4-2019

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Recommended Citation
Lynn, Noelle Marita, "Women & ADHD Functional Impairments: Beyond the Obvious" (2019). *Masters Theses*. 933.
https://scholarworks.gvsu.edu/theses/933

Women & ADHD Functional Impairments: Beyond the Obvious

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A Thesis Submitted to the Graduate Faculty of
GRAND VALLEY STATE UNIVERSITY
In
Partial Fulfillment of the Requirements
For the Degree of
Masters in Social Work

School of Social Work

April 2019

Dedication

For Jan Louise Gornik, Gregory Dale Lynn, and Mary Anne Kenedy

Your lives inspire me every day to serve, love, grow, and learn. You taught me to live a life of integrity, wholeheartedness, and faith; without you I would not be who I am today. Thank you for believing in me and for your unfailing love.

Acknowledgments

This thesis would not have been possible without the unwavering support and encouragement of Dr. Cray Mulder and Dr. Lihua Huang. Your teaching, mentorship, guidance, wisdom and support have seen me through the hardest times and this project. Thank you for helping me learn to love research.

To Aaron Kates, who spent an enormous amount of time helping me navigate the ins and outs of this project and who told me to become a social worker. I wouldn't be here without you.

To Dr. Tamara Rosier and Dr. Oren Mason, without whom I would never have been able to learn to thrive in life, let alone complete a master's degree and thesis research project. You inspire me. Thank you for seeing and encouraging my potential.

To Sarah Denick, who faithfully walked through this project with me as a friend, fellow social worker, transcriber, and reader. Your insights, intelligence, and perspectives were priceless throughout this process. Thank you for believing in me and in the importance of this work.

To my husband, Michael Lynn, who put up with the endless hours of homework, research, and writing, and never complained, but instead insisted I keep working. Thank you for being able to see the finish line when I could not, for being my steadfast support throughout all our losses, and for your unshakable belief in my intelligence and ability to impact the world. This thesis would not have happened without you.

Preface

This Master's in Social Work thesis research project was an unexpected journey. I began this project in August 2017. Between then and now, April 2019, I lost my father-in-law and my mother, both unexpectedly and suddenly. There were many times I considered giving up, thinking it was far too much to do in light of everything life was throwing at me.

Yet, I persisted and I am glad I did. This project allowed me to connect with fourteen women from all over the United States who, in their own ways, were also going through challenging experiences; their experiences caused by ADHD. This project helped me to keep my own pain in perspective. Through this project I have grown personally in countless ways. I was pushed to become a deeper critical thinker, a better writer, and to begin down the path of scholarly research. This thesis project is, for me, living proof that perseverance, tenacity, and determination do pay off in the end.

I persisted also because I believe this research matters. I believe the voices, perspectives, pain, frustrations, and lived experiences needed to be shared. Our understanding of Attention Deficit Hyperactivity Disorder and its effects on women needs to deepen and grow. My goal with this study was to contribute to the body of research available on women and their internal lived experience of ADHD and its functional impairments. Through this study may those living with ADHD find hope; that they are heard, that they are seen, and that they can be understood. Most of all, I hope this study can encourage those of us working in clinical practice and research to take seriously the internal lived experiences of our clients, so our clients can learn what it is like to live in a kind, compassionate, hopeful internal environment.

Abstract

Women with Attention Deficit Hyperactivity Disorder are an understudied and underserved population. Research on women with ADHD has shown that they are significantly impaired by ADHD and its functional impairments. It also shows that women often internalize their symptoms and impairments. However, no research was found that explores what this internalization does to the women. The researcher chose to begin to address this gap in the literature through this qualitative phenomenological study. The purpose of this study is to explore the impact of functional impairments caused by ADHD on the internal lived experiences of women.

The researcher conducted fourteen interviews with women between the ages of 32 and 59 from across the United States. Once the interviews were completed the researcher applied a phenomenological coding process to the data. The essence of the phenomenon which came through the descriptions given by the women was that living with functional impairments caused them a negative and undesirable internal experience. This lived experience was described as intense, stressful, frustrating, draining, and isolating.

Several themes were also discovered through the fourteen interviews. The women described that they experience intense shame which is often exacerbated by societal gender expectations. It was also found negative automatic thoughts are often triggered in these women's minds. The participants also outlined the mental, emotional, and physical toll their internal experience of functional impairments has on them. This included an intense panic like response which often drained the women of energy. Finally, the women discussed how

challenging it is to live with an intense and harsh internal experience that no one else seems to be aware of and that is not being addressed in treatment.

Based on the study findings, it is evident that more research is needed on this topic. The researcher encourages those working with women who have ADHD to enquire about their internal lived experiences, especially to ask if they are having panic like responses. Finally, this study points to a need to improve our understanding of the ways in which functional impairments impact those living with ADHD in order to significantly improve their care and treatment.

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Introduction

Attention Deficit Hyperactivity Disorder is one of the most common mental health issues in the world. It is estimated that anywhere from 3% to 15% of the global population meets the diagnostic criteria for ADHD (Edbom, Lichtenstein, Granlund, & Larsson, 2006; Halleröd et al., 2015; Kooij et al., 2010). Attention Deficit Hyperactivity Disorder (ADHD) is a neurobiological disability that causes notable executive function impairments which can diminish an individual's capacity in many domains of life (Asherson et al., 2012; Asherson, Manor, & Huss, 2014; Gjervan & Nordahl, 2010; Nazar et al., 2016; Volkow & Swanson, 2013; Waite & Ivey, 2009). Executive functions are important processes which allow humans to plan, organize, create short term memories, emotionally regulate, pay attention, as well as do many other important, complex mental tasks (Diamond, 2013). It has been found that ADHD causes significant impairment in the pre-frontal cortex where these executive functions take place. (Hazel-Fernandez, Klorman, Wallace, & Cook, 2006; Szuromi, Bitter, & Czobor, 2013). This pre-frontal cortex impairment causes people with ADHD to experience significant disruption in their ability to perform executive functions. The term "functional impairments" is used in the literature and throughout this study to describe the practical ways in which this brain-based phenomenon effects those living with ADHD in everyday life (Able et al., 2013; Biederman et al., 2009; Canu, Hartung, Stevens, & Lefler, 2016).

Undiagnosed and undertreated Attention Deficit Hyperactivity Disorder has been shown, through extensive research, to significantly reduce overall quality of life, and consistently produce negative life outcomes which impact individuals, families and communities (Bernfort, Nordfeldt, & Persson, 2008; Das et al., 2012; Kooij et al., 2010; Secnik, Swensen, & Lage, 2005). Those with ADHD have been found to have high rates of educational and occupational stagnation and failure, as well as financial difficulties and increased numbers of traffic accidents and fines (Barbaresi et al., 2013; Das et al., 2012; Gjervan, Torgersen, Nordahl, & Rasmussen, 2012; Küpper et al., 2012; Sasane et al., 2007; Smyth et al., 2016). ADHD has also been found to increase the lifetime likelihood of developing a substance use disorder and being involved with the criminal justice and incarceration systems (Appelbaum, 2008; Behnken et al., 2014; Dunne, Hearn, Rose, & Latimer, 2014; Liebrenz et al., 2014; Moody, 2016; Vingilis et al., 2015; Westmoreland et al., 2010). Research has shown that ADHD significantly impacts social and emotional functioning. Difficulties with emotion recognition, interpersonal relationship struggles, high divorce rates, lack of supportive relationships, and feelings of isolation and loneliness have been found to be more common among this population than in the general public (Bailey, 2005; Biederman et al., 2009; Faraone et al., 2000; Holthe & Langvik, 2017; Michielsen et al., 2015; Safren, Sprich, Cooper-Vince, Knouse, & Lerner, 2010; Shany, Wiener, & Assido, 2012; Waite & Ivey, 2009). All of these outcomes, as well as others, cause those who live with ADHD to be less satisfied with their lives when compared with those around them.

While the majority of studies on ADHD have had predominately white male participants, some research has included or focused on life outcomes among adult women living with ADHD. Women have consistently been found to be just as, if not more, negatively impacted by ADHD as their male counterparts (Biederman, Faraone, Monuteaux, Bober, & Cadogen, 2004; Fedele, Lefler, Hartung, & Canu, 2012; O'Callaghan & Sharma, 2014; West et al., 2009). The presence of ADHD in a girl or woman has been found to exponentially increase the likelihood that she will experience trauma at some point in her life (Fuller-Thomson, Lewis, & Agbeyaka, 2016; Guendelman, Ahmad, Meza, Owens, & Hinshaw, 2016; Hosain, Berenson, Tennen, Bauer, & Wu, 2012; Waite & Tran, 2010). ADHD has been found to be a highly comorbid disorder. In women, depression, anxiety, and eating disorders are the most common comorbid diagnoses

(Brewerton & Duncan, 2016; Fuller-Thomson et al., 2016; McLean, Asnaani, Litz, & Hofmann, 2011; Nazar et al., 2016; Quinn, 2008). While these diagnoses are often comorbid, it also has been found that many women are incorrectly diagnosed with disorders such as anxiety or depression instead of ADHD which is the underlying issue (Quinn & Madhoo, 2014; Sasane et al., 2007). Unplanned pregnancies, domestic violence, and increased risk for self-harm and suicide completion have also been found to be more common among women with ADHD than in the general population (Bussing, Koro-ljungberg, Gary, Mason, & Garvan, 2005; Froehlich et al., 2011; Furczyk & Thome, 2014; Guendelman et al., 2016; Rogers, Dittner, Rimes, & Chalder, 2017).

While the negative impact of living with ADHD has been found in the literature to effect both men and women, research has not extensively explored the nuances of gender differences among those with ADHD. Yet this research is needed because the diagnosis of women with ADHD has been on the rise in recent years (Quinn & Madhoo, 2014). This is primarily driven by the increased awareness among practitioners that not only does ADHD persist into adulthood but also it is not a gender discriminating disorder (Biederman et al., 2006; Guelzow, Loya, & Hinshaw, 2017; Holthe & Langvik, 2017; Kessler et al., 2006). Women, whose impairments may have gone unnoticed or misunderstood in childhood and adolescence, find themselves struggling to handle the inevitable increase in responsibility that comes with adulthood. This trend has been picked up by and written about in the popular press:

> The years between 26 and 34 are rife with those kinds of life changes so heavy they earn moniker of ‘milestones.’ College gives way to the greater demands of grad school, gainful employment, and career planning. Time and money management become paramount. The pressure to find a long-term partner is ratcheted up, cohabitation is the

> norm, and many women become mothers for the first time. A tall order for anyone, but for women with undiagnosed ADHD, each added pressure comes closer and closer to breaking the coping camel's back. 'The bar,' says Dr. Markel, 'gets so high their strengths can no longer circumvent their weaknesses'. (Jacobson, 2014 p. 6 - 7)

An increase in the diagnosis of ADHD among women will hopefully improve their lives and overall functioning. However, the lack of research on women with ADHD may cause gender specific needs and challenges to go unaddressed in this population.

Chapter Two: Literature Review

ADHD has been researched in many settings throughout the world. The understanding of this disorder has evolved through research; from the belief ADHD was a boy's childhood disorder, to today when it is understood that ADHD can be found in every gender and age group throughout the world (Asherson, Manor, & Huss, 2014; Biederman, Petty, Clarke, Lomedico, & Faraone, 2011; Guelzow et al., 2017). As research on ADHD has continued to expand, a consistent finding has been that ADHD can, and often does, reduce overall quality of life and also lowers life expectancy (Barkley, 2002; Lensing, Zeiner, Sandvik, & Opjordsmoen, 2015; Newark, Elsasser, & Stieglitz, 2016; Yoshikawa, Aber, & Beardslee, 2012). Studies using fMRIs of the brain have provided helpful insights about the brain process involved in ADHD. It is now understood that ADHD is not a lack of will power or based on a personal character flaw, but is instead an issue with the executive functioning processes in the pre-frontal cortex of the brain (Cavallet et al., 2016; Morsink et al., 2017; Mowinckel, Pedersen, Eilertsen, & Biele, 2015; Nussbaum, 2012; Volkow & Swanson, 2013). This knowledge has helped researchers to begin to focus on issues caused by this brain-based malfunctioning such as functional impairments and internalization.

Functional Impairments

The term "functional impairments" is used in the literature and throughout this study to describe the practical ways in which ADHD is experienced and seen in daily life (Able et al., 2013; Biederman et al., 2009; Canu et al., 2016). There are several well researched scales used throughout ADHD clinical practice to assess the rates of functional impairments experienced in those living with ADHD. One of the most commonly used scales is the Weiss Functional Impairment Rating Scale (WFIRS) which has been undergone validation studies in seven languages and is in the public domain (Canu et al., 2016; Dose, Hautmann, & Doepfner, 2016; Gajria et al., 2015; Lin, Lo, Yang, & Gau, 2015; Tarakçıoğlu, Memik, Olgun, Aydemir, & Weiss, 2015). This scale provides a helpful list of functional impairments those living with ADHD may experience. The person completing the scale rates how often they encounter these experiences, which are known as functional impairments. Table 1 lists examples of the statements found on the WFIRS. The full WFIRS can be found in Appendix A.

Table 1

Examples of ADHD Functional Impairments from the WFIRS

FAMILY	WORK	SCHOOL	LIFE SKILLS	SELF CONCEPT	SOCIAL	RISK
Having problems with family	Problems with getting your work done efficiently	Problems completing assignments	Problems keeping an acceptable appearance	Feeling bad about yourself	Trouble concentrating	Aggressive driving
Relying on others to do things for you	Getting fired from work	Problems with teachers	Problems getting ready to leave the house	Feeling frustrated with yourself	Trouble getting along with people	Doing other things while driving
Problems taking care of the family	Problems with being late	Problems with attendance	Getting hurt or injured	Feeling discouraged	Problems having fun with other people	Taking “street” drugs
Problems balancing your needs again those of your family	Problems taking on new tasks	Problems working to your potential	Problems keeping regular appointments	Not feeling happy with your life	Problems making/keeping friends	Sex without protection
Problems losing control with family	Poor performance evaluations	Problems with inconsistent grades	Problems keeping up with household chores	Feeling incompetent	Saying inappropriate things	Being physically or verbally aggressive

The experience of living with functional impairments caused by ADHD has been directly linked in the literature to the negative life outcomes seen among this population (Barkley, 2002; Behnken et al., 2014; Biederman et al., 2009; Holthe & Langvik, 2017; Szuromi et al., 2013; Vingilis et al., 2015; Waite & Tran, 2010).   In a large study of a community-based sample, in which 1001 people self-reported having been diagnosed with ADHD, functional impairments were found to be connected with many negative life outcomes. With the aim of better understanding the impact of functional impairments on a non-clinically referred population, this study determined which impairments led to specific negative outcomes. One finding of this study was that those with ADHD were less likely to graduate from high school. The study participants who had ADHD reported they regularly experienced the following functional impairments: inability to cope with a large amount of work, inability to concentrate, and difficulties organizing their school work. This study sample also reported having a hard time paying attention, often making careless mistakes, and struggling to follow directions. This study proceeded to find that these impairments continued into adulthood and significantly impacted the participants ability to succeed in the work place. The above list of functional impairments were found to lead to less stability in employment and more job loss. The specific functional impairments outlined in this study were directly linked to the lack of educational attainment and work instability in the lives of the study participants with ADHD (Biederman et al., 2009).

Another study that explored the impact of functional impairments on life outcomes reviewed the driving history of participants. The study found that those with ADHD were three times more likely to lose their licenses than other drivers. The author of the study pointed out that this may not be fully due to their bad driving, but also due to their inability to navigate bureaucratic systems. “In short, they may be so disorganized that they do not attempt to defend themselves. When they fail to appear in court, their licenses are revoked. Thus, disorganization on the part of the people with ADHD may account for the loss of some licenses” (Barkley, 2002, p 13). This insight into their study findings provides a clear example of how functional impairments impact many domains of life and are highly multifaceted.

The existence and impact of functional impairments caused by ADHD has been well documented in the literature. Studies comparing healthy controls and those living with ADHD have consistently found the ADHD cohort to experience significantly more functional impairments (Babinski et al., 2011; Fedele et al., 2012). Research has found functional impairment rates to be similar among men and women who have ADHD (Able et al., 2013; Biederman et al., 2009; Canu et al., 2016). However, several studies have found women report higher levels of functional impairments than male comparison groups (Fedele et al., 2012; West et al., 2009) No studies reviewed found that men experience more functional impairments than women.

In a small, qualitative interview-based study specifically exploring the lives of adult women with ADHD, many functional impairments that led to negative outcomes were well documented.

> Poor time management leads to problems with making realistic and manageable plans for the day, and with getting to work and social events on time, which, in turn, lead to self-blame, chaos, and stress…Closely tied to poor time management is procrastination, understood as a form of self-regulatory failure and associated with academic and professional underachievement; feelings of guilt; negative mood; and chronic stress. The majority of the participants have struggled with procrastination from childhood, and several describe high levels of stress because they do everything last minute, which leaves them with a constant feeling of running out of time. It can be hard to plan and execute daily tasks due to problems with obtaining an overview and knowing where to begin, and small tasks often grow into seemingly complex and overwhelming operations, which lead to procrastination and missed deadlines. (Holthe & Langvik, 2017. p 5-6)

In a quantitative study on sex differences in ADHD impairments among emerging adults, the researchers provided speculations as to the cause of their finding of higher levels of impairments among women:

> The current study showed significantly higher rates of self-reported impairment in college women with ADHD than in college men with ADHD in the following areas: home life, social life, education, money, daily life, and overall impairment… Given the differential value men and women place on maintaining close social ties and relationships, it is reasonable to speculate that the symptoms of ADHD may be more distressing to young women than men. Young men may perceive social/ relational deficits as less impairing than young women as a result of differential socialization. One possible explanation for this difference is that young women's expectations for their own performance are negatively influenced by societal expectations. (Fedele et al., 2012, p 114)

The discussion of societal and gendered expectations and functional impairments among women with ADHD was also discussed by Holthe and Langvik (2017) in their qualitative study of the struggles and successes women with ADHD experience. They write:

> However, ADHD is also shaped by—and thus needs to be understood in light of—the social and cultural environments in which it exists… Girls are encouraged to exhibit both traditional "feminine" qualities, such as being empathic, good with relationships, nice, obedient, good mothers and home- organizers, as well as traditional "masculine" qualities, such as being assertive, competitive, academically driven, and career focused. When girls display disruptive, hyperactive, impulsive, or disorganized behavior, they are at risk of harsh social judgment because these violate the norms for feminine behavior. In an attempt to avoid social sanctions, many girls with ADHD spend excessive amounts of energy trying to hide their problems, which in turn go unrecognized by others. (p. 2)

Despite the awareness of the likely impact of societal and gender expectations on the levels of impairment experienced by women with ADHD, no research was found that explored this connection. The impact of functional impairments on the lived experiences of women with ADHD has not been explored in any studies reviewed by the researcher. The qualitative interview-based studies specifically on women with ADHD provided basic insights to the readers. These insights included details of the problems and issues the women encountered on a daily basis as well as details on how helpful it was to be diagnosed with ADHD (Holthe & Langvik, 2017; Waite & Ivey, 2009; Waite & Tran, 2010). However, these studies did not explore the women's internal lived experiences or how these experiences are impacted by functional impairments.

Internalization

The concepts of "internalization" and "externalization" of symptoms and experiences have been studied for many years in a wide range of disciplines. Within the field of psychiatry and psychotherapy these concepts were described as two ends of a spectrum of responses to experiencing symptoms of a mental health issue in an article published in 1966 (Achenbach, 1966). The externalization end of the spectrum is described as "conflict with the environment", while the internalization end is described as "problems within the self". Both internalization and externalization are responses to encountering symptoms of a mental health issue or psychiatric disorder. While these responses may be to the same or similar events, internalization and externalization are very different experiences both for the individual responding and for those around them.

Throughout the literature, women have been found to internalize their ADHD symptoms and impairments more than men (Guendelman et al., 2016; Holthe & Langvik, 2017; Nussbaum, 2012; Owens & Hinshaw, 2016b; Quinn, 2005; Safren et al., 2010; Smyth et al., 2016). The impact of internalization on a woman's life is described well by Dr. Patricia Quinn (2005), who specializes in the diagnosis and treatment of women with ADHD, when she wrote:

> For a woman who has ADHD, often her most painful challenge is a struggle with her own sense of inadequacy in fulfilling the roles she feels are expected of her by her family and by society. Girls are raised to "internalize"—to take in and "own" negative feedback, to apologize, to accommodate, and not to fight back—in short, to take the blame. p. 585

This means the observed external impairments may be only a small part of the experience for women who have been taught throughout their lives to internalize the experience of living with functional impairments as a way of mitigating the impact of their disability on the world around them.

Internalization of functional impairments caused by ADHD has been found to have a negative impact. Those who internalize their impairments often report low self-esteem. Many of the studies that have researched the impacts of ADHD and its impairments on self-esteem use basic screening questionnaires. This means the majority of the studies reporting that those who have ADHD also often have low self-esteem do not elaborate on the causes of this finding. The few studies which indicated the causes of low self-esteem in women with ADHD consistently linked this outcome to functional impairments (Babinski et al., 2011; Fleischmann & Miller, 2013; Garner et al., 2013; Owens & Hinshaw, 2016a; Rasmussen & Levander, 2008; Robinson, Jacobsen, & Foster, 2015; Swanson, Owens, & Hinshaw, 2014). A description of how functional impairments may negatively impact how a woman sees herself was well documented in a qualitative study of adult women with ADHD:

> Poor self-esteem has been identified as a serious and common problem among girls and women with ADHD ... inattention, disorganization, poor time management, motivational difficulties, and problems with planning and structuring daily tasks have resulted in significant academic, occupational, and psychological challenges for most of the women. In the absence of a better explanation, the women blamed their struggles on perceived personal flaws, such as laziness, lack of effort and capability, which, over time, contributed to a negative self-image that followed several of the women into adulthood. (Holthe & Langvik, 2017, p. 2)

Several qualitative studies of women with ADHD contained discussions of self-esteem. However, in all of these qualitative studies, the negative impact of ADHD on self-esteem was related to how the women felt about themselves before they were diagnosed. None of the qualitative studies reviewed by the researcher discussed if low self-esteem continued after diagnosis and treatment. However, the continuation of lower than average self-esteem has been found, among adult women who have been diagnosed with ADHD, in quantitative studies but without providing insight as to the cause of the reduced self-esteem (Fleischmann & Miller, 2013; Holthe & Langvik, 2017; Waite & Ivey, 2009; Waite & Tran, 2010).

The high rates of symptom internalization and its impact on self-esteem among women with ADHD has been a key finding in multiple studies. Yet no studies were found that explored how symptom internalization impacts women beyond the reduction in self-esteem. It is unclear from the literature reviewed what happens to a woman once a symptom is internalized and how that impacts her overall quality of life. A clearer understanding of the ways in which ADHD interacts with the internal lived experience of women is needed. Through research on this topic, it is possible that more effective assessments, diagnosis, treatments and interventions can be developed for this population.

Qualitative Research

The majority of studies on ADHD have been quantitative research studies. These studies have provided a solid base of research and quantitative data which verifies the existence, impact and prevalence rates of ADHD. Within the literature on ADHD, the researcher found significantly fewer qualitative and mixed methods studies. The researcher found a disproportionate number of the qualitative studies focused on children or adolescence with ADHD and their caregivers or teachers. There were far fewer qualitative studies on adults who live with ADHD. The majority of the qualitative studies reviewed on adults with ADHD focused on the experience of being diagnosed in adulthood (Fleischmann & Miller, 2013; Halleröd et al., 2015; Ramsay & Rostain, 2005; Stenner, O'Dell, & Davies, 2019; Waite & Tran, 2010; Young, Bramham, Gray, & Rose, 2007). The researcher was able to find only several qualitative studies of adults with ADHD which focused on other experiences. These studies focused on issues such as challenges in the work place, issues navigating the health care systems, and the struggles of living without a diagnosis for the majority of life (Adamou, Graham, MacKeith, Burns, & Emerson, 2016; Henry & Jones, 2011a; Holthe & Langvik, 2017; Schreuer & Dorot, 2017; Swift et al., 2015).

Qualitative Studies of Women with ADHD

Due to the general lack of qualitative research on adults living with ADHD, the researcher found very few qualitative studies specifically of adult women. The majority of the qualitative studies on women focused on the women's experiences of living without an ADHD diagnosis and then explored their experience of receiving an ADHD diagnosis in adulthood

(Henry & Jones, 2011b; Ramsay & Rostain, 2005; Stenner et al., 2019; Waite & Ivey, 2009; Waite & Tran, 2010). A 2017 phenomenological study of women with ADHD and their experiences of work was one of the few studies which provided new and detailed insights into women's experiences of living with ADHD outside of their diagnosis and treatment experience (Schreuer & Dorot, 2017). The researcher found one other study, also published in 2017, which explored the "complex ways in which ADHD might affect the everyday lives of adult women" (Holthe & Langvik, 2017, p. 3). This study provided deeper insights into known challenges adult women with ADHD experience as well as expanded the discussion in the literature of the impact of gender and motherhood on the experience of living with ADHD. However, this study did not explore or emphasize in the data analysis or findings the internal experiences of the women or explore how these internal experiences may be connected to ADHD.

Phenomenological Research

Within qualitative research, the phenomenological research method seeks to explore the essence of a particular phenomenon in order to better understand the common experience of a specific population. Phenomenological studies can provide much needed insights as this research method delves deeply into a specified phenomenon and encourages participants to provide vivid and rich descriptions of their unique experiences (Creswell, 2013; Hycner, 1985). This research method is especially relevant when applied to mental disabilities such as ADHD which are internally experienced.

Very few phenomenological studies of ADHD were found by the researcher. The most commonly cited phenomenological study was published in 2007, had eight participants and explored the experience of receiving a diagnosis of and treatment for ADHD in adulthood. This study provides insights and descriptions of the three theme areas discovered in the data: review of the past- feeling different from others, the emotional impact of the diagnosis and rumination about the future. While this study does add to the research on the experience of the phenomenon of being diagnosed with ADHD, there was no exploration of the continued impact of ADHD on the participant's external or internal lived experiences after their diagnosis (Young et al., 2007).

In 2017, a phenomenological study of women with ADHD and their experiences of employment was published. This study had eleven participants and provided excellent descriptions of the women's experiences in the work place as well as in depth analysis of both the challenges and joys which were part of these women's lived experiences. The findings of this phenomenological study provided helpful direction, not only for future research but also for employees with ADHD as well as employers. The findings of this study could also be utilized in clinical practice to help clients explore challenges they may be facing in work environments (Schreuer & Dorot, 2017). Hopefully this recent study will encourage others to utilize the phenomenological research method when exploring ADHD so as to be able to deepen our understanding of how ADHD impacts day to day life functioning.

Gaps in the Literature

The researcher found three main gaps in the literature. First, the number of studies which focus on adult women living with ADHD continues to fall far behind the studies of men. This is a concerning gap because the diagnosis of women with ADHD is on the rise (Quinn & Madhoo, 2014). Without more research on this population, evidence-based interventions will be slow to develop and gender specific needs, symptoms, and responses to treatment will remain understandings in clinical practice that are not understood and legitimized more widely through scholarly research. Studies of women and their experience of ADHD after their diagnosis were found to be especially lacking.

The second gap in the literature was the lack of qualitative studies exploring ADHD. Qualitative research, while often consisting of smaller sample sizes, analyzes and explores in depth responses and descriptions provided by participants. Participant responses in qualitative research provide insight, imagery, characteristics, and definitions related to the topic being explored. These non-numerical data nonetheless can contribute important knowledge and understanding of a given concept or experience to scholarly and clinical audiences. Qualitative inquiry is needed because not all experiences are able to be understood, described, or explored through quantitative methods.

Within the lack of qualitative studies, there was also found a distinct lack of studies utilizing the phenomenological method. While there are many qualitative methods available to researchers, the dearth of phenomenological studies was notable to the researcher. This is because phenomenological studies are specifically designed, by exploring the essence of a phenomenon, to provide detailed insights and rich descriptions of a shared experience. Since ADHD is a unique disorder, a better understanding of the multifaceted nature of living with this disorder is needed so as to improve both clinical care and research. The use of a qualitative research design and more specifically a phenomenological research method was not found to be commonly utilized in the literature on ADHD. However, it is important that these methods be employed more often in the study of ADHD, as gaining a better understanding of the internal experience of this disability is essential to future research and clinical practice.

The final gap discovered in the literature is the absence of study of the lived experiences of adults who have ADHD. According to *The SAGE Encyclopedia of Qualitative Research Methods* (2008):

> Lived experience responds not only to people's experiences, but also to how people live through and respond to those experiences. The body of work on lived experience focuses on everyday life occurrences and self-awareness. As a life history or life story, lived experience concentrates on ordinary, everyday events (language, rituals, routines) while privileging experience as a way of knowing and interpreting the world. (p 3)

The researcher found several studies of the lived experiences of parents, teachers, caregivers, children and adolescence related to their experiences of working with, parenting or living with ADHD. One study of college students explored the lived experience of having ADHD in a college setting (Lefler, Sacchetti, & Del Carlo, 2016). However, the researcher did not find any studies which explored the lived experiences of adults living with an ADHD diagnosis. Research into the lived experiences of adults with ADHD is needed because without clear understandings of the many and complex ways ADHD impacts a person in their daily experiences, it is very difficult to determine if there are variations in the disorder, what interventions are appropriate, and if treatment is effective.

A facet of lived experience is the exploration of internal lived experiences. The researcher was unable to find any research that specifically explored the internal lived experiences of people living with ADHD. This is a substantial gap in the literature as ADHD is a brain based, mental disability. By definition as a mental disability ADHD is invisible and as such understanding the internal lived experience of those living with this disorder is essential. Currently, ADHD is diagnosed through a diagnostic interview. This interview which takes place in clinical settings specifically explores the internal lived experience of an individual in order to make a correct diagnosis. However, if the internal lived experience of those with ADHD is not explored in the research, a gap between clinical practice, the experience of the individual with ADHD, and those researching this topic will widen.

Clinical Practice and Scholarly Research

The topics reviewed in this literature review are ones which the researcher was familiar with from a clinical practice setting. Currently, there are a wide range of resources and interventions available for those working with individuals and groups who have ADHD within clinical practice. This includes knowledge and interventions for functional impairments and issues of symptom internalization, as well as a wide body of clinically based literature on adult women and ADHD. Some of these resources and interventions, such as Cognitive Behavioral Therapy for ADHD as well as Group Narrative Therapy and several others, have gone through the scholarly research process and are now considered evidence-based interventions for ADHD (Flückiger et al., 2016; Robinson et al., 2015). However, there is still a large body of clinical experience-based literature which substantially adds to the current understanding and treatment of ADHD. These books and resources integrate current understandings of ADHD which have been gained through research with interventions which have been found in clinical practice settings to be effective (Hallowell & Ratey, 1995; Kelly & Ramundo, 2006; Mason & Baron, 2009; Matlen, 2014; Nadeau, Littman, & Quinn, 2015; Solden, 1995; Tuckman, 2011; Zylowska, 2012). Yet, much of this clinically acquired knowledge has not been subjected to the scholarly research process. This has created knowledge, insights and understanding among practitioners who work with people living with ADHD that are not included as part of the conversation in the research community. This creates a gap between those working directly with people who have ADHD and those researching this disability. Without research which seeks to bridge this gap, the knowledge acquired through clinical experience may not have as broad of an impact as it could, and the discoveries made through research may not be relevant to clinical practice. It is important that both clinicians and researchers work to undertake research which can significantly improve our understanding of ADHD, as well as our diagnosis and treatment of this disability in all populations. This research is needed so that the wealth of knowledge acquired through clinical practice can be translated into study findings and eventually evidence-based interventions and more widely accepted and taught to those working with people who have ADHD. Through more qualitative and mixed methods studies, as well as engaging more practitioners in research, this gap can be bridged. This study hopes to be a part of bridging this gap by bringing the voices and experiences of women living with ADHD, which are often heard in clinical settings, into scholarly research.

Conclusion

Through this study the researcher aims to begin to address these gaps in the literature as well as the gap between clinical practice and scholarly research. The researcher discovered a need for exploration of the internal lived experiences of women living with diagnosed ADHD through qualitative phenomenological research. This research will hopefully substantially deepen the current understanding of this disorder among adult women.

Chapter Three: Methods

Research Question

The purpose of this study was to explore the impact of functional impairments on the internal lived experience of women with ADHD. To explore this phenomenon, the researcher sought to address the following question: How do women describe the internal experience of living with functional impairments caused by ADHD?

Research Design

This study was a phenomenological, qualitative, interview-based study. The use of the phenomenological study design was chosen because it enabled the researcher to capture the lived experiences of the participants, and explore the essence and meaning of the phenomenon experienced by all of the women (Creswell, 2013). The phenomenological study design provided helpful guidelines for each step of the research process. These guidelines included recommendations on the size of the study sample, suggestions on how to develop an interview protocol, and instructions for analyzing the data (Creswell, 2013; Hycner, 2012). Utilizing a phenomenological study design enabled the researcher, who had not previously undertaken a study of this size, to be more comfortable in performing each part of this study.

Sample

Sample Recruitment

The researcher recruited participants through a network of women with ADHD as well as ADHD organizations, practitioners, coaches, and doctors. Through mailing fliers and sending emails, the researcher spread the word about the study during the weeks leading up to the recruitment window (Appendix B). The two-week recruitment window opened at 8 AM on Wednesday, September 26th 2018 and closed at 8 AM on Wednesday, October 10th 2018. Women who were interested in participating in this study were asked to complete a screening survey via a link provided in emails and on fliers. Over these two weeks, 120 women fully completed the screening survey. This survey was administered by the Statistical Consulting Center at Grand Valley State University (see Appendix C for confidentiality agreement). The screening survey consisted of a short demographic questionnaire and the Weiss Functional Impairment Rating Scale. The screening survey first asked possible participants to review and confirm whether or not they met the participation criteria. If the participation criteria were not met, the survey would be closed and could not be completed by that specific person (Full list of Participation Criteria can be found in Appendix D).

Response Grouping for Maximum Variation

The researcher used the purposeful sampling method of maximum variation (Creswell, 2013). The researcher chose the women's scores on the Weiss Functional Impairment Rating Scale as the variation for this study. This method acknowledges that while all women with ADHD experience functional impairments, they may experience different levels of impairment. This variation in impairment may also impact how they internally experience life with functional impairments. The researcher sought this experiential diversity so as to gain as much insight as possible into the impact of functional impairments on the internal lived experiences of women with ADHD.

The researcher chose to utilize the Weiss Functional Impairment Rating Scale (WFIRS) because this scale has been tested for validity and widely utilized as a way to measure functional impairments caused by ADHD and it is in the public domain (Appendix A). Dr. Weiss provided verification for the use of this tool for this study (Appendix E). The WFIRS is broken into seven life domains: Family, Work, School, Life Skills, Self-Concept, Social, and Risk. A list of short statements, which describe experiences the person with ADHD may have encountered, are listed under each life domain. When completing the scale, the person indicates how often they experience a given statement by marking a number 0 through 3 or “Not Applicable”. These numbers are connected to statements about the frequency with which they experience the specific functional impairment. The meaning of each number can be seen in Table Two.

Table Two

Definitions of Numerical Response Options for Each Question on the WFIRS

Never or Not at all	Sometimes or Somewhat	Often or Much	Very Often or Very Much	Not Applicable
0	1	2	3	NA

The final score is calculated by adding up all of the numbers selected as a response to each question (0 through 3), and then dividing the total number by the number of questions answered. If “Not Applicable” is selected, that question is not included in the total number of questions answered. Total scores are often a non-whole number because very few people respond with the same number for every statement. The same scale used for scoring the individual questions is applied to the final score. The non-whole number indicates where between the specified levels of impairment the person falls. There is one other layer to the WFIRS. To find specific life domains where a person may be considered “impaired” by ADHD functional impairments, the responses are reviewed for each life domain to see if “two items scored ‘2’ or one item scored ‘3’”(Weiss, 2000, p. 1). According to Dr. Weiss, if two phrases were scored ‘2’ or one phrase was scored ‘3’ in a specific life domain, this indicated there is substantial impairment in functioning within this life domain.

Participant Selection

Once the recruitment window closed, the researcher received the results of the screening survey from the Statistical Consulting Center via a password protected file. Next, the researcher scored all of the completed responses to the WFIRS. The participants were then grouped together based on the range (example 0.3-0.4) in which their WFIRS score fell. This method of sampling created eighteen different groups of possible participants. Using a random number generator, which was used to reduce sampling bias, the researcher selected one woman from each grouping to be contacted about participating in the interview portion of the study. An alternate was also selected using a random number generator. Both the chosen participant and alternate were emailed about possible study participation (Appendices F and G). If the first selected participant did not respond to the email within one to two weeks, the alternate was then invited to participate in the study. If the alternate did not respond, the researcher again used a random number generator, excluded the contacted women, and again selected a possible participant to contact. No alternates were selected after the first round. If there was only one possible participant in a specific score range, that woman was automatically chosen to be contacted, and no alternate was selected.

This method of sampling resulted in a sample of fourteen women who were interviewed. The researcher was successful in recruitment in that each woman who participated had a different level of impairment when they completed the WFIRS. The individual total impairment score of the participants ranged from 0.34 to 2.24. The WFIRS score ranges not represented in the sample are 0.5-0.6, 0.7-0.8, 0.9-1.00, and 1.8-1.9. After reviewing the responses, all but one of the study participants met Dr. Weiss' criteria for "impairment" in at least one life domain.

Study Participants

The outlined sampling process produced a sample of fourteen women who lived across the United States. The sample consisted of twelve women who were Caucasian and two women who were "Mixed Race". All the women in the sample graduated from college. Two of the women had completed some graduate school, and four of the women hold at least one graduate degree. It is important to note that the lack of racial and educational diversity was due to the random selection of participants from groups of women with similar WFIRS scores. Due to the small sample size, the researcher chose to have only one point of variation for the maximum variation sampling process. This point of variation was the women's WFIRS score. The researcher anticipated it would be difficult to recruit a racially and educationally diverse sample within the short time allotted for this study. However, 120 women responded to the survey and expressed interest in study participation. While this group of women was substantially more diverse than the final sample, the researcher chose to stay with the chosen participant selection process. This was to ensure the legitimacy of the study and avoid any appearance of data or outcome manipulation.

The women who were interviewed ranged in age from 32 to 59 years old. When asked on the basic demographic questionnaire to report their estimated age of ADHD diagnosis, only one of the women reported being diagnosed with ADHD in childhood. She was diagnosed at the age of 7. The rest of the women were diagnosed in adulthood, between the ages of 24 and 50. The women in this study had a diverse range of environments in which they lived and worked. Occupations held by the participants currently or in the past included teacher, researcher, lab technician, project manager, physical therapy assistant, marketing manager, life coach, video editor, nurse, IT technician, disability advocate, secretary, and stay at home mom. Five of the women reported being recently fired from their jobs because of impairments caused by ADHD. These participants reported still being unemployed despite looking for work. Four other participants reported having been fired at some point in their career or being currently underemployed. Seven of the women had at least one biological or step child. Six of the women had been divorced or are no longer with their long-term partner.

All of the interviewed women met the study participation criteria (Appendix D). While all of the women in this study were clinically diagnosed with ADHD, the researcher did not factor medication use into the screening survey, selection process, or overall analysis. During the interview process many of the women disclosed whether or not they were using medication for their ADHD. Yet, medication use did not emerge in the data analysis as a contributing factor which improved or worsened the internal lived experience of functional impairments.

Data Collection

This research study was reviewed and approved by the Institutional Review Board at Grand Valley State University to ensure the safety of all participants and the ethical practice of the researcher (Appendix H). No part of this research began before this approval was received. Once recruitment had finished and participants were selected and scheduled for an interview, they were emailed the informed consent document as well as instructions on how to sign it (Appendices I and J). The researcher has completed informed consent documents from all fourteen participants. Participants who requested the interview questions in advance were provided with this document before their interview.

The interviews took place over a web-based video calling system via computers or mobile devices. The researcher assisted participants in accessing this technology when help was needed. There were several women who initially were contacted and expressed interest in participating in the study. However, for a variety of reasons they were unable to participate, and a different woman from their WFIRS score group was selected. Only one woman was prevented from participating due to not being able to use web-based video calling on account of her hearing challenges. She and the researcher tried to connect in person for the interview, but winter weather prevented this from happening and so another participant was selected.

Interviews ranged from 24 minutes to 67 minutes in length. The interviews all began with the researcher answering any questions about the informed consent document, requesting permission to record the interview, and reviewing privacy and confidentiality protocols. The researcher then went into a short description of the purpose and aims of the study. The participants where then asked if they had any questions for the researcher or about the study. Once any and all questions about the research and interview process were answered, the interview began.

The researcher recorded the interview audio on a password protected Android Mobile app as well as a Live Scribe pen that only the researcher had access to. During the interviews, the researcher asked the seven questions listed on the semi structured interview protocol (Appendix K) as well as appropriate follow up questions. Once the interview was over, the researcher thanked the participant for her time. The researcher had no other contact with the interview participants. Once all of the interviews were complete, the women who completed the online WFIRS but were not selected for study participation were each individually emailed by the researcher and thanked for her interest in the study. They were invited to contact the researcher if they were interested in other research study participation opportunities (Appendix L).

Interview Protocol

To develop the interview protocol, the researcher reviewed the interview protocols for available qualitative studies of women with ADHD as well as literature on constructing a phenomenological interview protocol. The researcher also reviewed studies of functional impairments to gain a clear understanding of how to discuss these experiences with participants

(Able et al., 2013; Conners, 2003; Creswell, 2013; Hinshaw et al., 2012; Holthe & Langvik, 2017; Swanson et al., 2014; Waite & Tran, 2010). Once a draft of the interview questions was written, the researcher asked several qualitative researchers to review the protocol. The final interview protocol used by the researcher contained seven questions (Appendix K). The first question asked what functional impairments the participants experienced throughout their daily life. The purpose of this question was to help the researcher and participant ensure they both understood what was being discussed when the phrase "functional impairments" was utilized. This question also helped the researcher to get a sense of the kind of struggles the women experience throughout their lives. The following two questions explored the impact of encountering a functional impairment caused by ADHD on the participant's mind, body and emotions. By asking about the mental, emotional and physical experiences had by the women, the researcher sought to gain detailed insights about the participant's internal lived experiences. The fourth question explored how living with functional impairments impacted their view of themselves as women. This question was designed to explore what, if any, impact ADHD functional impairments have on how the women internally experience their gender. The fifth question asked the women to share with the researcher any common "tapes" or "mantras" which happen in their minds when they encounter a functional impairment. With this question the researcher aimed to capture the internal dialogue which may be going on inside of these women. The sixth question asked if there were any benefits or positive aspects of living with ADHD and its functional impairments. Finally, the researcher asked what aspects of living with ADHD functional impairments did the women wish were better understood by those around them. Through this question, the researcher aimed to capture more about the impact of internalization, and what it is like to have an internal lived experience of which others may not be aware.

The semi structured interview protocol, which is often utilized in phenomenological studies, allowed the women to express themselves freely and share their stories in the interview setting. The researcher asked each participant the same seven questions from the interview protocol. Because of the semi-structured nature of the interviews, the researcher was also able to ask appropriate follow up questions based on participant responses. These follow up questions were spontaneous, and gave the researcher the ability to explore more deeply what the participant was sharing.

Interview Transcription

Before receiving interviews to transcribe, the transcribers were given a privacy and confidentiality agreement to review and sign (Appendix M). The researcher has completed agreements from both transcribers. Once this document was signed the researcher provided the audio recordings to the transcribers within several days of the interview. The recordings were provided to the transcribers on USB drives in password protected files. The transcribers emailed password protected finished transcriptions to the researcher and returned the USB drive with the audio recording to the researcher. The researcher saved all of the transcripts on her computer in password protected files. When all of the transcriptions were received, the researcher began the data analysis. This analysis process was undertaken in a way that ensured participant were de-identified and that maintained privacy and confidentiality of the participants.

Chapter Four: Findings

Data Analysis Process

The researcher followed the guidelines for phenomenological data analysis and coding (Creswell, 2013; Hycner, 1985). This process began with the researcher listening to each recorded interview one or two times completely through. Only after listening to each interview did the researcher begin the first round of coding. The researcher put meaningful words and phrases from the transcript onto a spreadsheet. Once general coding was completed, the researcher reviewed the codes and combined duplicate codes, noting their frequency. Next, the researcher placed each general code onto the tab or tabs with the question the code answered. Once all of the general codes were put with the question they answered, the researcher reviewed the data to develop themes for participant responses which corresponded to the research and interview questions. The researcher then combined all fourteen sets of themes on one large spreadsheet and utilized this document to analyze themes across interviews. Finally, the researcher wrote up their findings in this final report.

Through the use of the phenomenological data analysis process, the researcher determined the process the fourteen interview participants went through when they internalize functional impairments. The researcher was also able to describe in detail the essence of the phenomenon of the internal impact of living with functional impairments. Finally, the researcher found common themes among the participants related to their internal experience of living with functional impairments caused by ADHD. While there were many themes discovered, the most prominent themes were: Emotions and expectations, negative automatic thoughts, mental, emotional and physical toll, the external impact of internalization, and discrepancy between lived experience and WFIRS scores. The participants provided excellent descriptions and examples which helped illustrate these themes and provide firsthand accounts of the internal lives of women with ADHD.

The Process of the Internalization of Functional Impairments caused by ADHD

The central aim of this study was to better understand the impact internalization of functional impairments has on the internal lived experience of women with ADHD. Since the existence of internalization had already been confirmed throughout the literature, the researcher did not expect to add to this specific area of study. However, this study had an unexpected yet important finding. Through this study the researcher was able to document the process by which functional impairments are internalized by women. This finding is important because it provides needed insight into the specific process through which internalization takes place among this population.

The process of internalization was described by the study participants as follows: A woman encounters a functional impairment, such as running late for an appointment; immediately there is either a mental and physical panic response or the triggering of automatic negative thoughts such as “Why can't I figure this out”. Once the moment of the impairment is over, the woman will likely ruminate about what happened for a few hours to a few weeks. During this rumination, negative automatic thoughts will often come unbidden into her mind. These thoughts are targeted specifically at her personhood, and include thoughts such as “What’s wrong with you”, “You’re a failure”, and “I hate myself and I want to die”. These internal negative automatic thoughts can lower her self-esteem. She may also experience increased anxiety because she is constantly worried another functional impairment will take place. Meanwhile, while she ruminates about the experience or is reminded of it externally, she experiences the emotions of shame and frustration, as well as a sense of being a failure or being flawed. This internal experience was reported by the participants to be triggered whenever a functional impairment is encountered, even though the woman likely had no actual control over what happened.

Since functional impairments were happening in these women's lives multiple times a day, it can be inferred that the process outlined above was also taking place multiple times a day. The women reported that when this process took place, it demanded a substantial amount of mental, emotional and physical energy. Given this finding, it was not surprising the study participants reported functional impairments caused by ADHD had significantly reduce their overall functional capacity.

The Essence of the Internal Lived Experience

This study found that functional impairments caused by ADHD significantly impacted the women internally. This internal impact was found to be negative and undesirable. Functional impairments could occur in every domain of life and these impairments could cause a substantial internal impact no matter where they took place. None of the women in this study reported feeling they had their internal experience of functional impairments under control and effectively treated.

Each of the participants provided rich, vivid descriptions of the many ways functional impairments influenced their thoughts, emotions, and views of themselves. The women encountered functional impairments multiple times a day, and each of these encounters almost always internally impacted them negatively. If a woman reported she was able to stop the impairment from having a negative impact, this was found to be because she put in considerable work and effort to do so. Functional impairments were found never to have a positive impact on these women's internal experiences.

Experiencing functional impairments multiple times each day caused the women to described their internal lived experience as intense, stressful, frustrating, and draining. The inability to control the triggered thoughts and emotions meant these women were at the mercy of their minds, an experience several of them described as being "on a rollercoaster". The women often described the feeling of their internal experiences as relentless, especially because the women tended to ruminate about past impairments they encountered. This meant that these women were rarely not experiencing the internal effects of functional impairments caused by ADHD.

The women also reported experiencing loneliness, isolation and misunderstanding because their internal experiences affected their external behavior, yet this was not understood by those around them. This was compounded by the fact these women often felt unable to share what they were internally experiencing for fear of being judged, treated differently, or being seen as someone who is unable to handle life's challenges. Instead of sharing their internal experiences with others, the women continued to internalize. It was consistently expressed by the women in this study how difficult it was to live in a loud, unkind, and somewhat out of control mind, that others were unaware they experienced.

Themes

Each woman used her own unique descriptions and language to share her internal experiences with the researcher. Yet the similarities in the internal experiences of these women was striking. In this section, the researcher described the shared experiences of the study participants.

Emotions and Expectations

The researcher explored with the participants the impact functional impairments had on the emotions they experienced internally. The participants consistently described a similar set of emotions functional impairments produced in them. The set of reported emotions included frustration, sadness, irritation, anger, inadequacy, disappointment, fear, anxiety, self-doubt, helplessness, overwhelm, guilt and shame. Each woman described the emotional impact of functional impairments, without prompting, by naming at least two of the emotions listed here. Woven through the range of emotions expressed was the theme of shame and being ashamed of themselves. Only one participant, "Laura", said that she did not currently experience shame as part of her internal lived experience. However, she shared that shame had been a significant part of her experience for many years and that her recent ADHD diagnosis had helped her overcome it. The rest of her described internal emotional experience was found to be very similar to that of the other participants.

The study participants were able to clearly describe what it is like to live with the shame created by functional impairments. "Erica", who is a 30-year-old who recently lost her job because of some of her ADHD functional impairments, identified that shame is a common emotion she experienced:

> Probably a lot more shame than guilt. Probably, also depending on the situation, but I think a lot of it, it sort of just encourages my own feelings about who I am and what I'm doing, and what I should be doing, and all of that. Um, like when I was essentially fired, I basically told everybody that I was laid off and that they were restructuring because I couldn't figure out a way to tell anybody that it was my fault.

When “Felicity”, who was struggling with work and finances due to impairments caused by ADHD, was asked what other emotions she experienced other than many layers of anxiety, she responded right away:

> Shame. The shame that I, yep, shame, um, that I had a wonderful job, I have an awesome work ethic, and yet I can't perform. The shame that I could get so close to losing my house, losing our, our home, when I’m doing my best. But yet, there's still shame.

“Martha” has worked in a disabilities service office for many years. After working at this job for several years, she began to realize she had many of the symptoms she was observing and subsequently got diagnosed with ADHD herself. “Martha” shared that she still regularly experiences shame as an emotion triggered when she encounters a functional impairment.

> (when) I'm not as productive… shame is the big one for me, like, “Why can't I get as much done in the day as my coworkers? Why can't I have these conversations I need to have? Why can't I keep my house up and balanced the way other people can?” Those kinds of things.

“Katie”, who maintained a successful career, nonetheless reported experiencing shame around the impairments and deficits she had because she lived with ADHD. “Um, definitely lots of shame around having these, quote unquote, “problems,” definitely a lot of shame around not being able to manage my overwhelmed, my lack of motivation, all those things. And, guilt for imposing them on other people.” The participants in this study articulated that experiencing functional impairments caused by ADHD triggered a host of negative emotions. At the core of the women’s emotional experience was found to be an intense experience of shame.

The Impact of Expectations

Shame was found to be at the core of the emotional impact of functional impairments caused by ADHD among these women. Yet shame was also found to be exacerbated by a sense among the women that they were not living up to their own or society's expectations. When asked to explain further how shame manifested in her life, "Hannah" described how she encountered shame when she realized she was not living up to the expectations of herself and others.

> if I'm actively not living up to my expectations for myself, um, I feel shame. Because, um, I, I rationally know I can do something, but I can't get a hundred percent of the way there, and I feel like I'm a, I feel like I'm failing and I feel shameful, shame for that.

"Hannah" also shared that her family members have also all been diagnosed with ADHD.

> I know that all of them (women in her life with ADHD) have, at various times, felt a sense of, like a profound sense of shame and embarrassment in themselves, to the point where, self-esteem is definitely affected. And that affects your ability to do other things that could, you know, make your self-esteem better, but because you feel so crappy about yourself, and you're sure that like, "Well, this is just going to happen the way the last time happened," you know. [sighs] It's a constant thing.

The stories, feelings, and internal tapes shared by these women often contained the theme of experiencing intense shame around not living up to their own or societal expectations.

Gender Expectations

Many of the participants highlighted societal based gender expectations as the reason they felt inadequate or unable to live up to what was expected of them. They spoke about how much pressure they experienced as women to always "be on the ball", taking care of life's practical details. Yet many of the women shared that they had substantial impairments around feeling they “lack capacity” or they struggled with inconsistency. The women acknowledged they were often unable to do everything they believed was expected of them, but instead of recognizing this as caused by a mental disability, they often internalized it at as a personal shortcoming. The women reported that comparison contributed significantly to how harshly they internally judged themselves. “Naomi” shared about how societal expectations have caused her to compare herself to those around her; “you're comparing yourself to your peers, and you can't figure out, why the hell can't I do what she can do?” This internal comparison caused the participants to experience even more shame around who they were as women living with ADHD.

When asked what specific aspects of societal gender norms frustrated her, “Gloria” elaborated on how she believes the expectations placed on women in our current society are unreasonable;

> Gender expectations) …But it's too one-sided. … the reality is, even without ADHD, it's hard raising kids, and having a career, and keeping a house going, and with ADHD, it's, it can feel like things are exploding, and there's a roller coaster, you know, it can feel chaotic.

When “Hannah” was asked how ADHD functional impairments impacted her view of herself as a woman, she shared that these impairments made her feel inadequate and flawed. “I feel like, less than other women, like a little bit dirtier than other women, a little bit more late than other women, and it's like, damn, still not making the brownies for the bake sale.”

The societal gender expectation of women being the caregiver, which implied women were to constantly care for others as well as themselves was conveyed by many of the participants as feeling overwhelming, unfair, and impossible to achieve. “Abbie” was a 39-year-old wife and mother of one child. She found life as a mother to be overwhelming. The other mothers she interacted with seemed to have everything under control, and were managing to do countless extra activities with their children and families. However, “Abbie” found herself unable to meet the perceived expectations of motherhood she saw projected around her. “I'm doing the bare minimum, but um, anything beyond that seems to kind of be too much.” The majority of the women identified society-based gender norms as a burden which caused their experience of functional impairments to be exacerbated due to the increased external and internal pressures of these expectations. It was also found that this negative experience was often intensified by the women’s awareness and internalization of the gender-based expectations and pressures of the society around them.

Negative Automatic Thoughts

Another consistent and notable finding was that the women recognized and articulated negative automatic thoughts which were triggered during and sometimes after experiencing a functional impairment. While the negative automatic thoughts varied between participants, the researcher identified the universal theme of self-loathing. Functional impairments triggered negative automatic thoughts such as “What the hell is wrong with me?” It is important to note that these thoughts targeted the woman and her personhood, not the event that took place. These thoughts were not deliberate on the part of the women and were reported to be unwelcome and undesirable. Yet, these thoughts were often triggered spontaneously and significantly contributed to the women’s experience of shame and the feeling that they were flawed. This was an important finding because it highlighted how little control these women felt they had over their minds. “Hannah” shared that she has put a lot of work into getting help for her ADHD. She has read books and sought out professionals to help her gain more control over her symptoms and impairments. Yet, despite this effort she shared:

Table Three

Number of Participants who reported this thought	Direct Quotations from Participants
6	“(Oh shit) it happened again/I did it again" “Why is this happening?”
5	"What (the hell) is wrong with me?"
4	“I’m not good enough”
4	“You’re a fuck up!” “FUUUUCCK!!!”
3	"I can't do it"
3	“What do I need to do, what am I forgetting??” "Why can't I just remember?"
2	“I’m so stupid. Idiot!”
2	“You’re a failure and you can’t do …”
2	“I feel like I'm supposed to be better at this”
2	“Why am I struggling to do these basic life things?”
2	“Why can’t I figure this out?”
1	“I hate myself and I want to die”
1	“This shouldn't be this hard"
1	"You're a terrible person"
1	“You're so irresponsible. Look what you screwed up now.”
1	“Why can't you just fix this?”
1	“No wonder nobody wants to hire you, because you're incompetent,”

Table Notes: These are direct quotes from interviews with study participants. Swear words were kept in the direct quotations so as to accurately portray the participants experiences.

> "(I feel) somewhere between fifty percent and seventy-five percent, (in control) every day. Because some days, I feel more in control than normal, some days it's like, 'Well Jesus, nothing is going to go right today''.

The women reported being harassed by negative automatic thoughts in a way that they found very difficult to stop, manage or change. Every woman had at least two internal tapes they were able to share with the researcher and many of them were the same or very similar. Table three lists some of the internal tapes shared by the women as well as how often a specific tape was referenced by participants.

Six of the participants reported intentionally working to address their negative automatic thoughts through therapy or by using skills they discovered on their own. However, these participants reported they found it very difficult to change these thought patterns. The main reason given for this difficulty was that the negative thoughts were often triggered incredibly quickly. The negative automatic thoughts were often accompanied by other mental, emotional and physical responses to functional impairments, which made focusing on the thoughts difficult. When discussing automatic thoughts which were triggered when experiencing a functional impairment, "Abbie" shared how uncontrollable the negative thoughts felt. She reported that she was working hard to change how her brain responded in these moments;

> Lately, as I work through some other issues in therapy, I tried to replace those (thoughts) and understood more about my condition, you know. I tried to be a little bit more forgiving of myself. But that's, that's a conscious thing that I have to do, you know, the negative ones just pop up without trying, you know, without me thinking about it, so it's something that I have to correct.

Negative automatic thoughts triggered by functional impairments caused the interviewed women to feel out of control and overwhelmed as well as even more ashamed of themselves. These thoughts were also reported to undermine the women's efforts to address their impairments. Negative automatic thoughts were found in this study to be one of the main contributing factors to the adverse internal experiences these women reported living with on a daily basis.

Mental, Emotional, and Physical Toll

The study participants each shared that living with functional impairments had a high mental, emotional and physical cost. This cost was felt not only when a functional impairment occurred, but also when their minds brought memories of the impairments back to them. As outlined above, there was an internal process that took place when a woman encountered a functional impairment caused by ADHD. Twelve out of the fourteen participants reported having a panic like response when faced with a functional impairment. For the women who experienced this response, it was reported to be stressful mentally, emotionally, and physically.

When asked what happens in her mind and body when she encounters a functional impairment, "Hannah" explained exactly what she experienced internally: "My brain will literally, I will go into full blown panic mode, like, uh, shaking, so nervous, my voice gets all shaky, I might cry." "Felicity", who experiences so much impairment from ADHD she was applying for disability, shared about her intense internal experiences when she encountered a functional impairment; "What happens in my mind, "You did it again. How could you do this?" So, beating up in my mind… (also) severe panic attacks. I've learned what a panic attack is." "Janet", who reported regularly trying to use the serenity prayer when faced with a functional impairment, none the less still experienced negative mental and physiological responses;

“probably my breathing, like, I find when I’m in crisis my breathing is heavier, or, or lighter… I don’t get deep breaths.”

The described panic like response included experiencing a pronounced physical reaction. The women described a range of physical responses such as heart rate increase, sweating, shortness of breath, chest tightness, tension in various parts of their bodies, crying, agitation and notably increased anxiety. These symptoms lasted for at least several minutes. The women also shared that their minds became flooded, chaotic, overwhelmed, or shutdown when they encountered or were reminded of a functional impairment. This made it difficult for them to pull themselves out of the situation and regain a sense of control. When they regain some mental clarity, the women reported often going directly into self-criticism and beating themselves up internally as negative automatic thoughts were activated. This then would trigger a host of negative emotions that could linger with the women for quite some time after the impairment occurred. The core set of emotions that were reported are the same as those outlined previously and included: frustration, anger, sadness, shame, guilt, overwhelm and disappointment. For the two women who reported not having a physical panic like response, it was found that their minds jumped right to the self-criticism, negative automatic thoughts and intensely felt emotions. The only difference found in the women who did not report having a panic response was that they did not experience any physical discomfort when they encountered a functional impairment.

Rumination

Rumination emerged as a common response to functional impairments among the women interviewed. Thirteen out of the fourteen participants reported that they ruminated after the fact about functional impairments they had experienced. It is interesting to note that the participant who did not report rumination did struggle with significant anxiety, which could be considered a form of rumination, since both involves worrying about something that was out of the woman’s control. The women reported that depending on the severity of the impairment they encountered, they could ruminate about the same event for up to several weeks. When asked if she ever ruminated about a functional impairment after it took place, “Katie” described how she continued to internally experience negative automatic thoughts and self- criticism even long after the functional impairment had passed.

> Yes. It definitely replays in my mind, um, I continue to self-criticize. [laughs] And it's, it, it um, it becomes that spiral, that downward spiral, and it becomes, “What's wrong with you? Why can't you just fix this?” And especially before I knew I had ADHD, you know, like, “You're so broken, you know, everyone else can manage this stuff, why can't you manage it?” Um, yeah, so, there's the initial like, “Oh, shit, I should have done that,” and, “Oh, crap, now I've got to like, talk my way out of this.” And then there’s the, “Oh, yes, see, I knew it, I'm a terrible person, I should figure this out

“Clare”, a 55-year-old woman who had an active social life and fulfilling career, reported that she often took impairments she experienced as well as the comments of others deeply personally, and this caused her to ruminate.

> I’m like a pig ruminating. I ruminate and ruminate and ruminate, yeah. Yes, over and over and over. Yeah, I mean I feel, I feel very sad, I feel rejected, I feel, you know, like, “Oh gosh, what did I say now?” Or, you know, “What did I do now?” Um, and then I try to process it and, you know, “How can I do, have the same situation but do something differently that will have a more positive,” so I try to process through all that.

“Hannah” also provided a vivid description of how she experienced rumination about functional impairments.

> I will replay it that night, and depending on how severe the issue was, it will, I will replay it multiple times a day for weeks. I'll get a similar but less intense physical reaction, in that like I'll get hot, and feel nervous, and you know, but it's not as intense as when it's happening. But it's almost like, an echo of the same physical and mental feelings that I feel when it's happening at the time.

For the women who had a physical response in the moment to a functional impairment, they shared that a similar, though less intense, physical reaction could be triggered when ruminating about their impairments later. The purpose of this rumination seemed to be to try to figure out what went wrong and how to ensure it didn't happen again. The problem was that these women reported trying for years to overcome their impairments without much success. This meant that by this point in their lives, the rumination had become an experience of negative automatic thoughts and reminders of their failures and inadequacies without the redemption of developing creative solutions.

External Impact of Internalization

The final question the researcher asked participants was "What aspects of living with ADHD functional impairments do you wish were better understood by those around you?" Each woman talked extensively about how they wished the people around them understood their functional impairments were not intentional. This was a significant finding in this study, as all of the participants discussed the concept of their impairments not being malicious or deliberate and wishing this was better understood by the people around them. The women also said they wished people understood that the women themselves were experiencing intense, negative, internal thoughts and emotions and so they didn't need to be reminded of the negative impact of their impairments. "Katie" found it difficult to live with the internalization of functional impairments because the people around her didn’t realize she was beating herself up internally for what happened; “I think if people knew already how intense the internal messages were, they would be much more understanding, perhaps, and forgiving, knowing that you're already, like, harassing yourself.”

Several participants provided poignant examples of how they experienced people around them responding to their impairments. “Abbie” shared a specific example of how her impairments impacted her marriage.

> My husband will ask me to call the plumber... If it’s a passing conversation, I will absolutely not remember to do it. And um, so, he gets you know, he asks me again and again and again, and I say, “Oh yeah, absolutely, I forgot,” or “I ran out of time,” That’s another thing, is, I’m just doing so many other important things that things fall through the cracks. Um…those are big functional impairments. And then what happens is my husband and I just, you know, went to therapy for this … he feels it like, “Well, I’ve asked her to do this so many times and she still hasn’t done it, this is important to me. If she really cared, she would have done it… (but) it doesn’t mean that I don’t care. Um, I wish that people understood … my reality, and everybody’s reality with ADHD which is this whole idea of like, a reduced capacity for you know, um short-term memory.

“Clare” also had several stories to share about how the people around her didn’t seem to understand she was struggling with impairments.

> So I went out on the weekend and took um, a little, a separate purse, an evening purse ... So, I didn’t have my wallet with me, but I put my driver’s license and credit card in the bag by itself. Come Monday morning, I go to work, I pick up my regular purse, and I don’t have a driver’s license or credit card, and I'm out of gas. So, I had to call a friend

> and say, “Okay, I’m you know, can you come give me ten dollars so I can put gas in my car?” Um, and another time, I had my wallet next to my laptop, I was paying bills. And I met some friends for dinner and left the wallet by the laptop. So, just stuff like that and I don’t think they understand that I’m not doing it on purpose.

“Erica”, who lives with a very understanding and supportive partner, none the less expressed how challenging it can be for the people around her to fully understand that her impairments, such as forgetfulness, are not connected to how she feels about the person.

> I think when it comes to…somebody is telling you, “Can you just do this?... Can you just work on getting better at this?” and it's like, yeah, this is not something that I’m good at, and … it doesn’t mean that I don’t care about it, or that I don’t want to do this for you, it's just, you know, I think it's just that it’s to sort of separate your feelings about a person and about doing something for them, I guess.

When asked what she wished others around her understood about functional impairments, “Danielle” responded right away that she wished others understood “it's not (to be) rude, it's not intentional, oh, and it's not for attention.” It was evident from the stories, comments and emotions behind the words that functional impairments, which are already negatively impacting them internally, caused these women to experience even more stress, frustration, and shame when the impact of their impairments was reflected back to them by their lives and loved ones.

The cause of these women’s impairments, which was ADHD, was reported to be misunderstood by those around them. The experience of being misunderstood was compounded by the fact that the majority of the women in this study reported consistently trying to prevent or reduce their external functional impairments, but with little to no success. This meant that if someone asked them to change a behavior caused by a functional impairment, they would put great effort into changing, but not see significant results. This perceived failure would intensify their negative internal experiences, as well as cause the people around them to be upset, hurt, frustrated or angry with them. The lack of change was often seen by others as the woman not caring about the other(s) desires, concerns, or preferences. The participants shared that the world around them did not understand that they are impaired by a mental disability. "Martha", who works with people who have a variety of disabilities expressed how challenging it can be to get help for an internal disability when she said:

> We wouldn't say that to any other kind of physical disability, you know, "If you just tried harder, you could walk! If you just try harder, you could read," so, you know, that people (with ADHD) would get that same type of grace.

"Naomi", who had been fired from multiple jobs due to impairments, expressed how difficult it is to be constantly misunderstood, and have your talents and skills not appreciated because of perceived weaknesses:

> You have all these gifts that you just want to offer, and you want to be accepted, and you want to be, you know, have your work appreciated, and you want to do good things, and, and excel! You know? And so, it feels like this often, a huge disconnect between myself and the people around me.

This lack of understanding of these women's impairments and experiences caused conflicts, job loss, relationship breakdowns, anger, resentment, and a lack of trust. These negative external experiences were found to feed right into the internal experiences outlined previously and caused them to intensify. This intensified internal experience made many of the participants unable to believe they could be capable, functional, happy adults.

Gender

The women expressed they believed their experiences of misunderstanding were often exacerbated by their gender. As “Hannah” said "Men, for some reason, are allowed to lose their keys forever". This sentiment was echoed throughout the interviews. The women in this study felt they, as adult women, were expected by society and those around them to take care of the tasks which require executive functioning in adult life. However, for these women, who live with ADHD which significantly reduces the ability to perform executive functions, this felt like an impossible task. Again, “Hannah” put the descriptive words on the experience:

> We have a joke “God, I wish I had a wife who could help me do things! Men have wives who do their shit for them!” I’m supposed to be the wife! How am I supposed to do this shit?! [laughs]

Many of the women felt that because of societal gender norms, they did not receive the understanding, help, support and accommodation for their impairments which they needed. This was found to be intensified by the fact the women internalized their impairments and so those around them were often unaware of their need for support and accommodations.

The women who participated in this study shared that their internal experience of functional impairments was one of shame, harsh self-criticism, and intense self-loathing caused by negative automatic thoughts. Yet, instead of receiving empathy, support and understanding from the world around them, these women reported feeling judged, publicly shamed, humiliated and not tolerated. The combination of the internal experiences caused by functional impairments with the external judgement and disregard of their disability created for these women a very painfilled, lonely world, in which they didn’t know where to find help for an experience no one knew they lived with every day. The women who participated in this study reported that they longed for understanding, support, and most of all grace. As “Clare” expressed “…a thousandfold is that, you never know what somebody's going through. So, where they may want to react to something I said, just hang on, because it is ten thousand times more noisier in my head than you will ever know."

Lived Experience and Weiss Functional Impairment Rating Scale Scores

As explored through the findings of this study, the fourteen women interviewed shared remarkably similar experiences of the internal impact of functional impairments caused by ADHD. As a phenomenological study, this study was designed to explore a particular phenomenon which was experienced among a specific population. This study was designed to incorporate a wide range of scores on the WFIRS in order to capture the essence of the phenomenon from women who all experience functional impairments but at differing levels. The study sample had a very wide range of impairment scores, from 0.3 which does not register as impaired by functional impairments on the WFIRS, to 2.20 which indicates overwhelming impairments throughout daily life.

Yet, as seen through the findings of this study, the participants did not report drastically different internal lived experiences. Each woman described to the researcher an intense and negative internal lived experience which they found to be difficult to change and undesirable to live with. Overall, the study participants described their internal experience with similar intensity. When analyzing the data, the researcher was unable to distinguish, solely from their interview transcripts, the level of impairment the participants reported experiencing on the WFIRS. This is a notable and unexpected finding. The researcher was intentional about including a wide range of impairment levels in this study so as to be able to explore the possible diversity of the lived experience. And yet, the internal lived experience was not found to express the diversity of external impairment levels included in this study.

Chapter Five: Discussion

The findings of this study illuminated the internal lived experiences of fourteen women who have Attention Deficit Hyperactivity Disorder (ADHD). These findings paint a picture of women who are suffering internally. The study participants directly linked their feelings of shame, negative automatic thoughts, uncomfortable mental and physical responses and the misunderstandings in their lives to functional impairments caused by ADHD. This indicates that assessing the internal impact of functional impairments on women with ADHD may be important to incorporate into the diagnosis and treatment process. This study contributes significantly to the current research on adult women with ADHD. By exploring the internal lived experiences of these women, this study highlights issues and struggles had by these women that may have otherwise gone unnoticed and unaddressed.

Discrepancy between WFIRS scores and lived experience

The lack of relationship between the internal lived experiences of the participants and their WFIRS scores is an important finding. Rating scales, such as the WFIRS, which measure the severity of external functional impairments, are used throughout both clinical practice and research to assess the impact of ADHD on an individual’s life. However, the study finding of the discrepancy between the participants WFIRS score and their internal lived experiences highlight the need to consider how the impact of ADHD is being assessed and measured. If treatment and recommended interventions are based on rating scales which assess the impact of external impairments, the findings of this study suggest that there may be many people with ADHD who have significant internal deficits and negative internal experiences which their treatment does not address. When their external impairment scores reduce, it may be assumed that this individual is doing well and is not experiencing many of the negative aspects of ADHD. However, if their internal experiences have not been discussed and addressed by treatment, these individuals could continue to have distressing and draining internal experiences which are directly caused by ADHD.

The researcher was unable to find any tool or measure which incorporates the internal lived experiences of the individual beyond the questions about self-concept found on the WFIRS. Without such measures, those who internalize their experiences of functional impairments will likely continue to go undertreated and without the care and interventions they need to overcome the challenges in their internal lives caused by ADHD.

Energy Impact

As heard from the study participants, when this internal lived experience goes unaddressed it causes significant distress. The internal experiences reported took a significant amount of mental and physical energy. Many of the participants reported feeling “drained” and “exhausted” by their internal experiences of functional impairments. This intense internal experience is causing them to utilize significant amounts of their internal energy, so it could be surmised that this may actually increase their overall level of impairment because they have less energy and ability to avoid or prevent further functional impairments.

Panic Response

The responses to functional impairments described by many of the participants significantly resemble panic attacks. A panic attack is defined by the Anxiety and Depression Association of America as “the abrupt onset of intense fear or discomfort that reaches a peak within minutes and includes at least four of the following symptoms.” (see Appendix N for full list of panic attack symptoms). The symptoms listed include many of the physical responses to functional impairments reported by study participants. The researcher is not suggesting that these women have a panic disorder or are constantly having panic attacks. Instead, what is important to note is that none of these women reported having this panic experienced addressed as part of their ADHD treatment. None of the women reported that their providers asked them questions about these experiences at their appointments. Due to the substantial toll these experiences of panic have on these women, those in clinical practice may consider discussing panic responses with their female clients who have ADHD.

Ineffective Intervention

Six of the participants shared with the researcher that they are working to address their negative automatic thoughts. However, it was discouraging to hear how difficult they found addressing and changing these thoughts to be. When the researcher reviewed the data, they found that the women who reported working to address their automatic thoughts also reported having panic like responses to functional impairments. The researcher speculates that the reason these women are struggling to reduce their automatic thoughts is that they are still experiencing panic responses on a regular basis. From the researcher's understanding of the brain as well as how to address negative thought patterns in clinical practice, it would seem important to first address and eliminate the panic response. It could be reasoned that only after the brain is no longer being hijacked by panic responses could the client see progress in changing thought patterns. However, none of the participants reported having been taught to effectively address and eliminate panic responses, even those who were attending or have attended therapy.

Lack of control and ability to change

The participants in this study expressed they often felt out of control when it came to managing the internal impact of functional impairments. This lack of control caused the participants to feel discouraged, angry, sad and overwhelmed. Many of the participants talked about trying to take control of both their internal and external impairments and responses, with very little success. The women also talked about trying a large variety of methods to change or stop their functional impairments. Again, the women reported it was very difficult to achieve consistent success. The combination of feeling out of control and feeling unable to change could cause these women to experience hopelessness. Yet ADHD treatment has been designed and tailored to specifically address issues such as feeling out of control and an inability to change. While these women had been diagnosed with ADHD, it is concerning that their treatment has yet to effectively address these core elements of ADHD. Feelings of hopelessness are essential to address early on in treatment, as these feelings could potentially lead to outcomes such as self-harm or suicide. This finding highlights the need for more training of those who are treating ADHD, so that those living with this disorder are kept safe and are able to live productive, joyful lives.

Relationship to previous study findings

The women who participated in the study reported many of the negative life outcomes which have been found to be common among people living with ADHD. These included but are not limited to job losses, divorce, financial issues and not achieving life milestones when it is societally expected (Biederman et al., 2009; Brassett-Harknett & Butler, 2007; Durães, Gomes, Borralho, & Paiva, 2015; Faraone et al., 2000; Halmøy, Fasmer, Gillberg, & Haavik, 2009; Michielsen et al., 2015; Waite & Ivey, 2009). Also, as found in previous studies, the participants reported that living with functional impairments cause by ADHD reduced their overall quality of life (Biederman, 2006; Gudjonsson, 2009; Lensing et al., 2015; O’Callaghan & Sharma, 2014). This study also supports the previous findings that women internalize their impairments, though this study lacked a male comparison group to determine if women internalize more than men (Guendelman et al., 2016; Holthe & Langvik, 2017; Nussbaum, 2012; Owens & Hinshaw, 2016b; Quinn, 2005; Safren et al., 2010; Smyth et al., 2016). This study also found that there may be a connection between higher rates of functional impairments among women and societal gender expectations, though this will need to be more specifically researched to be verified (Fedele et al., 2012; Fuller-Thomson et al., 2016; Ghosh, Fisher, Preen, & Holman, 2016; Quinn, 2005; Robinson et al., 2015).

The researcher expanded the research on functional impairments by exploring how internalization of impairments impacts women's internal lived experiences. This research study adds value to the current literature as it provides a unique perspective for both researchers and practitioners to consider. More research of the internal lived experiences of people living with ADHD is needed so as to improve our understanding of this disorder and be able to more effectively treat it.

Limitations

Alternative explanations of study findings

A limitation of this study is that only women who have been diagnosed with ADHD were included. This means that the internal lived experience described by these women may not actually be the lived experience of just women with ADHD but also the internal experience of women with other mental health issues or possibly even women at large. Due to the lack of a control group, it cannot be definitively stated that the experiences described here only apply to women with ADHD. It is possible that, due to societal gender norms as well as issues of mental load, women across the United States are struggling internally just as much as the women who participated in this study.

Bracketing

An important aspect of phenomenological research is the process of the researcher "bracketing" their own lived experiences (Creswell, 2013; Hycner, 1985). The researcher took time to do this before beginning the interviews. I went through the interview questions and responded to them myself so as to set aside my own lived experiences and be open to new ideas and ways of understanding the studied phenomenon. The bracketing of the researcher's experiences is meant to continue throughout the interview phase of the study. However, the researcher found this to be difficult as the participants and the researcher connected and resonated often throughout the interviews, which the researcher believes may have helped the participants to share more of their internal experiences. The researcher acknowledges this as a limitation to the implementation of the phenomenological theoretical frame work. It is important to note that when analyzing the data, the researcher took great care to bracket her experiences and only go with where the participant's data took the findings. The researcher was surprised by some of the findings in this study, and believes the lack of bracketing during interviews did not invalidate the findings.

Lack of member checking

Though not included in all phenomenological models, member checking as part of the data analysis process is often encouraged in this theoretical framework. This was not built into the study design for several reasons. As a master's in social work thesis project, this study had a limited amount of time in which to be completed. Member checking also requires a significant time commitment from study participants. The researcher was concerned that this would reduce the ability for women with busy schedules to participate in this study. Finally, the study participants often reported difficulty completing tasks. As such, member checking may have been more difficult to accomplish for this study. The lack of member checking is a limitation found in this study.

Chapter 6: Implications for Social Work and Conclusion

Implications for Social Work

Women with ADHD represent an understudied and underserved population. As social workers we are charged to work to improve lives, especially for those who often go unnoticed. It is clear from the findings of this study that the internal experiences of these women can be easily overlooked, as the women reported not being asked about their internal experiences by their ADHD care providers. It was also found through this research study that women living with ADHD are in significant need of help, support, and guidance as to how to overcome their functional impairments and improve their internal lived experiences.

Research

More research into women with ADHD as well as the internal lived experiences of all those with ADHD is needed. Further qualitative research on ADHD is especially needed. This research will enable social workers to strengthen their practices and improve the general understanding of the importance of the treatment and diagnosis of ADHD in both adults and children.

While this study utilized the phenomenological research method, the grounded theory research method would also be appropriate to utilize when exploring the lives and experiences of those with ADHD. As more qualitative research takes place on ADHD, grounded theory would enable researchers to formulate new understandings of specific processes which take place in this disorder and would enable the development of new theories related to the experience of living with ADHD.

This study found gender substantially impacted the lived experiences of the participants. Future research on women and ADHD could be done utilizing the feminist theoretical framework and could explore the concepts of internalized oppression. This research would expand the current knowledge on women with ADHD and provide new insights and perspectives into this population. Social workers are compelled by the code of ethics to work towards social justice and equity. Engaging with the challenges and injustices women with ADHD face through the lens of feminist theory and internalized oppression would help to bring the plight of these women into the discussion of gender, disability and justice.

Understanding the Internal Experience

This research study highlights the need for continued study of the internal lived experiences of those who have ADHD. The women in this study were ready and able to quickly and effectively articulate the impact of functional impairments on their internal experiences. The observations and information they provided the researcher was rich, insightful data on their internal lives. With this data the researcher was able to capture the essence of the phenomenon and provide deep insights into the needs and struggles of this population. Without this and further studies like this, there will not be able to have a clear and accurate understanding of the ways in which ADHD and its functional impairments interact with the internal experiences of clients.

Development of Effective Interventions

Without a clear understanding of the internal effects ADHD and its functional impairments can have on women, it is very difficult to effectively treat this population. The knowledge that this population internalizes their impairments is useless information unless a way of helping and healing the damage caused by internalization is developed. More research on the internal lived experiences of women with ADHD is needed so that evidence-based interventions can be developed and studied so as to address the needs of this population. While there are several excellent and helpful books available written from a clinical perspective on addressing internal issues among people with ADHD, the lack of peer reviewed, scholarly, research on interventions that address the negative internal experience of ADHD means there is a significant dearth of evidence-based interventions available. As the number of women being diagnosed with ADHD increases, it is imperative that interventions be developed that directly address the needs of this population. Only through more research can we know what needs are to be addressed, and only with more research can effective treatment methods be developed.

Clinical Practice

For those working as clinicians, we are compelled by our ethics to provide therapeutic interventions which effectively treats the mental health issue we are addressing.

Diagnosis and Treatment of ADHD in Women

This study provides important insights which can inform social work clinical practice. While ADHD has been found to be one of the most common mental health issues in the world, women are still going underdiagnosed and undertreated(Quinn & Madhoo, 2014). As evident from the women who participated in this study, women are most commonly diagnosed well into their adulthood. For many of the women in this study, this diagnosis came after seeking help for many years for their impairments and challenges. It is important that clinicians evaluate their diagnostic practices so that gender and gender-based symptom presentations do not prevent us from making accurate diagnoses.

It is also important to consider the efficacy of our treatment. Through this study, it was found that the women who had received therapeutic interventions for their ADHD and to improve their internal experiences were not effectively treated in a way that improved their lives. It is important for social workers, as well as other health care professionals, to measure the effectiveness of our treatments and interventions. The women who participated in this study did not feel they had enough control over their impairments and ADHD. Yet, ADHD is a highly treatable mental disability. If clients are still significantly impaired after receiving treatment, then other interventions and treatments need to be employed. However, we will not know if our clients are still significantly impaired unless we evaluate the effectiveness of our interventions on an ongoing basis.

Discussing Internalization

The focus of this study was the exploration of the internal lived experiences of women who have ADHD. Discussing internalization and the internal lived experiences of our clients is an important part of clinical practice as it can help us to learn more about our clients and gain a better picture of what they are going through. It is important we find creative and empathic ways to inquire with all of our clients about their internal lived experiences of the mental health issues they are dealing with. This not only will strengthen our connections with clients, but will also help us to gain valuable insight into how our clients experience the world. These insights into our client's lives can do nothing but improve our practice and the efficacy of our treatment.

Policy

Americans with Disabilities Act

While much of the work of clinically based social workers is at the micro level with individuals or small groups of clients, it is important we remember our code of ethics compels us to stay engaged with mezzo and macro issues, including policy issues. The Americans with Disabilities Act (ADA) is one of the most comprehensive pieces of legislation which provides protections for people with disabilities. Included among the protected disabilities, which an employer needs to make accommodations for, is Attention Deficit Hyperactivity Disorder (ADHD) (*Americans with Disabilities Act of 1990*, 2008). However, the women in this study expressed that they feared disclosing they live with ADHD to employers because of past negative experiences, and fear of repercussions such as being fired or being treated differently. It is important that policies such as the ADA be strengthened so at to truly protect employees and provide the needed accommodations to employees so they are able to thrive. It is also important that work places be trained on the reality of and needs for support for those with mental disabilities. Social workers can be active advocates for all those living with disabilities as they seek to effectively navigate the workplace and contribute to the society around them.

Training in ADHD Treatment

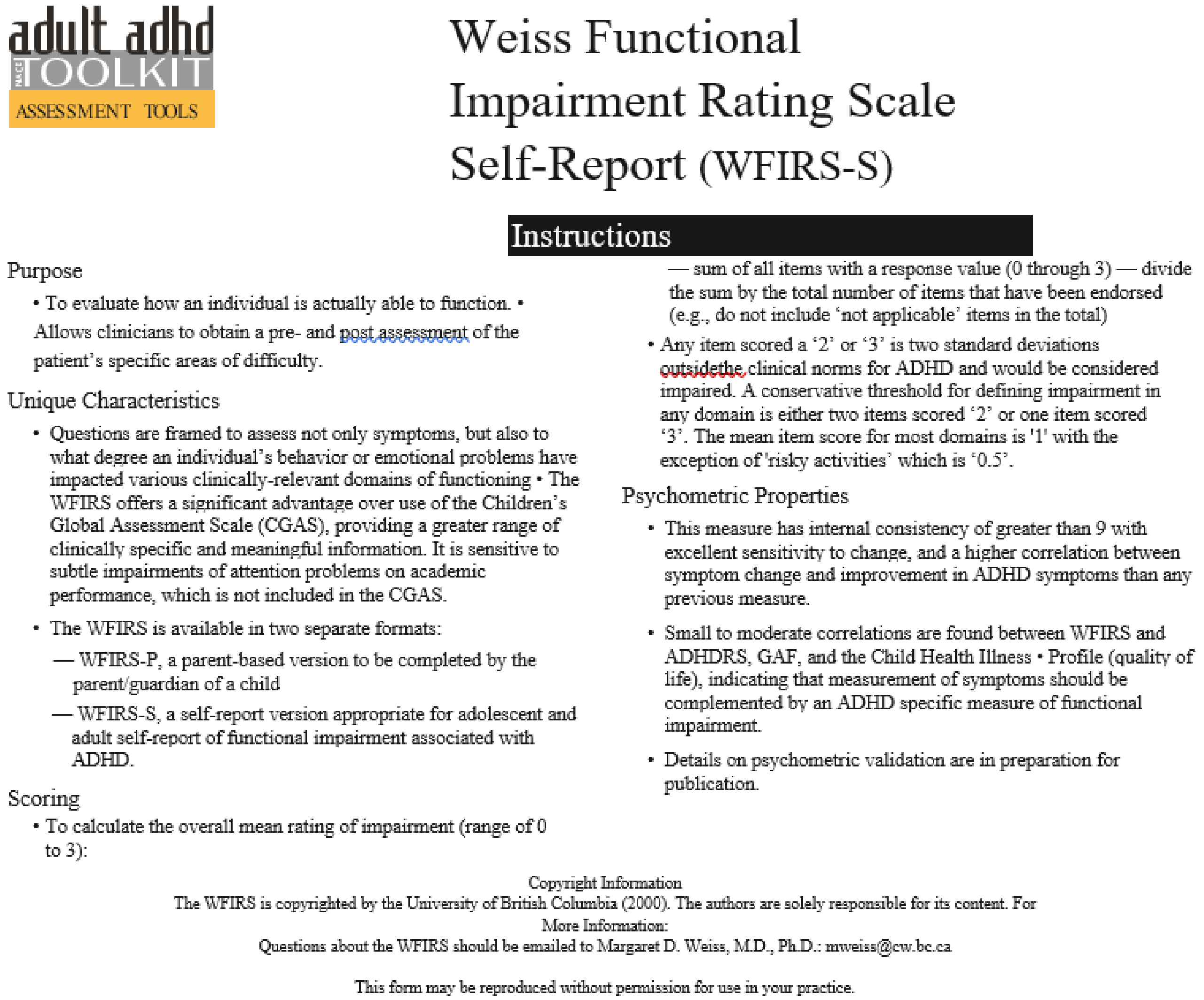
Given the estimated prevalence rates of ADHD among children and adults, it is important that those working in the mental and behavioral health fields be trained in diagnosis and effective holistic treatments for those living with ADHD. This is especially needed for those working in the fields of substance use, trauma, jail or prison settings and in the foster care system, where rates of ADHD have been found to be especially high (Babinski et al., 2011; Biederman et al., 2004; Hinshaw et al., 2012; Klein, Damiani-Taraba, Koster, Campbell, & Scholz, 2015; Niermann & Scheres, 2014; Westmoreland et al., 2010; Yang, Kadouri, Révah-Lévy, Mulvey, & Falissard, 2009). If the women in this study had had more access to clinicians, doctors, coaches or other professionals with training and experience working with those who have ADHD, they likely would have been provided with more effective interventions to address their impairments and negative internal experiences. It is essential that the care of those living with ADHD be standardized, and that best practices be put into place among licensed professionals so that all those living with ADHD have a chance to thrive.

Conclusion

This study is a first step towards gaining a better understanding of the impact of functional impairments caused by ADHD on the internal lived experiences of women. The findings of this study show that this area needs to be given more attention in both practice and research. The experiences shared by the interviewed women outline a stressful, intense, and shame filled internal life. Research and mental health care have come incredibly far in the care of those who experience brain-based challenges. It is time for these advances to be put to use for the benefit of women who have ADHD.

Appendix A

The Weiss Functional Impairment Rating Scale



adult adhd
TOOLKIT
ASSESSMENT TOOLS

Weiss Functional Impairment Rating Scale Self-Report (WFIRS-S)

Instructions

Purpose

- To evaluate how an individual is actually able to function.
- Allows clinicians to obtain a pre- and post assessment of the patient's specific areas of difficulty.

Unique Characteristics

- Questions are framed to assess not only symptoms, but also to what degree an individual's behavior or emotional problems have impacted various clinically-relevant domains of functioning
- The WFIRS offers a significant advantage over use of the Children's Global Assessment Scale (CGAS), providing a greater range of clinically specific and meaningful information. It is sensitive to subtle impairments of attention problems on academic performance, which is not included in the CGAS.
- The WFIRS is available in two separate formats:
  - — WFIRS-P, a parent-based version to be completed by the parent/guardian of a child
  - — WFIRS-S, a self-report version appropriate for adolescent and adult self-report of functional impairment associated with ADHD.

Scoring

- To calculate the overall mean rating of impairment (range of 0 to 3):
  - — sum of all items with a response value (0 through 3) — divide the sum by the total number of items that have been endorsed (e.g., do not include 'not applicable' items in the total)
- Any item scored a '2' or '3' is two standard deviations outsidethe clinical norms for ADHD and would be considered impaired. A conservative threshold for defining impairment in any domain is either two items scored '2' or one item scored '3'. The mean item score for most domains is '1' with the exception of 'risky activities' which is '0.5'.

Psychometric Properties

- This measure has internal consistency of greater than 9 with excellent sensitivity to change, and a higher correlation between symptom change and improvement in ADHD symptoms than any previous measure.
- Small to moderate correlations are found between WFIRS and ADHDRS, GAF, and the Child Health Illness
- Profile (quality of life), indicating that measurement of symptoms should be complemented by an ADHD specific measure of functional impairment.
- Details on psychometric validation are in preparation for publication.

More Information:
Questions about the WFIRS should be emailed to Margaret D. Weiss, M.D., Ph.D.: mweiss@cw.bc.ca

Weiss Functional Impairment Rating Scale Self-Report (WFIRS-S)

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Sex: Male Female Work: Full-time Part-time Other____ School: Full-time Part-time

Patient Name ______________________ Date _____________ Date of Birth _____________

A. FAMILY	Never or Not at All	Sometimes or Somewhat	Often or Much	Very Often or Very Much	Not Applicable
1. having problems with family	0	1	2	3	
2. having problems with spouse/partner	0	1	2	3	
3. relying on others to do things for you	0	1	2	3	
4. causing fighting in the family	0	1	2	3	
5. makes it hard for the family to have fun together	0	1	2	3	
6. problems taking care of the family	0	1	2	3	
7. problems balancing your needs against those of your family	0	1	2	3	
8. problems losing control with family	0	1	2	3	
B. WORK					
1. problems performing required duties	0	1	2	3	
2. problems with getting your work done efficiently	0	1	2	3	
3. problems with your supervisor	0	1	2	3	
4. problems keeping a job	0	1	2	3	
5. getting fired from work	0	1	2	3	
6. problems working in a team	0	1	2	3	
7. problems with your attendance	0	1	2	3	
8. problems with being late	0	1	2	3	
9. problems taking on new tasks	0	1	2	3	
10. problems working to your potential	0	1	2	3	
11. poor performance evaluations	0	1	2	3	
C. SCHOOL					
1. problems taking notes	0	1	2	3	
2. problems completing assignments	0	1	2	3	
3. problems getting your work done efficiently	0	1	2	3	
4. problems with teachers	0	1	2	3	
5. problems with school administrators	0	1	2	3	
6. problems meeting minimum requirements to stay in school	0	1	2	3	
7. problems with attendance	0	1	2	3	
8. problems with being late	0	1	2	3	
9. problems taking on new tasks	0	1	2	3	
10. problems working to your potential	0	1	2	3	
11. problems with inconsistent grades	0	1	2	3	

D. LIFE SKILLS	Never or Not at All	Sometimes or Somewhat	Often or Much	Very Often or Very Much	Not Applicable
1. excessive or inappropriate use of internet, video games or TV	0	1	2	3	
2. problems keeping an acceptable appearance	0	1	2	3	
3. problems getting ready to leave the house	0	1	2	3	
4. problems getting to bed	0	1	2	3	
5. problems with nutrition	0	1	2	3	
6. problems with sex	0	1	2	3	
7. problems with sleeping	0	1	2	3	
8. getting hurt or injured	0	1	2	3	
9. avoiding exercise	0	1	2	3	
10. problems keeping regular appointments with doctor/dentist	0	1	2	3	
11. problems keeping up with household chores	0	1	2	3	
12. problems managing money	0	1	2	3	
E. SELF-CONCEPT	0	1	2	3	
1. feeling bad about yourself	0	1	2	3	
2. feeling frustrated with yourself	0	1	2	3	
3. feeling discouraged	0	1	2		
4. not feeling happy with your life	0	1	2		
5. feeling incompetent					
F. SOCIAL					
1. getting into arguments	0	1	2	3	
2. trouble cooperating	0	1	2	3	
3. trouble getting along with people	0	1	2	3	
4. problems having fun with other people	0	1	2	3	
5. problems participating in hobbies	0	1	2	3	
6. problems making friends	0	1	2	3	
7. problems keeping friends	0	1	2	3	
8. saying inappropriate things	0	1	2	3	
9. complaints from neighbors	0	1	2	3	

G. RISK	Never or Not at All	Sometimes or Somewhat	Often or Much	Very Often or Very Much	Not Applicable
1. aggresivse driving	0	1	2	3	☐
2. doing other things while driving	0	1	2	3	☐
3. road rage	0	1	2	3	
4. breaking or damaging things	0	1	2	3	
5. doing things that are illegal	0	1	2	3	
6. being involved with the police	0	1	2	3	
7. smoking cigarettes	0	1	2	3	
8. smoking marijuana	0	1	2	3	
9. drinking alcohol	0	1	2	3	
10. taking "street" drugs	0	1	2	3	
11. sex without protection (birth control, condom)	0	1	2	3	
12. sexually inappropriate behavior	0	1	2	3	
13. being physically aggressive	0	1	2	3	
14. being verbally aggressive	0	1	2	3	

DO NOT WRITE IN THIS AREA

A. Family ____________

B. Work ____________

C. School ____________

D. Life skills ____________

E. Self-concept ____________

F. Social____________

G. Risk ____________

Total ____________

Appendix B

Would you like to share about your experience as a woman living with ADHD?

Now is your chance!

How? Through participation in a master's thesis research project entitled

"Women & ADHD Functional Impairments: Beyond the Obvious"

Participation Criteria

- I am a woman between the ages of 25 and 65 years old.
- I have been diagnosed with Attention Deficit Hyperactivity Disorder (ADD/ADHD)
- I have not been hospitalized within the last 3 months with a psychiatric illness
- I am able to participate in a 45 minute to 1 hour long interview either in person or over a video call with the researcher if I am selected for study participation.

Recruitment for this study is taking place between

Wednesday, September 26th at 8 AM through Wednesday, October 10th at 8 AM.

Please complete the survey anytime in this two-week window to be considered for study participation. The survey will take 15 to 25 minutes to complete.

To be considered for study participation, please complete this screening survey: https://www.surveymonkey.com/r/weiss_lynn

Appendix C

Statistical Consulting Center Confidentiality Agreement

GRAND VALLEY
STATE UNIVERSITY
STATISTICAL CONSULTING CENTER

CONFIDENTIALITYAND NON-DISCLOSURE

A. Consultant acknowledges that in performing the Services here under, Noelle Lynn and Dr. Cray Mulder may have to disclose to Consultant orally and in writing certain confidential information that Noelle Lynn considers proprietary and has developed at great expense and effort. As used herein, the term "Confidential Information" means any marketing, operating, financial, business, personal, or any other information provided in written, printed, graphic, audio or electronically recorded materials. Consultant further acknowledges that the Services and any deliverables may incorporate Confidential Information. Consultant agrees that all items of Confidential Information are proprietary to Noelle Lynn and shall remain the sole property of Noelle Lynn.

B. Academic use of information provided and developed under this contract is permitted only insofar as this use is confidential and disclosed only to parties already bound to confidentiality under the general terms of this agreement. Academic use is specifically prohibited where such use requires or promotes broader dissemination.

C. Consultant agrees as follows:

a) To use the Confidential Information only for the purposes described herein; to not reproduce the Confidential Information; to hold in confidence, protect the Confidential Information from dissemination to, and use by anyone not a party to this Agreement; and to not use the Confidential Information to benefit self or others.

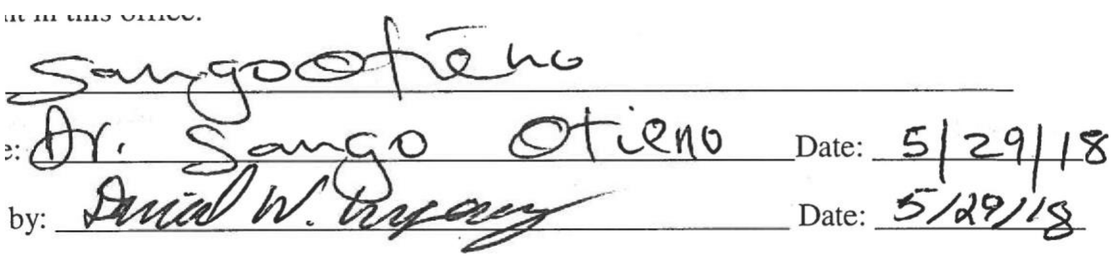
b) To restrict access to the Confidential Information to personnel of Consultant who (i) have a need to have such access and (ii) have been advised of and have agreed in writing to treat such information in accordance with the terms of this Agreement.

c) To return all Confidential Information in Consultant's possession upon termination of this Agreement or upon Noelle Lynn's request, whichever occurs first.

d) To hold in confidence information and materials, if any, developed pursuant to the Services hereunder.

D. All of the above "Confidentiality and Non-disclosure" clauses shall survive termination or expiration of this Agreement and shall continue for so long as the material remains confidential.

I understand that in the course of my employment with the Statistical Consulting Center, Grand Valley State University, I may have access to data involving sensitive records that are highly confidential. I agree that I will not share, discuss, or reveal any information about the persons or gathered information to any person other than Noelle Lynn and the appropriate staff of the Statistical Consulting Center. I will not release any information related to the research project by Noelle Lynn to anyone other than Noelle, for any reason. I understand that failure to comply with this confidentiality agreement may result in discipline, up to and including termination of employment in this office.



Signature: Sango Otieno

Print Name: Dr. Sango Otieno Date: 5/29/18

Witnessed by: Date: 5/29/18

Appendix D

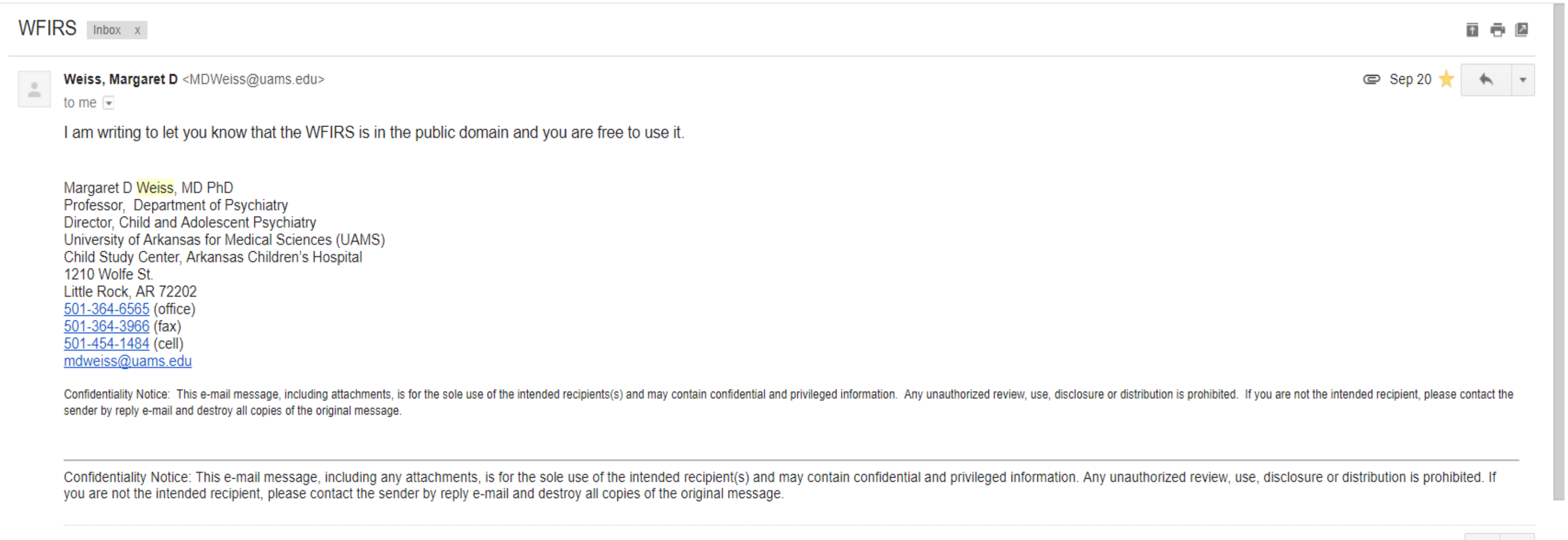
Study Participation Criteria

Participation Criteria

- I am a woman between the ages of 25 and 65 years old.
- I have been diagnosed with Attention Deficit Hyperactivity Disorder (ADD/ADHD)
- I have not been hospitalized within the last 3 months with a psychiatric illness
- I am able to participate in a 45 minute to 1 hour long interview either in person or over a video call with the researcher if I am selected for study participation.

Appendix E

Email from Dr. Margaret Weiss confirming the Weiss Functional Impairment Rating Scale is in the public domain.



Weiss, Margaret D <MDWeiss@uams.edu>

I am writing to let you know that the WFIRS is in the public domain and you are free to use it.

Margaret D Weiss, MD PhD
Professor, Department of Psychiatry
Director, Child and Adolescent Psychiatry
University of Arkansas for Medical Sciences (UAMS)
Child Study Center, Arkansas Children's Hospital
1210 Wolfe St.
Little Rock, AR 72202
501-364-6565 (office)
501-364-3966 (fax)
501-454-1484 (cell)
mdweiss@uams.edu

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Appendix F

Email to Selected Participants

Dear (Insert Name),

Thank you for completing the screening survey for participation in this research study on Women & ADHD Functional Impairments. I'm happy to let you know that you've been selected to participate in the interview portion of this study.

The interview will take no longer than 90 minutes total, including travel time or technology set up. It can take place in person or via a video call. Assistance with technological access and support is available. Interviews are being scheduled now, and I am able to work around your time table to make sure that this interview is as convenient as possible for you.

If you could provide me with the following information, we'll be able to get the interview schedule soon. I'm looking forward to speaking with about your experiences

- Your Current Location (City and State)
- 2 to 3 Dates and Times within the next month that fit in your schedule for this interview (90 minute blocks)
- Whether or not you would like the interview questions sent to you in advance
- Is this your preferred email address? (Yes or No - If no, please provide the preferred email address)
- Any questions you may have about the interview or this project

Again, thank you for your interest in participating in this project. Please feel free to contact me with any questions you may have.

Take Care,
Noelle Lynn
Masters in Social Work Student
Grand Valley State University

Appendix G

Email to study alternates

Dear (Insert Name),

Thank you for completing the screening survey for participation in this research study on Women & ADHD Functional Impairments. I'm happy to let you know that you have been selected as an **alternate** for the interview portion of this study.

There are 15 women who have been invited to participate in the research interview but I expect that not all of them will be able to find time within the next four weeks to have the 90 minute interview. If a participant is not able to participate for whatever reason, I will contact you to schedule a time for you to be interviewed.

Please let me know if you for any reason you would like to not be on the alternate list or if you have any questions at this time. I will be in touch with you regularly to let you know if you will be called upon for an interview.

Again, thank you for your interest and willingness to participate in this study!

Take Care,
Noelle Lynn
Masters in Social Work Student
Grand Valley State University

Appendix H

IRB Approvals

GRAND VALLEY
STATE UNIVERSITY
www.gvsu.edu

DATE: September 05, 2018

TO: Cray Mulder
FROM: HRRC
STUDY TITLE: Women & ADHD Functional Impairments: Beyond the Obvious
REFERENCE #: 18-205-H
SUBMISSION TYPE: HRRC Initial Submission

ACTION: Approved
EFFECTIVE DATE: September 05, 2018
EXPIRATION DATE: September 04, 2019
REVIEW TYPE: Expedited Review

Thank you for your submission of materials for this research study. The Human Research Review Committee has approved your research plan application as compliant with all applicable sections of the federal regulations, Michigan law, GVSU policies and HRRC procedures. All research must be conducted in accordance with this approved submission.

Please insert the following sentence into your information/assent/consent documents as appropriate. <u>All project materials produced for participants or the public must contain this information.</u>

> ***This research protocol has been approved by the Human Research Review Committee at Grand Valley State University. Study No. 18-205-H Expiration: September 04, 2019.***

Please remember that <u>informed</u> consent is a process beginning with a description of the study and assurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. *Federal regulations require that each participant receive a copy of the signed consent document.*

This approval is based on the HRRC determination that no greater than minimal risk is posed to research participants. This study has received expedited review, 45 CFR 46.110 Expedited Categories 6 and 7, based on the Office of Human Research Protections 1998 Guidance on Expedited Review Categories.

Please note the following are required in order to comply with federal regulations and HRRC policy:

1. Any major change to previously approved materials must be approved by this office prior to initiation. Please use the *Change in Approved Protocol* form for this submission. This includes, but is not limited to, changes in key personnel, study location, participant selection process, etc. See *HRRC policy 1010, Modifications to approved protocols*.

2. All UNANTICIPATED PROBLEMS and SERIOUS ADVERSE EVENTS to participants or other parties affected by the research must be reported to this office within 7 days of the event occurrence, using the UP/SAE Report form. If the adverse event includes a fatality, hospitalization, or security breach of sensitive information immediately notify the Office of Research Compliance and Integrity (rci@gvsu.edu or 616-331-3197) **and** the Research Integrity Officer Jeffrey Potteiger at 616-331-7207.

   See *HRRC policy 1020, Unanticipated problems and adverse events.*

3. All instances of non-compliance or complaints regarding this study must be reported to this office in a timely manner. There are no specific forms for this report type. See *HRRC policy 1030, Research non-compliance.*

4. All required research records must be securely retained in either paper or electronic format for a minimum of 3 years following the closure of the approved study. This includes original or digitized copies of signed consent documents. Research studies subject to the privacy protections under HIPAA are required to maintain selected research records for a period of at least 6 years after the close of the study.

5. **At least 60 days prior to current approval expiration**, please submit a Continuing Review form:
    a. Protocols that are <u>active and open</u> for new enrollment require both the Principal Investigator and Authorizing Official to electronically sign the Continuing Review submission in IRBManager.
    b. Protocols that are active for <u>data analysis or long term follow-up ONLY</u> require the Principal Investigator's signature but do not need to be further authorized.
    c. A copy of the informed consent/assent form currently in use in the study must accompany the submission unless the study has been closed to enrollment, and active only for data analysis, for more than 1 year.

If you have any questions, please contact the Office of Research Compliance and Integrity at (616) 3313197 or rci@gvsu.edu. The office observes all university holidays, and does not process applications during exam week or between academic terms. Please include your study title and reference number in all correspondence with our office.

Appendix I

Interview Consent Document

Title of Study: “Women & ADHD Functional Impairments: Beyond the Obvious”

Researchers: Mrs. Noelle Lynn, Grand Valley State University and Dr. Cray Mulder, Grand Valley State University Faculty

Use of Research: This study is a Master’s in Social Work thesis project. The findings of this study will be published in a final report through Grand Valley State University. The researchers also plan to present at conferences and in journal articles

Purpose of Study: The purpose of this study is to explore how functional impairments caused by ADHD impact a woman’s internal experience.

Method: This is an interview-based study. Subjects will first fill out a screening survey. Those chosen to be interviewed will be contacted to set up a time and location. Interviews will take 60 to 90 minutes. This time includes travel or set up time. Subjects will be asked questions about living with functional impairments caused by ADHD.

Collected Data: Screening survey responses will be collected in SurveyMonkey. They will then be exported and sent to the researcher. After this, the responses will be deleted from SurveyMonkey. Any person at the GVSU who has access to this survey has signed a confidentiality agreement. The survey results will be saved on the researcher’s computer. All data will be saved in password protected files.

Interviews: With the consent of the subjects, interviews will be recorded. The researcher will use a LiveScrib pen and notebook. They will also use an android phone recording app. All audio files will be saved in a password protected file on the researcher’s computer. All physical documents will be kept in a locked file cabinet. Anyone who is hired to transcribe interviews will be required to sign a privacy agreement. All audio files and notes will be destroyed at the end of the study. Transcripts will be kept for several years. The transcripts will have no identifying information on them. They will be saved in a password protected file. There will be no identifying information in any reports on the study findings.

Risks and Benefits: This study will not expose participants to any significant risks. Subjects may feel some emotional discomfort during the interview as they discuss their life experiences. There is the possibility of data being compromised due to the use of technology for information gathering. All possible steps are being taken to protect subjects and data. This study will have no direct benefits to the subjects. Hopefully, this study will contribute to the ongoing research on ADHD.

Contact: If you have any questions about this study, please contact the Office of Research Compliance & Integrity at Grand Valley State University, 1 Campus Drive, Allendale, MI. Phone: 616-331-3197. E-mail: rci@gvsu.edu.

Study Participation: Involvement in this study is voluntary. You can withdraw from the study at any time, for any reason. There will be no penalties if you choose to do so. There is no cost to participant. Subjects will choose the interview location or video call program. They also will decide on the time of the interview.

Statement of Informed Consent:

I am 25 years old or older.

I have read and understand this consent form. I have been able to ask questions. I have received any needed information. I am choosing to voluntarily participate in this study.

You have been given a copy of this consent form for your records.

Participant Signature: ___________________________________

Date: ____________________________

Appendix J

How to Sign the Informed Consent Document Online:

1. Download the PDF of the Informed Consent document emailed to you by the researcher.
2. Go to https://smallpdf.com/sign-pdf
3. Upload/Drag the Informed consent document to the purple “Drop PDF here” or click on “Choose File” to select the document from your files.
4. On the next screen, you will be able to sign your name
5. Once you’ve signed your name, you can then scroll down in the document and place it on the signature line.
6. You can then “add text” to the Date line
7. Once it is complete, you can download the signed document and send it to Noelle Lynn at gornikn@mail.gvsu.edu

If the participant needs assistance with this process, the researcher will walk them through the process at the beginning of the interview call.

Appendix K

Note: Functional Impairments will be defined to the participant at the start of the interview. The participant will have already completed the Weiss Functional Impairment Rating Scale. The researcher will also have a copy with them, in case the participant gets stuck and needs to see a list of possible impairments. If desired, the participants will be able to review the questions before their interview.

Semi Structured Interview Protocol

1. What are the most common functional impairments caused by ADHD that you experience?
2. When you experience a functional impairment, what happens in your mind and in your body? This can be in the moment or after the fact.
3. In what ways do functional impairments impact you emotionally?
4. How has living with functional impairments impacted your view of yourself as a woman?
5. Do you have any common internal "tapes" or mantras; automatic thoughts that happen when you encounter certain situations? If so, can you give me an example?
6. In what ways do you find ADHD and its functional impairments to be beneficial or positive?
7. What aspects of the living with ADHD functional impairments do you wish were better understood by those around you?

Appendix L

Email to those not selected for study participation

Dear (Insert Name),

Thank you for completing the screening survey for participation in this research study on Women & ADHD Functional Impairments. At this time, you have not been selected for the interview portion of this study. There were a high number of responses to the screening survey, and participants were randomly selected once the recruitment period had ended.

If you are interested in being contacted about future ADHD research opportunities, please let me know and I'll be sure to reach out to you if I undertake or hear of any studies that are seeing participants. Also, please feel free to contact me if you have any questions, thoughts or concerns related to ADHD and I will do all I can to connect you with appropriate resources.

Again, thank you for your interest in participating in this study.

Take Care,

Noelle Lynn

Masters in Social Work Student

Grand Valley State University

Appendix M

Confidentiality Agreement for use with Transcription Services

Women & ADHD Functional Impairments: Beyond the Obvious

1. I, ______________________________ transcriptionist, agree to maintain full confidentiality of all research data received from the research team related to this research study.

2. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of interviews or in any associated documents.

3. I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically instructed to do so by the researcher.

4. I will not provide the research data to any third parties without the client's consent.

5. I will store all study-related data in a safe, secure location as long as they are in my possession. All video and audio recordings will be stored in an encrypted format.

6. All data provided or created for purposes of this agreement, including any back-up records, will be returned to the research team or permanently deleted. When I have received confirmation that the transcription work I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the research team or destroyed, pursuant to the instructions of the research team.

7. I understand that Grand Valley State University has the right to take legal action against any breach of confidentiality that occurs in my handling of the research data.

Transcriber’s name (printed) ____

Transcriber's signature ____

Date ____

Appendix N: Panic Attack Symptoms

A panic attack is the abrupt onset of intense fear or discomfort that reaches a peak within minutes and includes at least four of the following symptoms:

- Palpitations, pounding heart, or accelerated heart rate
- Sweating
- Trembling or shaking
- Sensations of shortness of breath or smothering
- Feelings of choking
- Chest pain or discomfort
- Nausea or abdominal distress
- Feeling dizzy, unsteady, light-headed, or faint
- Chills or heat sensations
- Paresthesia (numbness or tingling sensations)
- Derealization (feelings of unreality) or depersonalization (being detached from oneself)
- Fear of losing control or “going crazy”
- Fear of dying

From the Anxiety and Depression Association of America; https://adaa.org/understanding-anxiety/panic-disorder-agoraphobia/symptoms

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