self-Concept Development Impacts Psychosocial Functioning

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

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TABLE OF CONTENTS

AC	KNOWLEDGEMENTS	ii
TA	BLE OF CONTENTS	iii
LIS	T OF TABLES	iv
CH	APTER	
I	INTRODUCTION	1
**		
II	LITERATURE REVIEW	6
III	METHODOLOGY	19
111	WILTHODOLOG1	1)
IV	FINDINGS	26
V	DISCUSSION	45
REF	FERENCES	49
API	PENDICES	
		63
Appendix A: Participant Consent Form		
Appendix B: Pre-Interview Intake Questionnaire		

Appendix C: List of Free Referrals for Participants	70
Appendix D: Semi-Structured Interview Guide	71
Appendix E: Participant Recruitment Flyer	74
Appendix F: Participant Recruitment Web Posts	75
Appendix G: Participant Recruitment Email	76
Appendix H: HSR Approval Letter	77
Appendix I: HSR Amendment Approval Letter	78

LIST OF TABLES

Table

1.	Table 1: Internalized Shame as an Impact of Negative Feedback from Others	34
2.	Table 2: Conflation of ADHD Impairments with Inborn Personality Traits	38

CHAPTER I

Introduction

ADHD is a brain-based biological disorder, that we now know to affect between 5-10% of the world's population. It is characterized by a deficit in behavioral inhibition, sustained attention, resistance to distraction, and self-regulation of physical and cognitive activity. A large body of research has documented how impairments related to ADHD symptoms impede functioning across the lifespan in all major life domains. Several studies document the high rate of comorbidity between ADHD and internalizing behaviors and symptoms across the lifespan, such as depression, anxiety, low self-esteem, and poor self-concept. Although research suggests possible neurobiological correlations between ADHD and internalizing disorders, there has been little investigation into other causal relationships that take into account the reciprocal relationship between the person and their social environment. Only a few studies have explored causation beyond the hypothesis that ADHD-symptoms per se and symptom-related setbacks are to blame. Using lenses of Self-Psychology and disability theory, I sought to explore the subjective experiences of young adults with ADHD to illuminate other possible pathways between ADHD and the presentation of comorbid internalizing symptoms and behaviors. The current study was guided by two primary research questions: 1) How do young adults with ADHD construct their self-concept? and 2) How does their self-concept impact their psychosocial functioning? This study was intended to provide young adults with ADHD the opportunity to share their experiences of growing up with ADHD, to reflect on how living with the condition has impacted their self-concept, and to reflect on how their self-concept has affected psychosocial functioning. Through analysis of their retrospective accounts, the researcher hoped to gain a better understanding of how those with the disorder related to their environment and vice versa, how

this reciprocal process influenced their development of a sense-of-self, and, consequently, their cognitive and behavioral patterns.

While the link has been made between childhood ADHD, low self-esteem, and persistent internalizing symptoms behaviors in young adulthood, studies have tended to posit that an inborn neurobiological relationship exists among these constructs; that is to say that the neurobiological profile of ADHD makes one more prone to developing comorbid internalizing disorders. These hypotheses have been based upon neurobiological research from the last two decades that has revealed an underdeveloped prefrontal cortex in those with the ADHD, which is believed to result in decreased executive functioning. Executive functioning is a construct that refers to a set of cognitive tasks that involve brain's prefrontal cortex, including response inhibition, sustained attention, and the ability to manage emotions to achieve goals, complete tasks, and control and direct behavior (Dawson & Guare, 2003). While a diminished prefrontal cortex and the resultant executive functioning impairments may account for some of the emotional regulation difficulties seen in individuals with ADHD, emerging research has exposed multiple, intersecting psychosocial pathways to comorbid depression and anxiety.

Weyandt and DuPaul (2013) reported that children and adolescents with ADHD endorsed lower self-esteem ratings and suffered from depression, anxiety, and other psychological distress at a higher rate than the general population. Other researchers have found that social maladjustment, relational dysfunction, and internalizing behaviors often continue into adulthood for those with ADHD (Canu & Carlson, 2007; Meinzer et al., 2016). Within the meager body of literature that discusses the relationship between ADHD and internalizing behaviors, most studies attribute comorbid anxiety and depression to an individual's internalized negative selfperception due to impaired functioning in the environment. In other words, individuals with ADHD develop low self-esteem because their ADHD symptoms make it difficult for them to

function normally in multiple life domains; this in turn leads to clinical anxiety and depression. However, these studies fail to consider the reciprocal determinism at play. How might someone with ADHD be psychosocially impacted by an unaccommodating classroom environment? To what extent are comorbid anxiety and depression mediated by experiences of institutional and interpersonal ableism? To date, no research of this nature exists.

As mentioned, few studies have explored the relationship between ADHD and comorbid internalizing disorders using psychological or social theories to investigate how those with the condition are shaped by responses from the relational environment. In conducting a master's thesis project, I used perspectives from Self-Psychology and disability theories to elucidate subjective narratives related to possible pathways between ADHD and internalizing disorders. This study used an emergent, exploratory, qualitative, and inductive approach to explore for data analysis. The research is phenomenological in nature, so as to explore the complex subjective experiences of the participants. I recruited participants using convenience, snowball, and purposive sampling methods, which included posting on social media sites and online forums, placing flyers at local outpatient clinics and in public spaces in the community, and advertising the study via word of mouth of colleagues and friends. Ultimately, eight individuals participated in this study. I collected data through semi-structured, one-on-one interviews with participants, during which I asked open-ended questions designed to elicit the retrospective narratives of participant experiences. All interviews were audio recorded, subsequently transcribed, and coded for emerging themes with input from my thesis advisor. Four primary themes emerged in participant interviews in response to the two original research questions: 1) Negative feedback from others in response to ADHD impairments led participants to internalize shame; 2) A lack of psychoeducation about ADHD provided at the time of diagnosis and during treatment led the participant to conflate ADHD impairments with inborn personality traits; 3) Engagement with

activities, environments and individuals that made them feel less impaired supported the development of self-confidence and a sense of mastery; and 4) Acquisition of ADHD knowledge was a pathway to self-awareness and positive self-concept. Findings from this study strongly suggest that psychoeducation and multimodal treatments that facilitate skill building and selfinsight can help young adults with ADHD establish a more positive self-concept and improve psychosocial functioning.

In presenting these findings, I hope to contribute to existing literature by adding nuance to the conceptualization of comorbidity between ADHD and internalizing disorders such as anxiety and depression. Moreover, I aim to provide readers a window into the lived experience of those with the condition. By collecting data through narrative interviews, it was possible to analyze the complex relationships between participants' neurobiology, environment, and psychology. This method of inquiry highlighted how developing adults with ADHD make meaning of their experiences, understand their own psychological development, and construct a sense of self. Self-Psychology and disability theories were useful theoretical lenses when conceptualizing these experiences. I believe such psychoanalytic and social theories can help us find new ways of understanding how those with variant neurobiological profiles navigate and interact with the relational environment.

This thesis begins with a review of the extant literature related to ADHD, comorbidity between ADHD and internalizing disorders, the life outcomes and subjective experiences of those with ADHD, and development of self-concept among those with the disorder. I then outline the methodology of the current study, present its salient results and thematic findings, and discuss the implications of these findings in the final chapter.

CHAPTER II

Literature Review

This chapter aims to acquaint the reader with the extant literature and research relevant to the current study. The chapter will begin with a review of existing research on the life outcomes and burden of illness for children, adolescents, and young adults with ADHD. Then, I survey the most up-to-date literature addressing ADHD and comorbid internalizing disorders, symptoms, and behaviors. This chapter also includes a section presenting recent qualitative data highlighting the subjective experiences of those living with ADHD, paying particular attention to research that elucidates the correlation between ADHD and negative self-concept or low self-esteem. I then define the theoretical lenses I chose to use as frameworks for analyzing qualitative data from the current study.

ADHD and Life Outcomes

ADHD is a brain-based biological disorder, that we now know to affect between 5-10% of the world's population (Barkley, Murphy, & Fischer, 2010). It is characterized by a deficit in behavioral inhibition, sustained attention, resistance to distraction, and self-regulation of physical and cognitive activity, and leads to impairments across the lifespan in all major life domains (Barkley, 2012). The disorder is a chronic, lifelong condition with an onset of symptoms in childhood, the presentations of which may change in adulthood. Those with ADHD experience unstable relationships, poor work or school performance, low self-esteem, and other psychosocial problems (Barkley, Fischer, Smallish, & Fletcher 2006; Barkley 2012; Gjervan,

Torgersen, Nordahl, & Rasmussen 2012; Cadman et al. 2016)

Kent et al. (2011) found that adolescents with ADHD experienced significant academic impairment in high school relative to comparison adolescents, including lower overall and main academic subject grade point averages (GPA), lower levels of class placement (e.g. remedial vs. honors), and higher rates of course failure. In addition, teacher reports indicated that adolescents with ADHD completed and turned in a significantly lower percentage of assignments and were significantly less likely to be working up to their potential. Adolescents with ADHD were also significantly more likely to be absent or tardy during the academic year, and they were over eight times more likely than adolescents without ADHD to drop out of high school, which often is a predictor to failed social status, criminal behavior, depression and low self-esteem.

A major finding in the Gjervan et al. (2012) study was the high impairment in terms of low educational attainment and poor occupational outcomes in youth with ADHD. Approximately 48% of the participants reported junior high school as their highest degree of education compared with 29.8% in the general Norwegian population in 2009 (Statistics Norway, 2010). Thus, more than half of the sample had an educational level not suited for most domains in the work market. Only 8.9% reported having a college or university degree, compared with 20.8% in the general Norwegian population at the time of data collection (Statistics Norway, 2010).

Cadman et al. (2016) study showed that "the average age of the ADHD group at followup was 17.6. Most were males (89%), and still living at home (88%). Fifty-three percent reported using illegal drugs in their lifetime; 20% had used drugs in the last month and 22% had been in trouble with the police within the last year. Over half of the sample met the cut-off score on the AUDIT suggesting high levels of alcohol consumption. Twenty-seven percent exceeded the cutoff on the CIS-R, which indicates high levels of comorbid psychopathology. Fifty-five percent of the sample was in full-time education and 12% in full-time employment."

Comorbid Presentations of ADHD and Internalizing Disorders

This section presents existing research findings on comorbid presentations of ADHD and internalizing disorders, such as anxiety and depression, as well as subclinical internalizing behaviors and emotional regulation deficits that are often seen in tandem with ADHD.

Students with ADHD report lower self-esteem ratings and suffer from depression, anxiety, and other psychological distress at a higher rate than the general population (Weyandt & DuPaul, 2013). Social maladjustment, relational dysfunction, and internalizing behaviors often continue into adulthood for those with ADHD (Canu & Carlson 2007; Meinzer et al. 2016).

Weyandt (2013) found significantly higher levels of psychological distress in participants with ADHD than non-ADHD participants, including obsessive-compulsive symptomatology, depression, anger, aggression, anxiety, and hostility, as well as impaired global psychological functioning. These findings support previous studies exploring young adults with ADHD confirming that young adults with ADHD are more likely to exhibit symptoms of comorbid mood disorders (Heiligenstein and Keeling, 1995), depressive symptoms (Norvilitis et al., 2008); Rabiner et al., 2008), aggressive behaviors (Kern et al., 1999), impulsivity and criminal behavior (Young, 2010), internal restlessness and overall psychological distress (Blasé et al., 2009; Rabiner et al., 2008; Weyandt et al., 2003; Weyandt, 2009, as well as lower levels of self-esteem (Dooling-Litfin and Rosen, 1997; Norvilitis et al., 2008) and overall psychological functioning (Richards et al., 1999).

Cadman et al. (2016) followed 118 adolescents and young adults diagnosed with combined type of ADHD in childhood for an average of six years. Young adults with a childhood diagnosis of ADHD showed increased rates of comorbid mental health and psychosocial problems correlated to current levels of ADHD symptoms, but not by childhood ADHD severity. Investigators in this study reported increased rates of anger, fatigue, sleep

disturbances, anxiety, and substance use problems among those with ADHD. Also of note, they found that whether the disorder persists into adulthood or not, childhood onset ADHD was associated with higher levels of drug use and police entanglement compared to population norms.

In their 2015 study, Bondü and Esser found that among their study population, participants with ADHD symptoms reported significantly higher victim justice sensitivity, more perceptions of injustice, and higher anxious and angry rejection sensitivity, but significantly lower perpetrator justice sensitivity than control participants.

Within the meager body of literature that discusses the relationship between ADHD and internalizing behaviors, most studies attribute comorbid anxiety and depression to an individual's internalized negative self-perception due to impaired functioning in the environment. In other words, individuals with ADHD develop low self-esteem because their ADHD symptoms make it difficult for them to function normally in multiple life domains; this in turn leads to clinical anxiety and depression. However, these studies fail to consider the reciprocal determinism at play. For example, how might an unaccommodating classroom environment impact the selfconcept development and psychosocial functioning of someone with ADHD? To what extent are comorbid anxiety and depression mediated by experiences of institutional and interpersonal ableism? To date, no research of this nature exists.

Subjective Experience of ADHD

Emerging literature is beginning to elucidate the internal emotional experience of ADHD. In this section, I present data from previous studies on the subjective, lived experiences of those with ADHD. Such studies report on life outcomes, self-concept development, and the burden of illness for those with ADHD.

Harpin et al. (2016) conducted a systematic review of literature published between 1980 and 2011 on long-term self-esteem and/or social functioning outcomes of individuals with untreated and treated ADHD. They found that those with untreated ADHD had poorer long-term self-esteem and social functioning outcomes than the non-ADHD control groups, and to those receiving treatment for ADHD symptoms. This suggests that the severity and duration of ADHD symptoms across the lifespan is positively correlated with low self-esteem and poor relational outcomes. But, the researchers did not conclude how individuals with more severe ADHD symptoms may interact with their environment in a way that contributes to their poor selfconcept.

The significant burden of illness for adults with ADHD has been documented in studies across multiple regions of the world. Brod et al. (2012) conducted focus groups and interviews with 108 adults (51=women; mean age=36) diagnosed with ADHD from seven European and North American countries (Canada, France, Germany, Italy, The Netherlands, United Kingdom, and the United States) and found that participants shared similar life narratives with regard to primary symptoms, domains of impairment, burden of illness, and related impacts of the disorder. The study was designed to elicit participants' narrative accounts of having ADHD, with regard to their symptoms, activities of daily life, and social relationships. Using grounded theory as a framework, interview and focus group transcripts were analyzed and coded for major themes. Forty-five to sixty-five percent of participants endorsed experiencing the following primary symptoms associated with ADHD: hyperactivity, impulsivity, inattention, and impairing disorganization. Notable in these results are the frequent reports of hyperactivity (56%) and impulsivity (62%) as primary symptoms of the disorder among participants, while other researchers have theorized that these symptoms decrease with age. As in other studies, the majority of participants noted impairments in multiple life domains, including difficulties with

occupational functioning (63-73%) and productivity (29%), problems with finances and spending (49%), difficult relationships with parents (20-25%), tensions and challenges in partner/dating relationships (50%), and difficulties with friendship and meeting new people (3944%). In associating ADHD symptoms with behavioral traits, most participants (91%) reflected on their self-image and self-esteem, and 69% endorsed having problems with self-image and self-esteem. The investigators noted that participants' experience of their impairments appeared to contribute further to their psychological conflict and diminished well-being.

While the Brod et al. (2012) hypothesis is informed in part by the sizable cohort (42%) of participants with comorbid disorders, the narratives of subjects who reported other conditions were generally concordant with those who did not. This study has similarities that parallel my study. The self-selection of study participants, while a sound research practice, may not be an adequately representative sample of a nation's population of adults with ADHD. Volunteer participants' narratives and reports may not express the lived experiences of more silent individuals living with ADHD. Survey participants in the Brod et al. (2012) study were overwhelmingly Caucasian (73%) and from western countries. This limitation impacts its validity to a nation's population. Both the Brod et al. study and my study used convenience, purposive, and snowball sampling to survey participants. Unlike my study, Brod et al.'s study participants were older than participants in the current study. Because the focus of Brod et al.'s study was on the disabilities associated with ADHD, it did not fully explore how participants might perceive elements of the condition as positive contributions to their self-concept.

In a study of 728 Dutch adolescents between age 11 and 25, Roy et al. (2015) found that pathways from ADHD symptoms to depression were mediated by peer dislike and victimization to a statistically significant but limited extent. Grygiel et al. (2014) conducted a quantitative study from a data set of 718 Polish students between ages 9 to 12, of which 38 had been

diagnosed with ADHD. Results showed that children with an ADHD diagnosis are rejected more often by their peers and report lower levels of satisfaction with their social networks than other children. Grygiel et al. (2014) were able to endorse students' subjective assessments with classmates' objective accounts of popularity rankings. Interestingly, the study demonstrated the existence of peer bias against students with an ADHD diagnosis regardless of their level of ADHD symptomatology, or rate of negative behaviors. This runs counter to the belief that poor social functioning is exclusively due to the problematic behavior of children with ADHD.

In Mckeague, Hennessy, O'Driscoll, and Heary's (2015) qualitative study of the experience of stigmatization among young adults with mental health problems, 16 respondents (age 18 to 30) with either ADHD or depression diagnoses were interviewed about their retrospective experiences of childhood peer relationships. Key themes emerged from participants' responses: "The dominant characterization of the experience of having a mental health problem during childhood and/or adolescence was of being 'different' to others... [which] was interpreted negatively and contributed to negative self-evaluation" (McKeague et al., 2015). Furthermore, the majority respondents recounted being victimized and stigmatized by childhood peers for their disorders, and some described a "sense of injustice" at the way they were treated. While this study is limited in size and represents a homogeneous sample of white students pursuing higher education, it sheds light on the subjective experiences of social adversity for young adults with mental health disorders.

Self-Concept and Psychosocial Functioning

In this section, I operationalize the definition of self-concept and psychosocial functioning, as I use them for the purpose of this research. This is followed by a review of the literature regarding ADHD and its impact on self-concept.

Self-concept. Slight differences exist between definitions of self-concept and self-image, but the terms are generally understood to be closely related. The term self-concept has been widely used by researchers from the nineteenth century onward. Self-concept was defined in the psychological and psychoanalytic literature as an interrelated set of perceptions, beliefs, and expectations one holds about one's self in relation to others in the social environment (Sills 1967; Meffre 2004; Pines 2004; Cahn 2004). It has also been generalized to refer to a developmental formation in the psychological makeup of an individual, "consisting of interrelated attitudes that the individual has acquired in relation to his own body and its parts, to his capacities, and to objects, persons, family, groups, social values, goals, and institutions, which define and regulate his relatedness to them in concrete situations and activities (Sills, 1967). Self-image has been understood to mean one's internal representation of the self (Meffre 2004). Pines (2004), citing Burrow (1951), wrote that each individual's self-image was derived from social influences: "From infancy onward, society imposes concepts of what it is to be good and bad and each internalizes these social images and adapts to the demands of society" (Pines, p. 238). Meffre (2004) added that the self-image is also dependent on how other individuals see and assess us. Interpersonal evaluations, along with societal ideals, are then internalized by the self to engender the relational feeling of self-esteem. As Cahn (2005) posited, esteem for the self consolidates the sense of one's own value, and is therefore an evaluative component of selfconcept. A stable self-concept, independently of self-esteem, helps sustain self-regulatory action, or a focus on what one is, and on what one is becoming, based on where they know they have been (Sills, 1967). In defining self-concept as such, there is an assumed relationship between self-concept and patterns of behavioral, cognitive, and relational functioning, which may be grouped together under the term of psychosocial functioning.

Psychosocial functioning. Psychosocial functioning has been defined as the quality of one's intrapsychic well-being, interpersonal relationships, and adjustment to their environment (Goldstein 2010; Rucklidge, Brown, Crawford, & Kaplan 2007; Rucklidge & Tannock 2001; Schott 2013). Psychosocial functioning is, in various ways, influenced by one's self-concept, as self-concept is understood to consist of a schema of one's goals and one's standing in relation to others, which, in turn, impacts one's cognition, behavior, and performance (Sills, 1967).

As self-concept develops and crystallizes, based on reciprocal relationships between the self and its relational and social environment, so, too, do the individual's patterns of thinking, acting, and interacting with of others. This is reflected in an individual's consistent manner of dealing with others and situations from day to day (Sills, 1967). In other words, how someone defines their sense of self in relation to others directly affects the ways in which they behave based on that perception of self in relation to others. The idea of self-concept development and its impact on psychosocial functioning has been expounded by contemporary psychoanalytic theories and research on infant attachment (Schore and Schore 2007; Schore 2015; Wolf 1988). Self-Psychology, a psychodynamic theory developed in the 1960s and 70s by Heinz Kohut and Ernest Wolf, posits that, in order to achieve "cohesion and vigor," the developing self must be "embedded" in a social environment that is experienced as providing recognition, affirmation, acceptance, and appreciation (Wolf 1988). Kohut and Wolf termed these self-nourishing interactions as mirroring responses. A self that receives sufficient mirroring and is frustrated in a minor and non-traumatic manner by important others in the relational environment, develops self-esteem, assertiveness, and ambition (Wolf, 1988). According to Kohut and Wolf (1978), an environment that fails to respond appropriately to the needs of an evolving self impedes the development of reliable self-esteem, self-awareness, and a schema of attainable goals. From this, Kohut and Wolf postulated how thwarted self-concept development, stemming from conflictual

interactions between the developing self and its relational environment, impact later psychosocial functioning in deleterious ways.

ADHD and its impact on self-concept. In self-reports of self-esteem by children and adolescents with ADHD, having the disorder was correlated with low self-esteem regardless of the patient's symptom severity or presence of comorbid disorders. Regardless of symptom severity, comorbid disorders, or whether one received pharmacological treatment, children and adolescents with ADHD self-reported lower self-esteem across multiple domains and globally. These findings are interesting because they may indicate that self-esteem among patients with ADHD is not correlated to their experience of functional impairments necessarily, but more so to having the disorder itself.

Attention deficit hyperactivity disorder is not limited to children. Approximately 30% to 70% of children with diagnosed ADHD continue to exhibit symptoms in adulthood. It is also common that children never diagnosed in childhood may manifest symptoms of ADHD more obviously in adulthood, leading to problems at their job or in their relationships (Biederman et al. 1994; Barkley, et al. 1998; de Graaf et al. 2008). Many adults may not realize they have ADHD, and this leaves them mystified about why their goals seem to slip out of reach or why their emotions resemble a roller coaster (Barkley, et al., 2006; Fleischmann & Miller, 2012).

Rucklidge et al. (2007) examined the higher incidence of low self-esteem among adults with ADHD who were untreated in childhood. Their study combined data from two separate studies of adults for a final sample of 180 participants. Adults were divided in two groups (ADHD untreated in childhood; non-ADHD) and administered tests to rate level of ADHD symptomatology, self-esteem, childhood dissatisfaction, anxiety, and depression. The researchers also rated participants' attributional styles in childhood and at present. Respondents' data showed significantly lower self-esteem and sense of self-efficacy among the ADHD group compared to

the control group. Tests of attributional styles showed that those in the ADHD group more often considered negative outcomes experienced in adulthood to be a result of personal failings over which they have no control. Negative experiences in childhood were even more so attributed to personal shortcomings.

A study by Canu & Carlson (2007) examined levels of rejection sensitivity and its impact on romantic, friendship, and self-relational adjustment within a sample of 53 male, heterosexual college students. Contrary to Canu and Carlson's hypothesis, young men with ADHD did not show higher levels of rejection sensitivity than those without the disorder, but results did indicate that participants with ADHD held themselves in lower regard. Canu and Carlson speculated that those with ADHD might use denial and overestimation of social competency as self-protective defenses against feelings of rejection, which minimizes feelings of low self-esteem. They go on to suggest that more social psychological theories should be applied to ADHD research, given the chronic interpersonal challenges faced by many individuals with the disorder and the current paucity of research of that type.

In a similar study, Schrevel et al. (2016) found that although coping with ADHD symptoms can be a struggle for adults with the disorder, the resulting problems with interpersonal relations, feelings of being different from normal people, and repeated experiences of failure have particularly detrimental effects on their self-image. In eight focus group discussions with 52 adults diagnosed with ADHD, participants overwhelmingly endorsed feeling their symptoms were misunderstood as character flaws by those in their immediate social environment. In turn, participants felt pressure to adapt to meet - and often exceed - societal expectations, which contributed to their sense of continuous underachievement and low selfworth. Foley-Nicpon et al. (2012) found similar results in his study examining the self-concept of intellectually gifted children. He revealed that even exceptionally talented students

with ADHD scored lower on measures of self-esteem, self-image, and overall happiness than students with similar IQs but without ADHD.

In a cross-sectional study of clinic-referred children and adolescents (n=111; ages 815), Mazzone et al. (2013) found that low self-esteem was more common in subjects with ADHD than in healthy controls. In this study, investigators administered tests measuring six specific dimensions of self-esteem, as well as core global self-esteem, to 85 newly diagnosed patients with ADHD from two university clinics in Italy. Of the 85 patients with ADHD, 41 received a 6-month pharmacological treatment for the disorder before being assessed for selfesteem. In comparison to controls, all ADHD patients scored significantly lower on all selfesteem subscales and global averages. Within the ADHD group, results showed no significant difference in self-esteem between drug-treated and drug-free patients. Furthermore, higher symptom severity did not seem to have an exacerbating effect on self-esteem, nor did the presence of comorbid disorders.

CHAPTER III

Methodology

This was a preliminary, exploratory study that used an emergent, qualitative, and inductive approach to gain a deeper understanding of an evident social phenomenon among young adults with ADHD. As this research is phenomenological in nature, an inductive qualitative method seemed best suited for exploring the complex subjective experiences of the participants. As cited by Harvery (2014), Rubin and Babbie (2013) posit that an inductive qualitative approach ought to begin with observations of patterns and themes that allow the research to evolve as the researcher continues to make meaning out of the observations gathered (p. 1-2). Before embarking on this study in earnest, the empirical process began with the current researcher's clinical work with young adults with ADHD, as well as a survey of the extant literature on ADHD and psychosocial functioning reviewed in the previous chapter. I designed this study to investigate a subjective dimension of the well-documented prevalence of internalizing behaviors comorbid with ADHD. I used a semi-structured interview guide with open-ended questions in order to elicit participant narratives and reflections related to two central research questions: 1) How do young adults with ADHD construct their self-concept, and 2) how does their self-concept impact their psychosocial functioning.

Sample

Participants in this study were young adults with a diagnosis of ADHD who met the following criteria: 1) between the ages of 18 and 40 years-old; 2) received a formal diagnosis of ADHD in childhood or adulthood from a licensed professional; and 3) spoke English or Spanish.

Although the researcher engaged with approximately 15 potential participants and hoped to sample a minimum of ten participants, a total of eight participants are included in the present study. They range in age from 23 years-old to 40 years-old. All participants self-identified as having ADHD and reported being diagnosed by a licensed professional. All participants reported receiving treatment interventions for ADHD prior to this study, and most were receiving treatment in some form at the time of the interview.

I recruited participants using availability and snowball sampling methods, which included posting on social media sites and online forums, posting flyers at local outpatient clinics, asking participants to disseminate information to others they knew who met eligibility criteria, and emailing information about the study to colleagues and friends with connections to the study population. Flyers, web-posts, and e-mails advertising the study are available for review in Appendices E-G. As this is a preliminary and exploratory study that was subject to the time constraints of the thesis project, these sampling strategies seemed most appropriate. Engle and Schutt (2013) concur that "an availability sample is often appropriate in social work research when a researcher is exploring a new setting and trying to get some sense of prevailing attitudes," when conducting a preliminary, exploratory study, or when it is not feasible to access a random sample (p. 123-124). Snowball sampling allowed me to connect with additional participants through existing mutual relationships. I expected this recruitment strategy to be effective in fostering a sense of familiarity between participants and the researcher, which I hoped would then encourage participants to follow-through with the pre-interview process and share more openly in the interview itself. Engle and Schutt (2013) point out that snowball sampling is useful when researching "hard-to-reach or hard-to-identify populations for which there is no sampling frame, but the members of the populations are somewhat interconnected" (p. 126). Given the invisible nature of ADHD, and the societal stigma that keeps it as such, I

believed snowball sampling would be a helpful method of reaching individuals within this population.

Persons with an interest in the study were asked to contact me directly for an eligibility screening, during which I provided more information about the study. If they agreed to participate in the study, we arranged a day, time, and setting for the interview. During this contact, potential participants were given a copy of the informed consent, an intake questionnaire of demographic information, and a list of referrals to free mental health and ADHD resources. These items are available for review in Appendices A-C.

It proved challenging to sample this population, given the nature of the impairments in executive functioning that those with ADHD experience. Many potential participants demonstrated interest in the study but appeared to have difficulty following through to complete the screening process. In future research, recruitment strategies and the research setting should take into account issues of accessibility for participants with ADHD.

Data Collection

I collected data through qualitative, semi-structured interviews lasting 50-90 minutes, conducted at a prearranged time and setting, either in person or over web-based video call. In collaboration with my thesis advisor, I designed a broad set of questions designed to gather relevant biopsychosocial history, facilitate discussion of their ADHD diagnosis process, and to invite them to recall and reflect on experiences that have shaped their self-concept. Questions also aimed at assessing participants' psychosocial functioning at the time of this study. The semistructured interview guide used as the qualitative measurement instrument is available for review in Appendix D. All interviews were audio recorded, with salient portions subsequently transcribed and coded for emerging themes with input from my thesis advisor. By collecting participants' retrospective narratives and current reflections on their psychosocial functioning, I

captured data that offered a window into their subjective experience and the interactions between neurobiological profile and social environment. This method of inquiry highlighted how developing adults with ADHD make meaning of their experiences, understand their own psychological development, and construct a sense of self. The study design made it possible to elucidate pathways between ADHD and internalizing behaviors such as anxiety and depression, which existing literature shows are highly comorbid with ADHD. Furthermore, in choosing this approach, I sought to center the voices of those with the disorder by giving participants a chance to relate and make meaning of their own subjective experiences.

Ethics and Safeguards

Three major ethical concerns arose during the design of this study: consent, confidentiality, and the potential for psychological distress. To address these ethical concerns, I built several measures into the study design and maintained them throughout recruitment, data collection, analysis, and reporting. These measures are outlined in the following sections. To reduce the likelihood of psychological distress, recruitment materials and the informed consent letter alerted potential participants to the possibility that participation could create psychological distress due to the sensitive nature of the material discussed in the interview. Participants chose whether to contact me to participate in the study, and recruitment materials instructed them that they could do so confidentially. After our initial contact, I provided potential participants with the informed consent letter, which further explained the purpose, parameters, and details of my study. It also emphasized the participant's right to opt out of the study at any point in the process prior to May 20th, 2017. Along with the informed consent letter, I provided each participant with a resource sheet I created that included free mental health and ADHD-related services for participants to contact should the need arise.

All participants read and signed informed consent forms approved by Smith College School for Social Work before participating in the study. Signed consent forms and intake questionnaires were returned to me in person or via e-mail in electronic formats. Intake materials submitted electronically were promptly printed and their files deleted. Consent forms, intake questionnaires, and any written materials (interview notes, etc.) containing identifying information about participants were kept in a lockable file folder to which only I, the researcher, had access. At the beginning of each interview, I reminded participants that I was audio recording and asked if they were ready to proceed. Audio recordings and interview transcripts were redacted for identifying information, assigned numerical pseudonyms for identification, and saved on an encrypted, password-protected disc. After three years, in accordance with federal regulations, I will have either destroyed the material described above or will continue to maintain it in this secure fashion.

Confidentiality

Participation was kept confidential. Interviews took place in a private room or over webbased video call and only included the participant and researcher. Interviews were recorded using Express Dictate dictation software, saved in an encrypted format and stored on passwordprotected devices, and transcribed by this researcher. In addition to the aforementioned safeguards designed to adhere to the ethic of confidentiality, no information will be included in any published report or live presentation that would make it possible to identify study participants. In the following chapter, I report demographic data collected to describe the sample in the aggregate. Participants are quoted to illustrate the research findings, but these quotes are not connected to the demographic data and are referred to numerically, for example: *Participant #1*, or as *a participant* without numerical identification.

Risks and Benefits of Participation

Risks. In the consent form (Appendix A), I disclosed to participants the risk of feeling uncomfortable or emotionally activated when discussing negative life experiences and other sensitive autobiographical material. Prior to the interview, I provided all participants with a list of free referrals to local and national mental health and ADHD resources, including ADHD support groups, The National Resource Center on ADHD Helpline, and a local mental health crisis and provider access hotline. This list of referrals is available for review in Appendix C. During interviews with participants, the researcher paid attention to verbal and non-verbal cues indicating participant discomfort and, in such instances, responded in ways to help the participant feel more at ease.

Benefits. Participants of this study may have benefited from the opportunity to tell their lived experiences with ADHD and reflect on how ADHD has impacted their social and psychological well-being. The interview offered participants a forum for voicing their feelings regarding ADHD-related services and treatments they have received. Moreover, participants were able to share ideas about what supports should be available to best meet their needs and enhance their self-development.

As the researcher conducting this study, I benefited from the experience of gathering and synthesizing the narratives of participants as they made sense of the subjective experience of ADHD and how it affects self-concept development. This experience will inform my future practice of clinical social work with clients with ADHD. I also benefited from conducting this study because it is a requirement to complete my course of study at Smith College School for Social Work.

This research benefits the field of clinical social work by giving voice to the subjective experiences of a client population that has not often been researched qualitatively. Through

elucidating how neurobiological disability and ableism in the social environment may be reciprocal determinants of psychosocial development for people with ADHD, clinicians can better understand and treat clients with ADHD and advocate more effectively on their behalf.

Data Analysis

This study used thematic analysis. One of the primary benefits of thematic analysis is its flexibility, which is grounded in a method that is theoretically and methodically sound. I examined this data from two primary theoretical lenses: Self-psychology and disability theory, which I have reviewed for the reader in the previous chapter. These two lenses were then combined to produce the research data analysis. Hence, this thematic analysis identified, analyzed and reported patterns and themes within the data, which I refer to in the next chapter as *common narrative threads*. The themes found and presented in this research captured important data in relation to the research questions, and represent narrative threads that a majority of participants expressed to be true in their own lives. In the following chapter, I present these themes in order of commonality.

Chapter IV

Findings

This chapter presents a sample description and thematic findings from semistructured interviews with eight young adults formally diagnosed with ADHD. Two research questions guided this study: (1) How do young adults with ADHD construct their self-concept? and (2) How does their self-concept impact their psychosocial functioning? For the purposes of this study, ADHD was defined as a brain-based, developmental disorder characterized by a

deficit in behavioral inhibition, sustained attention, resistance to distraction, and self-regulation of physical and cognitive activity, with a mean age of onset in childhood and persisting through adulthood in a majority of cases. Self-concept was defined as an interrelated set of perceptions, beliefs, and expectations one holds about one's self in relation to others in their social environment (Sills 1967; Meffre 2004; Pines 2004; Cahn 2004). Psychosocial functioning was defined as the quality of one's intrapsychic well-being, interpersonal relationships, and adjustment to their environment.

Interview questions asked participants about their diagnosis process; how they perceived ADHD to have impacted their functioning; how caregivers, teachers, peers, partners, and colleagues have responded to them regarding their ADHD diagnosis, symptoms, and impairments; and how participants have responded to feedback from others in their social environment. Additional interview questions asked participants to identify their greatest personal strengths, their perception of how others evaluate those strengths, and defining moments and decisions in their lives. The interview closed by asking participants to share what it has meant for them to have ADHD, what they would like others to know about ADHD, and what barriers they have encountered in obtaining ADHD treatment or support. See Appendix D for the interview guide used in this study. This chapter begins with a summary of participant demographics, followed by thematic findings related to the two research questions. Excerpts from participant interviews are provided to further illustrate the common narrative threads that emerged in response to the original research questions.

Description of Sample

Eight participants were interviewed for this study, four were interviewed in person, and four were interviewed over web-based video calls. Of the eight participants interviewed, four identified as female, three identified as male, and one identified as transgender. Participants

ranged in age from 23 to 40 years-old, with a mean age of 28 years and a median age of 24.5 years. The racial composition of the sample was predominantly White-identified (n=6); one participant identified as Black/African-American and one participant identified as mixed race. Almost all participants (n=7) reported they were diagnosed as children or adolescents, and one participant did not receive a diagnosis until adulthood. The average age at time of diagnosis was 14.5 years.

Descriptions of the presenting symptoms of ADHD that prompted diagnosis differed somewhat among participants. Three participants (38%) reported inattentive symptoms, and another three participants (38%) reported both inattentive and hyperactive symptoms as the chief concerns at the time of diagnosis. Two participants (24%) mentioned only hyperactive symptoms when describing what prompted their diagnosis. The majority of participants (n=5) reported that they were assessed for and diagnosed with ADHD by a pediatrician or primary care physician; two participants reported receiving a diagnosis from a psychologist, and one participant could not recall specifically what type of licensed professional provided a diagnosis. Five participants disclosed that they were diagnosed with comorbid mental health conditions subsequent to their ADHD diagnosis. Three participants reported diagnoses of "depression," two reported diagnoses of both "anxiety" and "depression," and one participant reported a diagnosis of "anxiety." Among these five participants, one noted additional diagnoses of Oppositional Defiant Disorder and Dyslexia, and another disclosed a history of treatment for substance abuse.

Notably, all participants (n=8) stated that functional impairments manifest in educational settings precipitated seeking treatment for ADHD. When asked to list the types of ADHD treatment interventions offered to them over the course of their lifetime, all participants (n=8) stated they had been offered stimulant medications (i.e. methylphenidate, amphetamine) by a prescribing doctor, and most (n=6) were offered school-based accommodations in some form.

One participant reported being offered group therapy, and another participant reported being offered educational therapy. All participants (n=8) stated that they were treated with stimulant medications at some time since diagnosis, and a majority of participants (n=5) recalled receiving at least one school-based accommodation (e.g. extra time on tests, extensions on assignments). Only one participant recalled having an individualized education plan for comprehensive support at school.

Thematic Findings

Four primary themes emerged in participant interviews in response to the two original research questions: 1) Negative feedback from others in response to ADHD impairments led participants to internalize shame; 2) A lack of psychoeducation about ADHD provided at the time of diagnosis and during treatment led the participant to conflate ADHD impairments with inborn personality traits; 3) Engagement with activities, environments and individuals that made them feel less impaired supported the development of self-confidence and a sense of mastery; and 4) Acquisition of ADHD knowledge was a pathway to self-awareness and positive selfconcept. Each theme represents a narrative thread that a majority of participants expressed to be true in their own lives. Of course, these narrative threads existed alongside multiple others that operated and interacted in complex ways to shape participants' sense-of-self and patterns of cognition and behavior. I have chosen to highlight the four most common narratives to provide insight into how participants developed self-concept, and how their self-concept has impacted psychosocial functioning. I now illustrate each narrative thread in depth, using excerpts from participant interviews, in the following sections and subsections.

1) Negative Responses to ADHD Impairments and Internalized Shame

All participants reported receiving negative feedback from others in response to manifest symptoms and impairments of ADHD. Many participants described how such feedback often

framed their symptoms and impairments as intentional behaviors indicative of a participant's moral failing or flawed character. Participants recounted hearing this type of feedback in educational settings, from peers, and from caregivers. Most participants (n=6) spoke of how this negative feedback led them to internalize a sense of shame. To better illustrate this phenomenon, participant quotes from interviews regarding feedback they received from others is used highlight these negative responses to ADHD impairments. Later, I offer longer selections of participant commentary that represent how these recurrent messages led participants to internalize a sense of shame.

Negative feedback in educational settings. Most participants (n=6) remembered hearing recurrent negative messages about themselves in educational settings. For example, when asked about the messages she received about herself from teachers, Participant #6 recounted:

I got from teachers that, "she has so much potential," like, all the time. Everyone said that. "You're so smart," or, "if you would just try... you're not trying" and oh, "she talks too much." I remember teachers always used to say that, like, "oh, she's too talkative in class" or that I got up from my desk all the time-- And it would be to get something out of my book bag! Yeah, those are the main things that I heard, probably from the end of elementary school all the way through, I don't know, graduate school!

Participant #8 recalled hearing similar comments from teachers in middle and high school: It was like, "you're lazy," "you're not doing your work," or, "why are you not doing anything?" You know, all teachers say the same thing: "You need to apply yourself! I don't get it-- you are so smart but you just don't try."

Participant #4 remembered elementary school teachers calling her bossy for "being talkative" or "blurting things out" impulsively. Participant #3 noted his teachers' differential approach when addressing ADHD impairments versus co-occurring impairments of dyslexia:

I have dyslexia, and I think that was more talked about to me than the ADHD. So it was like, "Oh, we have these methods for you to help you read because you have dyslexia, which means it's hard for you to read. Your brain looks at words differently, or sees letters differently." Whereas with ADHD, it was like, "You need to learn to control yourself."

Participant #3 went on to describe how teachers and staff at school would try to subdue him through fiat and negative reinforcement, "like taming a lion with just keeping it in a cage." He reflected, "there was something happening in my body that I could not control." He reported that special education and applied behavioral interventions meant to target ADHD impairments were not appropriate for his needs and, consequently, ineffective and discouraging for him. For these participants, this type of feedback carried a negative and blaming context.

Negative feedback from peers. Some participants spoke about negative feedback they received from their classmates in response to their ADHD impairments, particularly regarding symptoms of hyperactivity and impulsivity. Participant #2 reflected on how peers responded to him as a child:

I guess I was a very handsy kid, and people didn't always love being touched. But I apparently loved to touch everything and everyone. And then, of course, as you get older you realize that people like their personal space and all that. So after a couple of years I started to realize I should let people have their space... [Question: How did you come to learn that?] Kids said, "quit fucking touching me!" One of my good friends growing up, he was like, "dude leave me alone!" I was like, "oh we don't goof around and punch each other any more?" I was always willing to rough-house, and I think it was just a constant need for touching and connection. If I'm not actively doing something with my hands or body, then I can't focus...

Participant #3 remembered classmates calling him "SPED" and "short bus" because he worked one-on-one with a behavior interventionist. He explained further how he had a difficult time keeping friends because he "didn't have a filter" and would make inappropriate comments impulsively. He reflected that although peers sometimes thought he was funny, he often felt he was laughing along with those who were laughing at him.

Negative feedback from caregivers. Participants also recounted misattuned responses from caregivers. Participant #2 described how his parents reacted to his hyperactive symptoms with annoyance and frustration.

Growing up, my mom got to the point where she had to tape me to a chair one time because I couldn't sit down when I was in elementary school [...] Thinking back to when I had to do my college applications, I had just gotten wrist surgery, and so [my dad and I] are sitting there trying to do my college applications, and I can't type. I have to tell everything to him and he has to write it, and I can't sit still. And he's like, "you have to sit down, you are distracting me!" And I'm like, "well, I'm focused. I'm one hundred percent focused because I'm getting rid of this built-up energy that I have elsewhere." And he's like, "no, you are distracting me! I need you to sit down and look at me when you talk!" So, I'd have to sit still and facing him, and that doesn't work for me... He thinks I'm distracted when really, I'm focused, but I have other outlets for the other thoughts. Similarly, Participant #7 recalled how her parents encouraged her to curtail her hyperactive and impulsive behaviors when she was a child with the expectation that she could control them. I was always bouncing off the walls and I didn't always pick up on people's social cues that I was being really annoying... I remember my parents would talk to me and be like, "You are annoying your uncle, you're not picking up on social cues. You don't know when to stop..."

Participant #8 reflected upon how his parents responded to the academic difficulties he experienced:

When I think back, I was really disorganized and I wouldn't be on top of my stuff, or I had a hard time really structuring myself to go sit down and do my homework [...] I think for my parents it was a lot more like, "why aren't you getting your stuff done? Why don't you care about school? You're lazy."

Participant #4 characterized her parents' attitudes towards her ADHD impairments in the following passage.

It was very problem-solving oriented, like, "what can we do to make this normal? What can we do to make this go away? What can we do to make it so you're doing stuff like everybody else? Can we just get through the day? Can we just stay organized? Can we just turn everything in today?"

She reported that her parents expected her to be able to function "normally" because she was taking stimulant medication, but remarks that she lacked skills and strategies to manage ADHD impairments that were unresponsive to medication and persisted in creating academic difficulties for her. In response to her expressions of frustration, she remembered her parents telling her, "Just get it together! Stop making excuses! Find a way to make it work, and just get it done."

Internalized Shame. Most participants (n=6) vividly recalled recurrent messages from childhood and adolescence that became ingrained in their psyche and integrated into their selfconcept over time. Their memories included caregivers, teachers, coaches, and peers expressing frustration, anger, and emotional depletion in response to participants' hyperactivity, forgetfulness, distractibility, impulsivity, and, more generally, their failure to function normatively at home and school. Participants described how recurrent negative feedback led

them to internalize a sense of shame about themselves. In Table 1, I present participants' reflections on how this process took place for them.

Table 1

Internalized Shame as an Impact of Negative Feedback from Others

Internalizea	d Shame as an Impact of Negative Feedback from Others
Participant	Participant Reflections
-	It goes back to being called a spaz, or being seen as like there's something wrong, all the way up to feeling like I'm not a very good friend because I didn't pick up on A, B, or C social cue, or I forgot this thing that we were supposed to do together [] I think the other part is no having a filter and feeling like when I'm around people, I am annoying. It's really hard feeling like I am annoying, and not wanting to be around people because of that.
Participant #4	My Dad would tell me, "just get it together. Find a way to make it work" [] And [my Mom] would be like, "stop making excuses; just get it done." That was the attitude for a long time. And I was like, well, I guess this is just me being dramatic, or me being awful [] I didn't want anyone to ask about it or know about it. I just took a pill in the morning and that's it. I'd go about my day [] That's when I convinced myself, "you're hopeless. It's all in your head. It's all you."
Participant #6	I think I just internalized it all as, "you don't measure up." Like no matter what, you don't measure up [] It almost was like the message I got was, "you can have a lot of value and do a lot of good things, but school's probably not going to be one of them for you." Even though my grandparents were physicians and my mom is really educated, it was almost like it changed the way I viewed what I could succeed at.
Participant #7	I was really hyper A very spirited, hyper child, and I could be pretty obnoxious at times. I remember my parents [] kind of telling me, "you're not picking up on [social cues], you don't know when to stop." So [it made me feel] that I was really an annoying person. And then in middle school I became really hypersensitive, and I went through a year where I just didn't talk, or I minimally talked. I went to the extreme opposite [of how I had been] and got really shy. And it was from friends and family just always being like, "you're loud and obnoxious, you're loud and obnoxious, no one likes you. People don't like that."

Participant #8

I think I did feel bad about it. I always really wanted to do well in school. And a lot of things I did do really well. Like I think I was really good at the maths and sciences in school. But I think I started to be kind of demoralized. So even in the things that I did do really well at, I kinda-- It was demoralizing to do any type of school work, because I didn't really care. At this point I was like, "well I'm not doing well in school anyways, so whatever." [...] I think I took those messages to mean that I was bad, because doing well academically is such a social thing.

Participants recounted how internalized self-beliefs based on responses from the environment shaped their behavior, life choices, and psychic well-being over the life span. In many cases, participants reported how internalized shame continued to impact their behaviors and relational functioning in young adulthood in significant ways. This researcher intends to present and discuss these findings in greater detail in a forthcoming paper.

2) Limited Psychoeducation and Conflation of Impairments with Personality

All participants (n=8) reported lacking clarity and understanding of how ADHD affected them, even years after receiving a diagnosis and beginning treatment. This led most participants (n=7) to conflate ADHD impairments with inborn personality traits. Participants diagnosed in childhood or adolescence (n=7) could recall little, if any, psychoeducation provided to them at the time of diagnosis or during treatment. Many participants explained that they were kept unaware of their diagnosis while educators, caregivers, and healthcare providers orchestrated assessments and interventions amongst themselves. For example, Participant #4 stated:

Throughout the diagnosis process, I felt like there was a conversation had about me behind my back. I didn't think there was anything wrong with my 11-year-old, M&Mloving self! And then, all of a sudden, my mom told me I needed to start taking a pill every morning.

Participant #8 recounted a similar experience:

I kind of remember doing some weird tests in some room when I was 11 or 12, and I don't think they said anything to me about why I was being tested [...] I don't really

know exactly when I was diagnosed. It must've been sometime toward the end of middle school or beginning of high school [...] But I'm not really sure because nobody was ever like, you have ADD [...] The thing is, my mom, who is also a pediatrician and worked with my pediatrician, just brought home Adderall one day and said, "you've been diagnosed."

Participants reported lacking accurate information about the nature of ADHD and the interventions being offered, which left them feeling confused about how ADHD impacted their functioning and what the objective of treatments were. As Participant #3 recounted:

When I was diagnosed, nothing was told to me about why I was being tested or why I had an IEP. I didn't know that something was different about me until probably fourth grade

[...] I remember having to go to social skills groups and thinking, "why am I here?"

Participant #5 reported not knowing what was going on during his diagnosis process either.

When asked about whether he understood why he was being assessed, he stated:

I just knew that it had to do with performance at school. I mean, I was making great grades, which was fine, but I didn't quite understand. I was like, "I'm doing good in school, so why?"

Participant #6, who thought she had been diagnosed at age nine, could not recall being informed at the time about her diagnosis or why she needed to take medication.

I don't remember them telling me at that age, you know, "you have X, Y, and Z." I remember getting pulled out of class to do the testing, or whatever [...] I remember getting pulled out for that, and I was mad. I was embarrassed, I guess... But, I remember having to take medication every morning, and I would get really mad at my mom because I didn't understand why.

Some participants (n=4) described receiving nebulous explanations from caregivers about the purpose and effects of the stimulant medication they were prescribed. Participant #4 recalled her mother telling her she needed a pill to "focus all the way through school, not get whacked in the face during sports practice [...] and make it home to do homework." Other participants remembered being told that medication would help them to feel "normal," "do better in school," be "functional." Misconceptions about medication and other treatment options made it difficult for participants to know how to manage their impairments as they got older. And, participants related that a lack of ADHD psychoeducation in general has made it harder to recognize what their own impairments are. Consequently, many participants, including those who were treated with stimulant medications, described struggling in multiple life domains and having little explanation for why.

Conflation of ADHD impairments with personality traits. As discussed in the previous section, all participants reported receiving negative feedback from others framing ADHD impairments as volitional behaviors. Among the subset of participants diagnosed in childhood or adolescence, the majority described how this recurrent messaging early in life led them to internalize a sense of shame about themselves. Without an adequate understanding of ADHD and the interventions offered to them, participants lacked a counter-narrative to this feedback. Furthermore, because treatment interventions were often explained in terms of "fixing" or normalizing something, participants described feeling that something was "wrong" with them. Participants described that, over time, they began to conflate ADHD impairments with their inborn personality traits, especially when treatment interventions failed to eradicate symptoms as others had hoped or expected. In Table 2, shown below, I present participant commentaries to highlight how a lack of psychoeducation about ADHD appeared to influence their self-concept and psychosocial functioning.

Table 2

Conflation of ADHD Impairments with Inborn Personality Traits

Participant	Participant Reflections
	thought of myself as being a "blonde," an airhead, and spacey. I've always been #1 we always had difficulties keeping things together.
Participant I #3	knew what ADHD was, like I had heard the name a lot, but I didn't know what that meant for my body. I just knew that sometimes my body felt really, really, really bad, and I did whatever I could to make it feel better.
Participant #6	Well, um this is a lot, but I started using drugs at like 13 So I don't know if I wanted to be like one of the kids who didn't care about school and, like, didn't I just wanted to be like one of the party kids. And everyone in my family was like super educated, and I just felt like I was absent the day you learn how to care about it. Now, looking back I can tell that it was kind of depression/ADHD stuff.
Participant #7	It's hard because that's definitely something I've internalized that I'm a dumb person and I'm not good enough. It would be really, really hard to work three times as hard as somebody that just pulls an all-nighter and does better than me. That is just the most frustrating thing. It makes me feel like I'm really dumb.
Participant #8	I've always wondered why I've had such a hard time in school, because I was always really good at math. It would come really easy to me, and I would be top of my class versus my English courses and history courses. And I don't know if it was because they were boring me, or if it was because they were just hard Or it's just because it's a framework of how the education is set up. But those classes I would not do well in those But now the only thing for me is that I'm like, "well, I should be able to do all this anyway, regardless. Like I shouldn't be failing school" So maybe I do use that as an excuse. I give myself an excuse not to complete this because it's hard for me. But it is harder for me to do this than other things, so maybe that's why I don't complete it. And sometimes I'm like, "maybe I am just lazy." It doesn't come as easy to me so I just don't do it. So, I mean, that is what part of it is. A lot of it is that I just don't do it. Or I don't try to do it, because it's too hard. I'll give up.

Many participants described how gaining more knowledge about ADHD, precipitated by an experience of continuing impairment in young adulthood, was significantly helpful in detangling

sequelae of the disorder from conclusions they had made about their identity. I present these findings in a later section of this chapter.

3) Developing Self-Confidence Through Positive Relational Experiences

All participants identified at least one setting in which they did not experience impairments due to ADHD symptoms. In such environments, participants described a sense of relief as they recalled feeling "normal," "good at something," and "motivated." These experiences offered participants an opportunity to receive positive feedback from adults and peers, and, consequently, were significant in the development of self-concept. One participant related how he began to feel a shift in his self-confidence during middle school after finding an interest and talent in theater.

I want to say it started in the theater. That's where I got my self-confidence, because I was able to be myself without restriction or the assumption that I was going to flip this or, "he's going to rip that," or, "he's going to sit on this person." [...] And I think because I was able to be larger than life on stage, and there were no restrictions on that, I found connection.

One participant in this study stated that he avoided internalizing stigma related to ADHD in part because his elementary school offered a support group for students with the disorder. Another participant attributes his perseverance in school to his involvement in athletics:

I played sports [...] When someone was like, "what do you do?" that's what I would say. That's what I really prided myself on. And for a while, that's what kept me in school. That was the reason I went to school even after I stopped caring about school [...] That's why I wanted to go to college [...] I would get a lot of praise for it, and I don't think that happened in other things [...] It brought me into a group of people who were like-minded, too.

While these experiences impacted participants' self-concepts, they also appeared to impact participants' psychosocial functioning. Describing her experience as a late adolescent working a summer job at an amusement park, one participant remarked, "I had to be really loud, so that started to bring me out of my shell. I had to make announcements to the amusement park over the loudspeaker and had to be really outgoing." Another participant explained how, since gaining a sense of mastery in a new career, she has had more confidence to "own" her impairments and practice learning new skills to manage them. She remarked, "people with ADHD should work in a setting that plays to their strengths. They should hone in on their strengths." New-found confidence from gaining a sense of mastery in an activity or environment seemed to strengthen resolve for many participants to persist despite adversities they faced in other domains of life.

In addition to activities and environments, most participants (n=6) described transformative relationships with others who were "patient and empathetic," who "understood the idiosyncrasies of ADHD," and offered supportive "structure and accountability." One participant recalled a coach from high school who remains a positive influence in the participant's life:

She was able to give the amount of patience that I needed [...] [She] saw through the aggression and through the disruption, and really saw it as, "I want to be good." Another participant explained how she "started to embrace [her]self again in college through making friends with people who appreciated some of the "behavioral traits" she had "learned to suppress." These relationships helped buoy participants' self-confidence and shore up a more positive self-concept. And, similar to participant experiences in settings where they felt less impaired, empathically attuned relationships seemed to have a lasting effect on participants' selfconcept and psychosocial functioning. Given this finding, it was not then surprising that participants benefited from psychotherapy and other adjunctive treatments that facilitated

selfinsight and provided psychoeducation about ADHD. I will now present findings related to participants' acquisition of knowledge about ADHD in young adulthood and the impact on selfconcept development and psychosocial functioning.

4) Gaining Knowledge About ADHD as a Pathway to Self-Awareness

Most (n=5) participants related how gaining knowledge about ADHD later in life has led to feeling more self-aware and better adjusted in their environment. However, this was not so easy to come by, even when looking in the obvious places. Some participants reported disappointment in services received from mental health professionals they consulted in hopes of finding additional, non-pharmacological support for ADHD. One participant recalled a recent experience of returning to see a psychiatrist after having stopped treatment with stimulant medications for a number of years:

I went back to see a psychiatrist again... I told him, you know, that I was having trouble in school and stuff... I think he thought I was just coming in to get Adderall, which I kind of was, but he was basically kind of like, "okay do you want the Adderall?" And that was the only solution to it. And then I asked, "are there other ways around it, like besides taking Adderall?" He didn't seem to put much effort into it. He printed something out that I could've printed off Google and said, "These are exercises you can do." He didn't even talk about them or anything. I thought that was weird. I guess medicine is just a quicker, easier solution for them.

Another participant reported going to a psychologist who provided "some helpful psychoeducation around ADHD," but he further remarked:

I had to learn how to adapt myself. I didn't have anybody holding my hand. I did a lot of my own research on ADHD [...] I feel like it's something I've been able to manage through constant self-reflection and adaptation.

Although all participants noted having to learn to "adapt" or "manage" their ADHD impairments in their own ways, some participants reported getting guidance from healthcare professionals.

For one participant, getting a full explanation of the nature of ADHD was revelatory for him.

Growing up, I never really put any thought into why I was the way I was. It wasn't until a doctor at college sat me down and was like, "these are your problems. This is where your developmental issues are. This is how you need to learn to overcome them."

He explained further that learning more about the disorder and its impacts has encouraged his use of new techniques to "deal with ADHD," and, in turn, improved his psychosocial functioning overall.

Knowing myself and how I work and learn gives me a sense of control [...] I've learned that I have to have a planning process. I've learned about how I need to think [...] I have to keep in mind that I might get distracted and think something is a great idea to do, and then realize it's not such a good idea. I have to give myself enough time to get where I want to get.

For this participant, self-knowledge has translated into more clarity for him around life choices. He explained:

I want to work in a fast-paced environment so that there is no time to get distracted by what's going on elsewhere-- Repetitive tasks with immediate feedback, singularly focused on one or just a few objectives.

Another participant described a profound experience of connecting with a therapist who, by providing psychoeducation and actionable coping strategies, helped her re-author the narrative that there was something "wrong" with her:

...Having someone finally break it down for me and be like, "this is what this is," I learned that this is normal for this subset of people. It's not just me, which I was led to

believe for a really long time [...] And being given strategies to retrain my brain... and realizing it's a thing! It's what makes you different! You gotta work with what you have.

If you fight it, you are just screwed [...] So I might as well embrace it and live with it.

Whether through psychotherapeutic treatment or self-study, participants who sought to learn more about ADHD and its impact on their lives reported that self-knowledge improved their selfconcept psychosocial functioning. Moreover, it appeared that these participants had integrated

ADHD into their self-concept so that impairment was no longer fused with identity.

Summary

In this chapter, I presented my findings from interviews with eight young adults diagnosed with ADHD. This study was guided by two research questions: (1) How do young adults with ADHD construct their self-concept? and (2) How does their self-concept impact their psychosocial functioning? Semi-structured interviews with each participant explored the lived experience of the disorder, their self-concept, and how self-concept impacted their psychosocial functioning. Four common narrative threads emerged in relation to the research questions: 1) Negative feedback from others in response to ADHD impairments led participants to internalize shame; 2) A lack of psychoeducation about ADHD provided to a participant at the time of diagnosis and during treatment led the participant to conflate ADHD impairments with inborn personality traits; 3) Engagement with activities, environments and individuals that made them feel less impaired supported the development of self-confidence and a sense of mastery; and 4)

Acquisition of ADHD knowledge was a pathway to self-awareness and positive self-concept.

The common threads in participant narratives, as illustrated in the preceding quotes and passages, suggest that young adults with ADHD are subject to misattuned and negative feedback from the

relational environment in response to ADHD symptoms and impairments. Further, such experiences appear to have a detrimental impact on an individual's self-concept and psychosocial functioning, thus exacerbating the burden of illness. This effect seems to be mitigated by counter-experiences in settings and relationships where individuals receive empathic encouragement, acknowledgement for their strengths, and unconditional acceptance. Finally, findings strongly suggest that psychoeducation and multimodal treatments that facilitate skill building and self-insight can help young adults with ADHD establish a more positive selfconcept and improve psychosocial functioning. The implications of these findings for educators, caregivers, and mental health professionals are discussed in the next chapter, along with an outline of study biases and limitations.

CHAPTER V

Discussion

This chapter discusses findings from the present study and data from previous research in this area. Results of the current study support findings from Shaw et al. (2012), Shrevel et al. (2016), Rucklidge et al. (2007), Varma (2015), Wehmeier et al. (2010), McKeague et al. (2015), Meinzer et al. (2015), Meinzer et al. (2014), Strohmeier et al. (2016), and Torrente et al. (2014). To investigate a subjective dimension to the high comorbidity of internalizing behaviors among young adults with ADHD, I designed this study to elicit participant narratives and reflections related to their lived experience of the disorder, their development of selfconcept, and their psychosocial functioning in young adulthood.

For the purposes of this study, I defined self-concept as an interrelated set of perceptions, beliefs, and expectations one holds about one's self in relation to others in their social environment. Psychosocial functioning was defined as the quality of one's intrapsychic wellbeing, interpersonal relationship, and adjustment to their environment. Self-concept is widely believed to influence psychosocial functioning in various and complex ways (Goldstein, 2010; Sills, 1967). For instance, one's sense-of-self is constructed, in large part, through one's interpretation of experiences in their social environment. The ways one thinks and behaves is based upon a perception of one's self in relation to others. As participants in the current study reported, the development of self-concept for an individual with ADHD can involve experiences where symptoms and impairments interact in conflict with others in the social milieu. Participants in the current study identified how they internalized a negative self-concept when ADHD impairments were attributed to character flaws and moral failings of the individual, instead of as related to a neurodevelopmental disability. Over time, these messages engendered an undergirding self-doubt that they could not measure up to expectations in academic, occupational, and social environments and relationships. This phenomenon appeared more frequently when participants as well as those in their relational environment lacked an understanding of ADHD. In such cases, the developing self-concept is constructed through recurrent experiences of failure and misattunement that feel out of the individual's control. Participants described the bewilderment of receiving negative feedback about their behavior without an internal awareness as to how the objectionable behavior became manifest. This led these participants to conclude that what others said about them was true: they were "lazy," "obnoxious," "aggressive," "annoying," and "spacey."

Participants also illustrated how self-concept impacted their psychosocial functioning in ways that were discrete from ADHD symptoms and impairments. Participants who reported

recurrent early experiences of others negatively reacting to ADHD impairments and attributing them to a deficiency in the participant's moral fiber, character, or personality grew up to exhibit comorbid internalizing symptoms and behaviors, including anxiety, depression, and substance abuse. Participant narratives seem to suggest that participants' internalizing behaviors and symptoms occurred in response to negative experiences in the environment. Otherwise stated, when participants were left to believe that what others said about them was true, they acted out those externally-imposed self-beliefs or internalized the conflict between how others saw them and what they felt to be true within their own bodies.

As participants of the present study described, feelings of loneliness, confusion, and isolation may contribute to internalizing behaviors and symptoms and that impair psychosocial functioning. Numerous studies have posited a causal association between developmental delays and the high rate of comorbid internalizing disorders among those with ADHD; however, the findings of this study suggests a stronger correlation between one's experience in their environment and one's internalizing behaviors and symptoms. In other words, it isn't that the disorder itself makes people depressed and anxious, it's the way that those with this neurobiological profile are *responded to* that makes them depressed and anxious.

In the present study, qualitative data was used in an effort to center the voices of persons with ADHD, as little qualitative research exists exploring the subjective experiences of individuals with the disorder, especially in adults. The widening recognition that ADHD persists throughout the lifespan has invited new questions about how individuals with the disorder develop a sense of identity and self-concept over the course of their lives. However, the design and approach of this study presented limitations with regard to generalizability and replicability. The study was limited by its sampling method, which unfortunately cannot ensure that the data collected is representative of the experiences of all young adults with ADHD. It should be noted

that availability, convenience, and snowball sampling strategies were chosen because of the study's preliminary nature and the time constraints of graduation requirements; to be sure, a year-long study would enable the researcher to recruit a much larger and more diverse sample, particularly in terms of educational attainment, race, and profession. Yet in light of these limitations, this study does add an important body of knowledge to how young adults with ADHD construct their self-concept and how their self-concept impacts their psychosocial functioning.

In conducting this type of research, I acknowledge that my personal biases are inherently implicated. There are several assumptions about this research. These assumptions include the supposition that ADHD is a real, diagnosable disorder, and that the lack of appropriate social supports, intervention and skill are detrimental to the psychosocial functioning and development of individuals with the disorder.

Findings from my research study support the imperative for clinicians, educators, parents to be more responsive to the needs of children with ADHD, because there can be a gap between how those with ADHD understand their experience and how their clinicians seem to understand their experience. These results also underscore the importance of helping youth with ADHD understand their diagnosis and participate in choosing treatment options. Psychotherapy appeared to have potential as a mediating factor, particularly when therapists provided psychoeducation about ADHD, facilitated skill-building, and helped support the development of self-concept that integrated ADHD but did not conflate impairments with character deficits. Further, engagement with activities, environments, and relationships that provided an opportunity to feel less impaired appeared to contribute to the development of positive selfconcept.

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Appendix A: Participant Consent Form



2016-2017

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

.....

Title of Study: Coming of Age with ADHD: Narrative accounts of young adults as they develop a sense of self

Investigator(s):	Malcolm Miller -	email:	mbmiller@smith.edu
0 ()			

.....

Introduction

You are being asked to be in a research study of young adults with ADHD. You are an eligible participant because you are between the ages of 18 and 40 and have a diagnosis of ADHD. Please read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

The purpose of the study is to try to understand how the experience of having ADHD impacts your selfesteem, life choices, and interpersonal relationships as a young adult.

This study is being conducted as a research requirement for my master's in social work degree at Smith College SSW. Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

If you agree to be in this study, you will be asked to do the following things:

- Complete a phone screening with me to determine your eligibility for the study and to schedule an interview.
- Complete a participant questionnaire to provide background information about your family and personal history related to education, occupation, health, and ADHD diagnosis and treatment.
- Meet with researcher one-on-one for a semi-structured interview lasting 50-90 minutes at a
 mutually agreed upon time and location in the Atlanta, GA area, over the phone, or on a video
 conference.
- Talk about your experience of living with ADHD, self-development, life choices, relationships, and current functioning.
- Permit me to take written notes and/or audio record during the interview.

Risks/Discomforts of Being in this Study

- There is a possibility that you may feel uncomfortable or distressed by sharing autobiographical material of a sensitive nature. The likelihood of this risk depends on an individual participant's level of comfort discussing content and emotions related to personal experiences.
- Most interview questions have been designed to be open-ended, so that you will have agency in deciding what personal information you disclose.
- You will be provided with a list of free referrals to local and national mental health resources for follow up support if needed.

Benefits of Being in the Study

The benefits of participation are:

- The opportunity to share your lived experiences with ADHD and to discuss how ADHD has impacted your social and psychological well-being.
- The opportunity to freely give voice to your emotions and feelings, and to share with others what needs to be done and what services should be provided to best support the self-development of people with ADHD.

The benefits to social work/society are:

- Giving voice to the subjective experiences of a population that has not often been researched qualitatively.
- Helping clinicians better understand, treat, and advocate on behalf of clients with ADHD.

Confidentiality

Your participation will be kept confidential. Interviews will take place in a private room, over the phone, or on video conference and will only include me and you. Interviews will be recorded using Nuance Dragon dictation and transcription software, saved in an encrypted format, and stored on a passwordprotected mobile device. All signed consent forms and other documents containing identifying information of participants will be kept in a secure lock box and stored separately from audio recorded data. When data is transcribed, I will use pseudonyms to protect the identity of participants. Consent forms and transcriptions, coded to protect participant identities, will be kept separate in an encrypted file to which only this researcher has access.

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

Payments/gift

You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the study *at any time* (up to the date noted below) without affecting your relationship with me, the researcher of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. If you choose to withdraw during the interview, I will not use any of your information collected for this study. You must notify me of your decision to withdraw by email or phone by 2/20/2017. After that date, your information will be part of the thesis.

Right to Ask Questions and Report Concerns

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

Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep. You will also be given a list of referrals and access information if you

Consent

experience emotional issues related to your participation in this study		
	•••••	
Name of Participant (print):		
Signature of Participant:	Date:	
Signature of Researcher(s):	Date:	

1. I agree to be audio recorded for this interview:

Name of Participant (print):			
Signature of Participant:		Date:	
Signature of Researcher(s):		Date:	
2. I agree to be interviewed, bu	nt I do not want the interview to be	recorded:	
Name of Participant (print):			
Signature of Participant:		Date:	
Signature of Researcher(s):		Date:	
Appen	dix B: Pre-Interview Intake Quo	stionnaire	
Date:	Name:	Age:	
Thank you for your interest in participating in this research study. You have been selected for this study because you are a young adult diagnosed with ADD/ADHD (18-40 years old). I'm seeking to learn more about how ADD/ADHD has impacted your self-esteem, relationships, and life choices. Please take a moment to fill out the autobiographical information below. Keep in mind that all information collected is for the purposes of this research study and will be kept confidential according to federal laws regarding Protected Health Information (PHI).			
Marital/relationship status:	Race (check all that apply):	Gender (check of	one):
Married□	Alaska Native□	Female□	
Partnered/in a relationship□	American Indian□	Male□	
Single□	Asian□	Non-Binary□	l
Divorced□	Black or African-American□	Transgender FT	
Separated□	Latino/Hispanic□	Transgender M	1 f∟
Widowed			

		Native Hawaiian or Pacific		
		White□		
Current living si	tuation:	List/describe primary occupation(s):	Employment	Number of hours worked/in school
□Owned		1 ()	status: □Full	per week: □50+
house/apartment	t/condo		time employee	□ 41.40
□Rented			□Part time	□41-49
house/apartment	t/condo		employee	□35-40
☐Staying in s			□Independent	□21-34
home			contractor	□15-20
□Group home	2		☐Sole proprietor	□5-14
□Adult Foster Care			□Unemployed	□1-4
☐Transitional Living Facility			□Student	□0/Not applicable
☐Correctional Facility			□Volunteer	
□Military Base				
□Homeless				
FAMILY HISTORY:	Mother	□Living □Deceased	<u>Father</u> □L	iving \(\sigma\)Deceased
Marital status:				
Primary occupation:				

Highest level of education completed:	□Less than 12th grade □12th	□Less than 12th grade □12th grade/HS	
completed.	grade/HS □Vocational/Technical	□Vocational/Technical □Some college	
	□Some college	□Bachelor's Degree (BA, BS)	
	□Bachelor's Degree (BA, BS)	☐Graduate degree (Master's or Doctorate)	
	☐Graduate degree (Master's or Doctorate)	□Don't know	
	□Don't know		
Does this family member have ADD/ADHD?	□Yes, they have been formally diagnosed with ADD/ADHD	☐Yes, they have been formally diagnosed with ADD/ADHD	
	☐They have not been formally diagnosed,	☐They have not been formally diagnosed,	
	but I/they suspect they have ADD/ADHD	but I/they suspect they have ADD/ADHD	
	□No, they have never been diagnosed, nor	☐No, they have never been diagnosed, nor	
	do I/they suspect they have ADD/ADHD	do I/they suspect they have ADD/ADHD	
	□I don't know/I'm unsure	□I don't know/I'm unsure	
FAMILY HISTORY	Do you have siblings?		
(CONTINUE D):	□Yes □No		
	If you have siblings (full or half), list them in birth order from eldest to youngest below. Include yourself, and check left-most box to indicate your place in birth order.		

□1. Gender:_		Age:	_ ADD/ADHD diagnosis: □yes	□no
□I/they suspec	et yes □do	on't know/unsure		
□2. Gender:_		Age:	ADD/ADHD diagnosis: □yes	□no
□I/they suspec	et yes □do	on't know/unsure		
□3. Gender:_		Age:	_ ADD/ADHD diagnosis: □yes	□no
☐I/they suspec	et yes □de	on't know/unsure		
□4. Gender:_		Age:	_ ADD/ADHD diagnosis: □yes	□no
☐I/they suspec	et yes □do	on't know/unsure		
□5. Gender:_		Age:	_ ADD/ADHD diagnosis: □yes	□no
☐I/they suspec	et yes □do	on't know/unsure		
□6. Gender:_		Age:	_ ADD/ADHD diagnosis: □yes	□no
□I/they suspec	et yes □do	on't know/unsure		
□7. Gender:_		Age:	_ ADD/ADHD diagnosis: □yes	□no □I/they
suspect yes \(\square\)don't know/unsure				
Please use space below to list additional siblings as needed, including gender, age, and whether they have an ADD/ADHD diagnosis.				
PERSONAL HISTORY:	The followin	g questions ask about you	r own academic and health history.	
111010111				
_	At what age were you first formally diagnosed with ADD/ADHD? Formal diagnosis given by:			
years old				

	□psychiatrist □psychologist □neurologist □school
	counselor/school psychologist \(\square\)social worker \(\square\)primary care physician
	□pediatrician □other □don't know/unsure
Approximate date of ADD/ADHD diagnosis:	Which ADD/ADHD treatment options have been <i>offered</i> to you? Select all that apply.
	□stimulant medications □non-stimulant medications □peer support
(month/year)	groups □individual psychotherapy □occupational therapy □group
	psychotherapy □family therapy □applied behavioral therapy □skills
	training \(\sum_{\text{life}}\)/academic coaching \(\sum_{\text{educational therapy}} \sum_{\text{school}} \)
	accommodations □special education (IEP/504 plan) □workplace accommodations
Highest level of education completed:	Which ADD/ADHD treatments have you <i>received</i> ? Select all that apply.
□Less than 12th grade	□stimulant medications □non-stimulant medications □peer support
□12th grade/HS	groups □individual psychotherapy □occupational therapy □group
Diploma/GED □Vocational/Technical	psychotherapy □family therapy □applied behavioral therapy □skills
Diploma	training \(\square\)life/academic coaching \(\square\)educational therapy \(\square\)school
☐Some college/university	accommodations □special education (IEP/504 plan) □workplace accommodations
□Bachelor's Degree (BA,	
BS)	Which ADD/ADHD treatments are you <i>currently receiving</i> ? Select all that apply.
☐Graduate degree	□stimulant medications □non-stimulant medications □peer support
(Master's or Doctorate)	groups □individual psychotherapy □occupational therapy □group
☐Decline to state	psychotherapy □family therapy □applied behavioral therapy □skills
	training \(\square\)life/academic coaching \(\square\)educational therapy \(\square\)school

	accommodations
Have you ever been diagnosed with or received treatment for any of the following conditions?	□Bipolar Disorder □Sickle-Cell Anemia □Cerebral Palsy □Tourette Syndrome □Autism Spectrum Disorder □Depression
	□Fibromyalgia □Anxiety □learning disability □Oppositional
	Defiant Disorder (ODD) □Diabetes □Obsessive Compulsive Disorder (OCD) □Substance Use Disorder □Conduct Disorder □Dyslexia
	□autoimmune disorder

Thank you taking the time to provide this information before meeting for the interview. You may send an electronic copy via e-mail to mbmiller@smith.edu, or bring this completed packet to your *in-person* interview. Participants interviewed via phone or video chat must send me an electronic copy before the interview.

^{***}Make sure to read and sign the participant consent form. I must have your signed consent before conducting an interview.

Appendix C: List of Free Referrals for Participants

Dear participant,

Thank you for your time and willingness to share your story of living with ADHD.

I hope that relating your experience felt beneficial to you in some way, too. The intention behind this project is for your narrative -in concert with those of others participating in the study - to give voice to the collective experience of young adults with ADHD so that we may be better understood and supported in society. I look forward to sending you a summary of the study results once the project is completed.

I also acknowledge that discussing the content and emotions of one's personal life can be uncomfortable or distressing. You may also find that participation in this study has led you to want more information about ADHD and/or available treatments. In such cases,

I encourage you to seek support from the **FREE** resources listed below:

Georgia Crisis & Access Line (GCAL) - (800) 715-4225

The Georgia Crisis & Access Line is staffed with professional social workers and counselors 24 hours per day, every day, to assist those with urgent and emergency needs. Those callers who need more routine services are directly connected with the agency of their choice and given a scheduled appointment.

SAMHSA Treatment Referral Helpline - (877) 726 4727

Get general information on mental health and locate treatment services in your area. Speak to a live person, Monday through Friday from 8 a.m. to 8 p.m. EST.

The National Resource Center on ADHD Helpline - (800) 233-4050

The NRC is the only national resource where people can receive an individualized response from a Health Information Specialist knowledgeable in the full range of issues concerning ADHD. Our English and Spanish-speaking Health Information Specialists respond to queries Monday—Friday, 1–5pm EST.

The ADDitude Directory - http://directory.additudemag.com/

Find ADHD treatment professionals, educational resources, and ADHD coaches and organizers around the USA. ADDitude Magazine (additudemag.com) also offers free online peer-to-peer forums, psychoeducational information, and articles about treatments and self-strategies to manage life with ADHD.

If you feel your participation in this study has caused you undue emotional hardship, please do contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974. If you have other concerns or questions about this study at any time, feel free to contact me, Malcolm Miller, at mbmiller@smith.edu or at 404-919-2676. Thank you again for your time, energy, and candor.

All the best,

Malcolm Miller Masters of Social Work Candidate Smith College School for Social Work

Appendix D: Semi-Structured Interview Guide

Participant:	Big takeaways:
THE CARPARIES :	
Talk about ADD/ADHD diagnosis process:	
• What led up to diagnosis?	
 What did you notice in yourself, or what did others notice in you, that prompted seeking attention from a professional? 	
 How do you remember feeling about getting diagnosed? 	
 If diagnosed as a child, what do you remember about your caregivers' attitudes towards the ADHD diagnostic process? 	
• If you were not diagnosed and/or treated for ADHD as a child, how did you name it, and how did others name it?	
Talk about how you perceive ADHD to	Looking back, how would you describe yourself as a child?
have impacted your functioning:	How were you able to identify those attributes in yourself at the time?

Reflecting back on experiences in your past:
(How did that make you feel about yourself? What messages did you internalize? How did you conceptualize yourself?)
Reflecting on present day experiences:
(What are the feelings you associate with these experiences? What messages have you internalized about yourself? How have you made sense of that?)
How would you describe yourself as you are today? What is life with ADHD like for you?

Talk about how others have responded	When others describe what you are like as a(child, student, friend, sibling,
to you with regard to your ADHD	coworker, partner, employee, boss), what do they say?
symptoms:	
 What feedback have you received from others, and in what circumstances? Relatives Siblings 	
PeersCoworkers	
o Employees	
SupervisorsPartners	
Teachers	
Talk about how you have responded to this feedback from your environment:	How do you feel when listening to people talk about how you are?

How has it made you feel?	
What has it made you believe about yourself?	
How has it impacted your behavior?	
Talk about your greatest personal strengths:	What do you value most about yourself? Why? How have these strengths served you?
What do you consider to be your most valuable assets?	
Where/how/why did you discover them?	
In what settings/how often are you able to put these assets to use?	
Talk about how you perceive others to recognize/value the attributes you consider to be personal strengths:	How have you been recognized by others for these strengths? In what settings do others seem to acknowledge your strengths?
What feedback do you get from others about the attributes you consider strengths?	
When you are assessed for your performance (at work or school) or given feedback from peers or partners, which of your positive qualities are most often recognized?	
Talk about defining moments in your life/important decisions:	

How did your thoughts/assessments about yourself influence how you made those decisions?	
When you reflect on these moments/decisions, how do you feel about yourself?	
How has the way you see yourself impacted the choices you have made about your life's direction?	
 What roles do you tend to take on in friendships/relationships/in groups? 	
What has is meant for you to have ADHD?	
What do you want others in your life to know about ADHD?	
What do you want health care providers, educators, and policymakers to know about ADHD?	
What barriers have you encountered in obtaining treatment or support related to ADHD?	

SEEKING

Adults (18-40) diagnosed with ADD/ADHD

I am conducting a research study of young adults with ADHD.

I want to hear your story about how ADHD has impacted your self-esteem, life choices, and relationships.

You are eligible to participate in this study if you:

- Have a diagnosis of ADD/ADHD
- Are between the ages of 18–40
- Speak English or Spanish
- Are willing to meet for a one-on-one, confidential interview to talk about your experience living with ADD/ADHD
- Are willing to disclose personal information related to your medical diagnoses and family medical history

There is no compensation for participation in this study

Please contact Malcolm Miller to schedule an interview <u>before April</u> <u>25th</u>. Interviews are offered via webcam, telephone, or in-person at a mutually agreed-upon location in the Atlanta, GA area.

This study has been approved by the Smith College School for Social Work Human Subjects Review Board.

Appendix F: Recruitment Web Posts

PARTICIPATE IN AN ADHD RESEARCH STUDY

If you have ADHD, are between the ages of 18-40, and live in the Atlanta area, you are invited to participate in an *Attention Deficit Hyperactivity Disorder* (ADHD) Research Study. I want to hear your story of how ADHD has impacted your self-esteem, life choices, and relationships.

If you are interested, please contact Malcolm Miller at (xxx) xxx-xxxx or mbmiller@smith.edu by April 25th, 2017. This research has been approved by Smith College School for Social Work Human Subjects Review Board, Northampton, MA.

Friends, and friends of friends: If you have ADD/ADHD and are 18-40 years old, I want to talk to you!

I want to hear how your experience of having ADHD has impacted your life and the way you see yourself. If you are willing to tell me your story (in an informal interview, over the phone or in person), please contact me via Facebook message, e-mail: mbmiller@smith.edu, or call: xxx-xxx-xxxx

This is project based on an independent investigation, to be submitted in partial fulfillment of the requirements for the degree of Master of Social Work. This study is approved by the Smith College School for Social Work Human Subjects Review Board.

Appendix G: Participant Recruitment E-mail

Dear colleagues and loved ones,

As some of you know, I am conducting a study on young adults with ADHD for my master's thesis project. As I bear down on the final stretch, I'm looking for more participants to interview for this study before 4/25. If you or anyone you know are willing/able to take part, please pass the word along!

You are eligible to participate in this study if you are:

• 18-40 years old (sorry Dad)

- Have a diagnosis of ADD/ADHD
- Are willing to be interviewed by me via phone or webcam for approximately 1 hour about your experience living with ADD/ADHD
- · Are willing to share information related to your medical diagnoses and family medical history

*This study is approved by Smith College School for Social Work Human Subjects Review Board

I encourage anyone who fits criteria to call me at xxx-xxxx or e-mail me at mbmiller@smith.edu to schedule a call this week!

Thank you for your support!

Appendix H: HSR Approval Letter



School for Social Work Smith College Northampton, Massachusetts 01063

February 13, 2017

Malcolm Miller

Dear Malcolm,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee. You may need to be ready to change dates on your recruitment and consent documents since you have February 22nd target dates for some things, and these may become wrong dates.

Please note the following requirements:

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

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

In addition, these requirements may also be applicable:

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

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

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

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.

Co-Chair, Human Subjects Review Committee

CC: Narviar Barker, Research Advisor

Appendix I: HSR Amendment Approval Letter



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

April 27, 2017

Malcolm Miller

Dear Malcolm,

I have reviewed your amendment and it looks fine. The amendment to your study is therefore approved. Thank you and best of luck with your project.

Sincerely,

Elaine Kersten, Ed.D.

Co-Chair, Human Subjects Review Committee

CC: Narviar Barker, Research Advisor