Abstract

Purpose Despite an increasing recognition of Attention Deficit/Hyperactivity Disorder (ADHD) as common among girls and adult women, the research and following knowledge on how women experience to live with the disorder remains sparse. Likewise, the wide-spread stigma of ADHD, which has been described as an underestimated risk factor for the course and outcome of ADHD, is seldom addressed in relation to the diagnosis. The purpose of this study was to explore and describe how women who are diagnosed with ADHD in adulthood experience the disorder and its associated stigma, guided by two problem formulations:

1. How are the everyday lives of (five) women affected by their ADHD?
2. What are these women's experiences with stigma of ADHD, and with the public assumptions regarding their diagnosis?

Methods The research questions were approached theoretically, through a comprehensive literature review, and empirically, through conducting qualitative in-depth interviews with five women diagnosed with ADHD as adults, in the age range 32-50 years. The methodological approach used in this study was inspired by descriptive/psychological phenomenology, and the interview material was coded and analyzed inductively, and in accordance with the constant comparative method.

Results The women have struggled with persistent symptoms of ADHD since early childhood, mainly in the form of inattention, disorganization, motivation deficit, and executive dysfunction. The consequences of these symptoms are evident on a daily basis, and secondary psychological effects, gender specific issues and self-esteem issues are commonly described. Despite their challenges, all the women have completed a higher university degree and are well employed. Public stigma and misconceptions of ADHD are experienced as common and burdensome. ADHD is described as an invisible disability, which becomes even harder to live with and manage due to the consequences of stigma. The negative impact of stigma in relation to the advantages of early identification and adequate treatment of ADHD for women is central topic in the conclusive discussion.

Preface

The process of writing this thesis has been full of exciting and challenging learning experiences. At times, it has also been marked by feelings of frustration and discouragement, particularly so when the thousands of words this thesis consists of have appeared to me as nothing more than disconnected fragments of a seemingly unsolvable puzzle. There are several persons who in each their ways have been essential sources of support, encouragement and inspiration throughout this process.

I would like to start with expressing my uttermost gratitude for the contributions made by the five women who volunteered to participate as interviewees in this study. The personal experiences and first-hand knowledge openly shared by each woman has been of crucial importance to this study. In addition to providing the research with both interesting and important data material, the women themselves and their stories have been among my main sources of inspiration and motivation for completing this thesis.

Professor Stephen P. Hinshaw had my greatest respect even before I met him, due to his commitment to his field of research and the high quality of his work. This has grown even stronger, after he on top of an already full schedule, took the time to advise me and share his knowledge with me during my stay at UC Berkeley. Professor Hinshaw's sincere interest and engagement in my research, and his constructive feedback on my work has been of critical importance to me academically and motivationally, for which I am utmost thankful.

My advisor, Assoc. Prof. Øyvind Kvello, was very supportive of my decision to study at UC Berkeley, which I appreciate. I wish to thank author Gina Pera for her interest and contribution to this study, and Assoc. Prof. Berit Groven for her helpful input. Sondre has been a great support, and also helped me with my proofreading.

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Trondheim, December 22, 2013
Mira Elise Glaser Holthe

Table of Contents

1 Introduction

1.1 Specification of the topic of research and it's scientific relevance

'Those, who have a lack of attention, are generally characterized as unwary, careless, flighty and bacchanal.' 'Every humming fly, every shadow, every sound, the memory of old stories will draw him off his task to other imaginations.' 'Such people only hear half of everything; they memorize or inform only half of it or do it in a messy manner.' 'A dull inactivity of the fibers can lead to inefficient sensations and perception, and also be inefficient for attention, because they are rarely moved actively enough, or because a case was rarely seen as important enough.'
(Weikard, 1775, translation by Barkley & Peters, 2012)

'In this disease of attention, if it can with propriety be called so, every impression seems to agitate the person, and gives him or her an unnatural degree of mental restlessness.' 'When people are affected in this manner, which they very frequently are, they have a particular name for the state of their nerves, which is expressive enough of their feelings. They say they have the fidgets.'
(Crichton, 1798, p.272)

The quotes above are excerpts from the German physician Melchior Adam Weikards' description of "Attention Deficit", which dates back to 1775, and from the Scottish physician Sir Alexander Crichtons' description of "Attention and its Diseases", published in 1798. Weikards' description represent the earliest known reference in medical literature to behavioral patterns consistent with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) (Barkley & Peters, 2012). ADHD is one of the most commonly diagnosed neurodevelopmental disorders today, and is estimated to affect 8.7% of schoolaged children and 4.4% of the adult population. Once thought to be a disorder that mainly occurred in male children, it is now widely recognized that a large number of girls and women suffer from ADHD, and that the condition persists into adulthood in 30-70% of cases (Barkley, 1997; Kessler, Adler, Barkley, Biederman, Conners, Demler, …. & Zaslavsky, 2006). Yet, most of the research that has been done on ADHD has referred to and included boys only, given that the diagnosis until quite recently was considered to affect mainly boys. The diagnostic criteria and the general understanding of ADHD today is therefore largely based on observations of how the disorder is manifested in young boys, while the existing knowledge about the impact and expression of ADHD in girls and women remains sparse

(Hinshaw, 2002). Barkley (2002) highlight the need for more studies that examine the outcomes of ADHD particularly in adult women past the age of 30 years.

Based on results from community samples, the figures for the number of boys to girls with ADHD is thought to be around 3:1 (Biederman, Faraone, Mick, Williamson, Wilens, Spencer, Weber, … Zallen, 1999). Intriguingly, by adulthood, the male/female gender ratio of ADHD is closer to 1:1 (Biederman, Faraone, Spencer, Wilens, Mick, & Lapey, 1994; Kessler et al., 2006), which suggest that ADHD is underdiagnosed in girls; an observation that also lends support from the many examples of women who first get diagnosed as adults (Nussbaum, 2012; Quinn, 2008).

Factors that might contribute to a missed or delayed diagnosis of ADHD in women, include; a tendency for women to internalize symptoms and problems; lack of knowledge about the presentation of ADHD symptoms in girls and women; and high rates of comorbid disorders (present in addition to the primary disorder) which mask the underlying ADHD. When ADHD is misdiagnosed or remains unidentified and hidden, the prospects of understanding one's problems and getting access to adequate treatment options are also lost (Quinn, 2005). This is a serious issue, considering that ADHD is associated with a significant risk of global impairment and serious negative health outcomes, especially if undiagnosed and untreated. Examples include social, educational, and functional impairment and maladjustment, high rates of comorbid disorders, and lowered self-esteem and quality of life (Goldman, Genel, Bezman & Slanetz, 1998; Hinshaw, 2002).

Genes are assumed to explain up to 76 % of the variability of ADHD-related symptoms in the population (Faraone, Perlis, Doyle, Smoller, Goralnick, Holmgren & Sklar, 2005; Rietveld, Hudziak, Bartels, van Beijsterveldt, & Boomsma, 2003), with dysfunction of the dopaminergic and noradrenergic systems in the brain believed to underlie the symptoms. Importantly, Hinshaw and Scheffler (in press) underline that although ADHD is a disorder with clear biological underpinnings, it's also shaped by – and thus needs to be understood in the light of - the social and cultural environments in which it exists. The prevailing social norms and educational system in a society will influence the standards for what is considered e.g. appropriate behaviors and not. Similarly, the way ADHD is perceived and portrayed by the majority of members in a society, e.g. as a 'moral deficit' versus a neurodevelopmental disorder, is of great importance for how individuals' with ADHD are met and thus experience to live with the disorder.

While there is limited focus on ADHD in girls and women, other aspects of the diagnosis are subject to considerable controversy and discussion these days. Common topics in public debates about ADHD include possible overdiagnosis of ADHD, the medical treatment of the disorder, and the non-specificity of several of the symptoms that are used to diagnose ADHD (which means that these also can be signs of other problems and disorders) (Goldman et al., 1998). While these are important and legitimate topics for discussion, they are often addressed in ways that undermine the validity of the diagnosis and trivializes the challenges met by individuals with ADHD, in biased and stigmatizing manners. This is especially the case in the many media stories and headlines that refer to aspects of ADHD in sensationalized and negatively charged terms, and/or romanticize and trivialize the disorder (Hinshaw et al., in press), illustrated by the following quotation from a piece in the New York Times:

> *"Ritalin and other forms of enforcement and psychological policing are the contemporary equivalent of the old practice of tying up children's hands in bed, so they won't touch their genitals. The parent stupefies the child for the parent's good. There is more to this than keeping out the interesting: there is the fantasy and terror that someone here will become pleasure's victim, disappearing into a spiral of enjoyment from which he or she will not return." (Kureishi, 2012)*

A growing amount of research show that ADHD, similar to other mental and behavioral disorders, carry a strong social stigma. Stereotypic portrayals, lack of information, and undermining of the validity of the diagnosis have been identified as main contributors to the construction and maintenance of social stigma (Heflinger & Hinshaw, 2010; Mueller, Fuermaier, Koerts & Tucha, 2012).

The terms stigma and stigmatization are used to describe an attribute, which by a society and its members has been labelled as a sign of inherent deviance and discredit of the individual who carries it (Goffman, 1963). Both terms also refer to a complex and situated process where social power is exercised in the construction of stigma, and to the resulting prejudice, stereotypes, and discriminatory behaviors directed toward a stigmatized group or individual (Hinshaw & Stier, 2008; Link & Phelan, 2001). The consequences of being labelled with a stigma are often so severe that individuals will try to avoid association with the label in the first place. For individuals with ADHD, the negative effects of stigma have shown to add significantly to the impairments caused

by the disorder itself, making the fear of social stigma a significant barrier against appropriate identification and evaluation of ADHD (see US National Institutes of Health, 1998). More research is needed in order to better understand the mechanisms that underlie and maintain the stigma of ADHD, as well as the impact of stigma on individuals' health and well-being (Mueller et al., 2012).

1.2 The purpose of this study

The purpose of this study is to provide the reader with a deeper understanding of the complex ways in which ADHD affect the everyday lives of adult women, through exploring and illustrating how clinical symptoms and encounters with stigma both shape and translate into lived experiences. This investigation is motivated by a conviction that more awareness and knowledge about the nature and impact of ADHD in women is necessary in order for them to have a real chance at experiencing positive health development. Furthermore, stigmatization is an important factor to include in this context, considering its negative influence on individuals' health and the course of ADHD symptoms, as pointed out by Corrigan (2000) in relation to stigma of mental illness; *"(…) addressing the disease is not sufficient to improve the course of severe mental illness; societal stigma and stigmatization must also be remediated."* (Corrigan, 2000, p.48).

Importantly, it is a strong wish that this study will benefit girls and women with ADHD, by providing the reader with an improved and more nuanced understanding of ADHD in women, which deals with common challenges associated with ADHD, as well as identification of strengths, coping mechanisms and experiences of mastery.

1.3 Problem formulations

Two broad problem formulations guided the selection of material for the theoretical framework and the choice of research method for the empirical part of this study:

- ***How are the everyday lives of (five) women affected by their ADHD?***

Included in this category are explorations of the ADHD symptoms the women experience as most prominent and persistent, from childhood and into adulthood. How these symptoms are manifested in women, as well as the challenges they result in, are also described. The women's experiences of being diagnosed with ADHD; of living with the disorder; and of gender specific issues are explored, and attention is paid to which treatment strategies and coping mechanisms they use in their management of ADHD symptoms and stigma. Implications of symptoms of

ADHD, early experiences of e.g. academic problems, stigma, personal and public conceptualizations of ADHD, and medical models for understanding the disorder, for self-esteem development is examined.

- ***What are these women's experiences with stigma of ADHD, and with the public assumptions regarding their diagnosis?***

In addition to exploring the women's thoughts about and experiences with stigma, this category deals with the consequences of both stigma and the public understanding of ADHD, for; the women's self-esteem; their degree of openness about own diagnosis; and their personal perceptions of ADHD and self. The impact of stigma on the challenges already presented by a diagnosis of ADHD is also explored.

A qualitative approach appeared to be the best fit for the main aim of this study, namely to thoroughly explore how women with ADHD experience the impact of the diagnosis and of stigma, on their everyday functioning. Qualitative inquiries allows for the researcher to examine the complex set of interacting variables which often underlie a phenomena, which enables a nuanced and thick description of the topic under study. The chosen approach is inspired by psychological/descriptive phenomenology, where the main focus is on the descriptions of how the participant's stories reflect their experiences with the phenomena under study, and less on the researchers own interpretations (Creswell, 2007; Finlay, 2009). The empirical data material presented in this study is the result of five semi-structured in-depth interviews of adult women diagnosed with ADHD, in the age range 32-50 years.

1.4 Academic and personal background for the choice of topic

My interest in ADHD in women was of a personal nature to begin with, as I was diagnosed with ADHD myself at the age of 25. This quickly developed into an academic interest, and I therefore chose to focus on women with ADHD in my Bachelor Thesis. Through the interviews I did as part of that work, as well as from personal experiences, I have become increasingly aware of the existence and effects of the stigma associated with ADHD. This inspired me to include the aspect of stigma in my Master Thesis, as an essential component for a more complete understanding of ADHD in women. The implications of my personal experiences and pre-knowledge on the research process is thoroughly discussed in the method section.

My perspective on ADHD and stigma is further inspired by basic values and principles from social- and community psychology, two closely tied disciplines that convey a similar view of developmental outcomes as shaped by the interplay and mutual transactions between individuals and multiple contextual factors. Reduction of the stigmatization of people with mental illness is a central objective for social- and community psychologists, who emphasize empowerment of the members of stigmatized groups as an important part of this process (Nelson & Prilleltensky, 2010). In the current study, the ideal of empowerment is approached through the emphasis on the stories the unique insight held and shared by women with ADHD, with the aim of generating an understanding of ADHD in women that is built on the lived experiences that these women find most relevant to the topic (Creswell, 2007). Further inspired by the notion that *"You never really understand a person until you consider things from his point of view . . . until you climb into his skin and walk around in it."* (Lee, 1960, p.30)

1.5 Structure

Chapter 2 include a comprehensive review of the theoretical and empirical background relevant to the research questions. The reader will get an overview of important findings regarding the expression of ADHD symptoms in women, common comorbid disorders, implications of ADHD for health and global functioning, and gender specific issues. The theoretical approach to stigma of ADHD include descriptions of the variables that contribute to stigma, and consequences of stigma for individuals with ADHD.

The choice of method and research design is described in Chapter 3. Ethical considerations and strategies for ensuring trustworthiness and rigor are accounted for, as it the role of the researcher in qualitative inquiries. Practical procedures are then explained, including the recruitment of research participants and the strategies used for coding and analyzing data.

Empirical findings are presented and discussed in Chapter 4, which is divided into three content-based sub-chapters, based on the study's research questions.

Chapter 5 include the summary and discussion of main findings, seen in the light of and compared to results from previous research. A critical review of this study's strengths and limitations, the representativeness of the sample and the transferability of the results follows, before the chapter ends with suggestions for future directions.

2 Theoretical and Empirical Framework

2.1 ADHD

2.1.1 Explanatory models of the impairments associated with ADHD

Rather than being a single and uniform disorder, ADHD represents a heterogeneous and multifactorial clinical disorder, defined by a complex etiology and a group of shared core symptoms, namely hyperactivity, impulsivity, and inattention (Biederman, 2005). Although these core symptoms point to central problem areas for individuals with ADHD, a model based on these concepts alone fail to capture the breadth and depth of the impairments associated with ADHD. Instead, some of the more recent explanatory models emphasize deficient response inhibition, executive dysfunction, and poor reward sensitivity as the main underlying causes of ADHD (Hinshaw et al., in press). The regulation of all these areas of functioning takes place in brain regions served by the brain's dopaminergic and noradrenergic pathways.

Barkley (1997) consider the core symptoms and major impairments seen in ADHD explained primarily by a deficit in response inhibition. The term response inhibition refers to the ability to keep one's goal in mind, and on basis of that, prioritize actions, withhold impulses, and resist temptation. This conscious, goal-directed impulse control is crucial for the successful management of executive functions (EF), understood as an umbrella term for a wide range of cognitive skills used to regulate, control, and manage the cognitive processes that are involved in goal-directed behavior. (Miller, Ho, Hinshaw, 2012; Nussbaum, 2012; O'Brien, Dowell, Mostofsky, Denckla, & Mahone, 2010). EF's appear to be implicated in the performance of critical cross-domain abilities, and EF abilities in childhood are predictive of poor young adult functioning in academic, interpersonal, and occupational settings (Miller et al., 2012). Patterns of weaknesses in EF have been found in male and female children and adults with ADHD (Barkley, 1997; O'Brien et al., 2010; Mahone & Wodka, 2008; Nigg, Stavro, Ettenhofer, Hambrick, Miller, & Henderson, 2005). These are evident as difficulties with poor time management, procrastination, and indecisiveness, and as problems with structuring and organizing tasks; initiate, sustain, and shift focus; regulate behavior and emotions, and trouble with short term memory and accessing stored knowledge when necessary (Brown, 2009; O'Brien et al., 2010).

Solden (1995) has described ADHD as a 'disorder of dis-organization', and emphasize the tremendous negative impact organizational difficulties have on women's everyday function, as the

ability to plan and structure is essential for conducting both minor and major tasks. For women with ADHD, internal and external disorganization can lead to 'chronic' feelings of being overwhelmed and out of control, as even seemingly simple everyday tasks can grow into complex operations.

The motivation difficulties seen in both children and adults with ADHD, have led to the development of a theory that emphasize dysfunction of the motivation and reward circuits in the brain as a core explanation of the impairments associated with ADHD. This model focus on how decreased activity of the reward system explain the difficulties with engaging in boring and repetitive tasks; the lowered sensitivity to both immediate and delayed rewards; and the inattention which is commonly seen in individuals with ADHD, and has received significant empirical support (Volkow, Wang, Newcorn, Kollins, Wigal, Telang, … Swanson, 2011).

2.1.2 ADHD in Women

While hyperactivity mainly is seen in young boys, girls and adults tend to show fewer symptoms of motor hyperactivity and other externalizing and disruptive behaviors (e.g. conduct disorder and antisocial personality disorder) (Faraone, Biederman, Weber & Russell, 1998). Instead, girls with ADHD tend to present with more symptoms of inattention, as well as mood and anxiety disorders (Biederman et al., 1999). In general, hyperactivity decreases as people get older, while inattention remains more salient and stable over time. When females do show hyperactive behavior it is commonly judged as less socially acceptable than would be the case with boys. Alternatively, symptoms of hyperactivity in girls are manifested in ways that doesn't make the surroundings consider them signs of ADHD, such as hyper talkativeness, high arousal, fidgeting, flight of thoughts, internal restlessness, and emotional reactivity (Hinshaw, 2002; Nussbaum, 2012).

As the hyperactive and interruptive behaviors often seen in boys are the symptoms that are most likely to lead to referral for evaluation and treatment of ADHD, statistics based on clinically referred samples will naturally reflect an image of ADHD as a predominantly male disorder. Quinn and Wigal (2004) have found that a significant part of the general public (58%) and teachers (82%) think that ADHD is more prevalent in boys than in girls, and that girls are more likely to remain undiagnosed because they don't act out. Common symptoms of inattention in females include forgetfulness; low arousal; internalizing symptoms (e.g. excessive worrying and rumination);

daydreaming; and disorganization, while impulsivity may manifest as a tendency to interrupt others; say whatever comes to mind; act out on impulses; and suddenly change directions in life (Solden, 1995; Waite, 2006/2010). In women, these symptoms are often interpreted as signs of emotional difficulties, disciplinary problems, and learning- or attention difficulties, instead of symptoms of ADHD (Groenewald, Emond, & Sayal, 2009; Hinshaw & Blachman, 2005; Quinn et al., 2004).

In addition to gender differences in the expressions of ADHD symptoms, difficulties related to the disorder tend to get more salient for girls as they reach puberty, in contrast to the childhood onset of symptoms that is seen more often in boys. This pattern might be linked to gender differences in brain maturation and the development of attention and other executive functions; to hormonal influences on biological processes associated with ADHD symptoms; or to an interaction between pre-existing vulnerabilities and the increased demands for independence and self-structuring abilities from early adolescence (Quinn, 2005; Waite, 2005/2010).

2.1.3 Functional impairment and long-term outcomes

The chronic and psychosocially disabling nature of ADHD significantly increases the likelihood of developing psychiatric, social, and relational problems that lasts into adulthood, especially in individuals who are left undiagnosed and untreated (Goodman, 2007).

After controlling for co-morbid disorders, a diagnosis of ADHD independently predict functional impairment, both in preadolescents and adults (Hinshaw, 2002; Miller, Nigg, and Faraone, 2007). Examples in girls and women with ADHD include interpersonal difficulties (affecting familial, peer, and romantic relationships) and peer rejection, lowered self-esteem, academic under-achievement, cognitive impairment, and occupational problems and working disability (Babinski, Pelham, Molina, Gnagy, Waschbusch, Yu,… & Karch, 2011b; Biederman et al., 1999; Hinshaw, 2002; Hinshaw, Owens, Sami, & Fargeon, 2006; Rasmussen & Levander, 2009).

Compared to other internalizing and externalizing disorders, ADHD is associated with a significantly higher risk of working impairment and disability in mid-adulthood, for both men and women (Mordre, Groholt, Sandstad and Myhre, 2012). Mordre et al. (2012) define psychosocial functioning in childhood as an important predictor of later employment functioning, and the authors thus strongly emphasize the importance of early social- and educational interventions for

children with ADHD, in order to promote psychosocial functioning and prevent academic underachievement.

Quinn and Wigal (2004) have found a greater likelihood for girls than boys with ADHD to report experiencing inappropriate talkativeness, social difficulties, problems with focusing and getting things done in general, and more conflicts with parents. Rucklidge and Tannock (2001) report that adolescent girls with ADHD are more likely to struggle with attention and organizational difficulties, to have a poorer self-concept, to experience more psychological distress and impairment, and to report feeling less in control of their lives compared to males with ADHD and undiagnosed females. These results suggest that females with ADHD are at a higher risk of psychological impairment than controls, although a greater likelihood for women to report psychological problems in general, may serve as a confound in this picture. Rucklidge et al. (2001) conclude by stressing the need for better education among primary professionals about ADHD in girls, and the importance of addressing and targeting secondary psychological effects more systematically in females with ADHD. In support of that, are findings that show that disorders related to chronic stress, such as fibromyalgia and chronic fatigue syndrome, seems to occur more often in women with ADHD than in the general population (Faraone et al., 1998; Rucklidge & Kaplan, 1997; Quinn, 2005).

Fedele, Lefler, Hartung, and Canu (2012) have found clear sex differences in the levels of inattention, hyperactivity, and impairment in college students with ADHD. Contrary to their hypothesis, they found that college women with ADHD showed higher rates of both inattention and hyperactivity, compared with men with ADHD and women without ADHD. Women with ADHD also reported significantly more impairment relative to men with ADHD in the following areas: home life, social life, education, money management, and daily life activities. No sex differences were found on measures of impairments in work, driving skills, leisure activities, or community living skills. Fedele et al. (2012) suggest that the higher levels of impairing hyperactivity reported by women might be influenced by social gender expectations, in the sense that the threshold for what is not acceptable in terms of hyperactivity, are lower for women than for men.

In contrast to their own previous findings (see Biederman et al., 1994), Biederman et al. (2005) have later failed to identify significant gender differences in levels of ADHD symptoms and related impairment. Rasmussen et al. (2009) and Babinski, Pelham, Molina, Waschbusch,

Gnagy, Yu and Sibley (2011a) have found patterns of consistent impairment, but few gender differences, on measures of internalizing problems, relationship impairment, educational level, and job performance among adults with ADHD.

Executive dysfunction, feelings of lack of control, and internalizing symptoms among women with ADHD might leave them more vulnerable to develop a ruminative thinking style and to worry excessively. Rumination has been defined as a form of maladaptive self-reflection that involve repetitive thinking about the causes, consequences, and symptoms of one's negative affect, and is strongly related to, as well as predictive of, both anxiety and depression (Nolen-Hoeksema, 2000; Smith & Alloy, 2009). Furthermore, rumination correlate with low mastery, hopelessness regarding the future, and self-criticism. Significant relationships have been found between a ruminating thinking style and symptoms of internalizing disorders, including binge eating, bulimia nervosa, self-injurious behavior, and suicidal ideation. It has been suggested that ruminators suffer from poor inhibitory control, e.g. of negative thoughts and former non-optimal strategies, and have difficulties with switching from unhelpful to helpful problem solving strategies; cognitive problems that also fall under executive dysfunction (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008).

Worry, which is a feature of most anxiety disorders, correlate strongly with rumination, and both of these cognitive thinking styles predict, maintain and exacerbate symptoms of anxiety and depression. Although very similar, worry is generally understood as a future oriented anticipation of threats, while rumination involve dwelling and questioning of past or present negative events and their meaning, and of own self-worth. Uncertainty regarding one's ability to control important life outcomes tend to lead to worry, while rumination occurs when people are more certain about the uncontrollability of situations and events (Nolen-Hoeksema et al., 2008).

2.1.4 Factors that influence the making of a diagnosis of ADHD in women, and consequences of a late or missed diagnosis

Adult women with undiagnosed ADHD often report to primary care practitioners with complaints concerning symptoms related to mood and anxiety disorders, substance abuse, and/or conflicts at home, at school, or at work (Hollon, 2004). Alternatively, women self-identify with ADHD as adults, and then consult with a professional on their own initiative for an evaluation of the diagnosis. Unfortunately, they run the risk of not being heard, as research show that many

primary care physicians do not consider making the diagnosis in adults that haven't been diagnosed in childhood (Faraone, Spencer, & Montano, 2004; Nussbaum, 2012). Instead, the irritability, symptoms of anxiety and depression, and feelings of being overwhelmed that women often experience as consequences of ADHD symptoms such as inattention and disorganization, are by health care providers commonly misidentified as symptoms of other disorders than ADHD (Waite, 2009).

A late or missed diagnosis of ADHD in women might prevent them from properly addressing and working on problems related to poor social skills, executive dysfunction, and poor emotion regulation. Over time, self-esteem and self-image are likely to suffer from repeated experiences of failure, alienation, and inadequacy. This increases the risk of developing co-morbid disorders, evident in findings that show that women who are not diagnosed with ADHD until adulthood are more likely to suffer from depressive symptoms, anxiety, sleep disorders, eating disorders, substance use, and low self-esteem (Hinshaw et al., 2006; Rucklidge et al., 1997; Waite, 2010). A late diagnosis is also associated with difficulties in being consistent as a parent, problems in managing jobs and household, and an increased risk of divorce and single parenting (Nadeau & Quinn, 2002).

2.1.5 Comorbid disorders

70-75% of individuals diagnosed with ADHD suffers from one or more additional psychiatric disorders (Quinn, 2008). Most common are oppositional-defiant disorder (ODD) and conduct disorder (CD); depression; bipolar disorder; anxiety disorders; eating disorders; obsessive-compulsive disorder (OCD); substance abuse; learning disorders (LD); personality disorders; post-traumatic stress disorder (PTSD); and Tourette's syndrome. Although depression and anxiety occurs more frequently in women than in men in the general population, women with ADHD outnumber both women without the disorder and men with ADHD regarding rates of internalizing disorders (Biederman et al., 2005; Rucklidge et al., 2001). Results from longitudinal studies that have followed girls with ADHD into adolescence, show persistent patterns of social, academic, and cognitive impairment in girls with ADHD. They also show higher rates of psychopathology, including internalizing disorders, externalizing disorders, substance abuse, and eating disorders, compared to girls without the disorder (Biederman et al., 1999; Biederman,

Monuteaux, Mick, Spencer, Wilens, & Klein, 2006; Hinshaw, 2002; Hinshaw et al., 2006; Nussbaum, 2012).

In 2002, Hinshaw published the first findings from one of the most comprehensive longitudinal studies (still ongoing) of preadolescent girls with ADHD that is done to date. Both girls with ADHD-C (combined type, include symptoms of both hyperactivity/impulsivity, and inattention) and ADHD-I (inattentive type, dominated by symptoms of inattention) had a history of speech and language problems, inattention, and academic difficulties, compared to controls. Rates of hyperactivity/impulsivity, comorbid oppositional defiant disorder and CD, and peer rejection were higher in girls with ADHD-C than in girls with ADHD-I (although higher for both ADHD-I and ADHD-C compared to controls), who scored higher on social isolation measures than did controls and girls with ADHD-C.

Results from a follow-up study after five years revealed that the girls diagnosed with ADHD in childhood continued to show higher rates of widespread psychiatric symptomatology and greater functional impairment than did comparison girls. Hyperactive symptoms, in contrast to inattention, tended to decrease with age, making the diagnosis of ADHD-C less stable than ADHD-I over time (Hinshaw et al., 2006). By 10-year follow-up (Hinshaw, Owens, Zalecki, Huggins, Montenegro-Nevado, Schrodek, & Swanson, 2012), when the sample had reached young adulthood, substantial impairments remained. Specifically, the ADHD sample was significantly more impaired academically, socially, and neuropsychologically than the comparison sample. Moreover, in the girls originally diagnosed with ADHD-C, rates of suicide attempts and non-suicidal self-injurious behavior were extremely high. Rucklidge et al. (2001) have reported similar findings.

Hinshaw et al. (2012) highlight the continuing severity of impairments associated with ADHD in females, and suggest that poor impulse control may explain some of the elevated risk of self-harm and suicide attempts in girls with ADHD-C, compared to ADHD-I. Accordingly, Chronis-Tuscano, Molina, Pelham, Applegate, Dahlke, Overmyer, and Lahey (2010) have found that childhood ADHD strongly predict adolescent depressive disorders, suicidal ideation, and suicide attempts, especially among girls with ADHD. For both sexes, a higher risk of suicide attempts (compared to non-ADHD controls) was primarily associated with ADHD-C and ADHD-H/I, while both ADHD-I and ADHD-C were predictive of adolescent depressive disorders. Barbaresi, Colligan, Weaver, Voigt, Killian, and Katusic (2013) recently found that the rates of

death caused by suicide were five times higher in their study's adult ADHD-sample, in comparison to the control group; a disturbing finding, which further stresses the importance of recognizing and addressing the potential impact of ADHD on areas that reaches far beyond childhood attentional and behavioral difficulties.

2.1.6 Gender specific issues

Social gender expectations

Hinshaw (2009) points to how changing gender expectations in today's society put girls and women under enormous pressure. While girls are encouraged to exhibit traditional 'feminine' qualities, they are also expected to demonstrate what previously have been considered 'masculine' properties, such as being competitive and driven in school and with their careers, to be assertive and to take advantage of their sexual freedom. Combining those with being empathic, nice and obedient, good mothers and home-organizers, and good at building and maintaining relationships, can be a challenge to any girl or woman. For women with ADHD, who tend to struggle with disorganization, social skills, and inattention, the task of mixing and master roles and conflicting expectations, might be even harder. As women are still bearing the main responsibility for child rearing and household management, they are facing heavy demands regarding organizational and structuring skills on a daily basis (Waite & Ivey, 2009).

Quinn (2005) emphasize that girls in general are raised to act polite and compliant, to apologize, to follow the rules set by parents and teachers, and to not fight back. Consequently, girls are at risk of being judged more harshly when they show the same hyperactive, impulsive, or disorganized behavior as boys do, since these behaviors violate the norms for what is considered appropriate feminine behavior. Furthermore, girls are expected to act mature and responsible, e.g. by suppressing feelings of anger and anticipate consequences of their actions to a greater extent than boys. Girls tend to show similar rates of hostility and anger as boys, but differ in their expression of these feelings, in ways that over time might result in internalized distress, indecision, and self-blame (Zahn-Waxler, Klimes-Dougan, & Slattery, 2000).

Fedele et al. (2012) have suggested that the negative impact from ADHD symptoms on social relationships might be even more distressing for women than for men, as women in general tend to rely on and value close relationships more than men do. Experiences of social deficits may place a heavier emotional burden on women with ADHD compared to men with ADHD, and have

them experience higher levels of rejection sensitivity and stereotype threat (when the fear of confirming a negative stereotype affects behavior/performance negatively). Consequently, many girls with ADHD isolate themselves, or try to hide or compensate for their symptoms in order to fit into their surroundings. By internalizing problems and keeping their struggles to themselves, withdraw socially, and spending excessive amounts of energy trying to live up to society's conflicting expectations, the symptoms of ADHD themselves and the negative impact of these on girls' and women's functioning, may go unrecognized by others (Quinn, 2005).

'They look without seeing, listen without hearing': Inattention and Academic Problems

Academic difficulties are common for individuals with ADHD and often attributed to hyperactivity. However, studies show that inattention is the strongest predictor of academic functioning and attainment by young adulthood, while hyperactivity as a single factor do not contribute significantly to academic problems (Pingault, Tremblay, Vitaro, Carbonneau, Genolini, …& Côté, 2011). Consequences of inattention often include patterns of significant inconsistencies in results and performance over time, and/or 'chronic' underachievement. However, teachers and health care practitioners will not necessarily attribute such academic difficulties to ADHD, unless accompanied by observable hyperactivity. Accordingly, inattention and disorganization can be kept hidden through compensatory work efforts, high IQ, and/or a structured and supportive home and school environment. This might keep ADHD 'hidden' for years, often until compensatory abilities are exceeded by increasing academic and organizational demands. Many will also experience that they in spite of their efforts end up with poor results, which in cases of unidentified ADHD, can result in self-blame and perceptions of self as less intelligent and capable than others (Solden, 1995).

Due to decreased activity in the reward circuits in the brain, individuals with ADHD commonly experience decreased sensitivity to reward and deficits in motivation. This is associated with inconsistent performances and problems with engaging in tasks that are not immediately rewarding, and might complicate the understanding of the disorder (Volkow et al., 2011). Many will experience that they are able to focus as long as they are under strong pressure or when the topic is particularly interesting, but then get frustrated and confused when they experience that the same level of focus often can't be reached when facing a boring and/or prolonged task. The context dependency of ADHD symptoms in general can make the disorder hard for people to understand, and lead to attributions of inconsistent performances to laziness, lack of willpower, or low

capabilities; perceptions which increase the risk of both lowered self-esteem and reinforcements of stigma (Brown, 2009).

Hormonal Influences

It has been suggested that female sex-hormones – estrogen and progesterone – might influence both the severity of ADHD-symptoms, and the efficacy of stimulant medications among women (Nussbaum, 2012). Fluctuations of female sex-hormone levels increase during puberty for girls, and lasts throughout life in association with the menstrual cycle, during pregnancy and breastfeeding, and during menopause. For many girls, symptoms of ADHD become more evident during puberty, and several women experience severe PMS-symptoms, combined with a temporary worsening of ADHD symptoms. These experiences might relate to the effects of estrogen on the functioning of the neurotransmitter systems implicated in ADHD, something that should informed about to women ADHD. The mere awareness of the possible link between hormonal fluctuations and severity of ADHD-symptoms may be of help to better understand, predict, and cope with the changes in mood and functioning that might occur as a function of hormonal cycling and changes (Nussbaum, 2012; Solden, 1995; Quinn, 2005).

2.2 Stigma of ADHD

"Mental illness is nothing to be ashamed of, but stigma and bias shame us all." (Bill Clinton)

In modern society, mental illness is identified as one of the most stigmatized attributes a person can have (Heflinger et al., 2010). Per now, there has been conducted limited research exclusively on stigma of ADHD, which is why much of the empirical literature used in the following chapter is from studies of stigma associated with mental illness. Although ADHD is defined as a neurodevelopmental disorder, and not a mental disorder, ADHD is still subject to much of the same suspicions, prejudices, myths, and poorly informed conclusions that define the stigmatization of mental illness. Based on that notion, relevant literature from previous research on both stigma of ADHD and mental illness have carefully been selected into a comprehensive overview of stigmatization of ADHD. The term stigma is first conceptualized, followed by an exposition of factors that contribute to the stigma of ADHD, and of the consequences of stigma.

2.2.1 Conceptualization of Stigma

The term stigma refers to an attribute that is associated with undesirable characteristics, and is also, along with stigmatization, used to describe the whole process in which certain attributes are defined as deviant, assigned with shame and discredit, and reduced to stereotypes to categorize the groups and/or individuals who meets the criterions for what society has labelled as discreditable. Public stigma is an important part of this process, and refers to the broad societal acceptance of stigmatizing, discrediting stereotypes, as well as to the resulting prejudice and discriminatory behavior that is directed towards the stigmatized group; all of which together serve as a way of separating and differentiating "them" (the discredited) from "us" (the normal) (Goffman, 1963; Hinshaw et al., 2008).

Link et al. (2001) include status loss as both a defining feature and a consequence of stigmatization, and state that social exercise of power is a prerequisite for stigma. For a (minority) group to be stigmatized and discriminated against, there need to exist an acceptance and agreement about the legitimacy of these practices among the members of the bigger group, who holds the defining power in regards of what's considered socially acceptable or deviant. The complexity of unequal power distribution in stigma processes can be particularly salient in cases of mental illness. Individuals with mental disorders receive harsh social stigma, yet they are also dependent on the help and treatment interventions that are offered and managed by more powerful members of the society over whom the stigmatized excess little or no control. Stigmatizing attitudes and practices are found among healthcare professionals who work with mentally ill patients, and include a lack of empathy and understanding, disparagement and low expectations of recovery or improvement, overly negative outcome predictions, and coercive treatment (Heflinger et al., 2010). A strong preference for social distance from individuals with a history of psychological problems have been found among members of the society in general, and as a consequence, persons with a known history of mental illness are less likely to be hired, and to find housing as well as friends (Corrigan, 2000; Hinshaw et al., 2008).

Feelings of inferiority, guilt, and low self-esteem accompany many mental disorders, and make individuals who suffers from these particularly vulnerable to internalization of negative attitudes and beliefs held by the public. This internalization commonly results in self-stigma, self-devaluation, and intropunitive emotions and self-blame. Even the family members of individuals with mental disorders receive stigma, referred to as courtesy stigma, e.g. in the form of blame for

genetic transmission of 'disease genes' and accusations regarding bad parenting, or they are simply avoided for their mere affiliation with the stigmatized individual (Hinshaw et al., 2008; Mueller, et al., 2012).

Although professional and public knowledge about mental illness has increased substantially over the last decades, individuals with mental disorders still receive severe, widespread, and even increasing amounts of stigmatization (Hinshaw et al., 2008). According to attribution theories, stigma arise from public beliefs about personal controllability of - and thereby responsibility for – symptoms of mental disorders (compared to physical illnesses). A reduction of stigma would therefore be expected to follow the now increasing acceptance of biogenetic explanatory models, in which the responsibility and thus blame for the illness is placed outside of the individuals control (Corrigan, 2000). However, research show that biogenetic models of mental disorders does not necessarily reduce stigma. On the one hand, they can offer some relief to individuals with mental disorders and their families, e.g. by providing them with a tangible cause and explanation for their difficulties, as well as by lessening personal feelings of guilt. On the other hand, biogenetic models can be interpreted in ways that make the course and symptoms of mental disorders seem genetically determined, which can leave individuals with the feeling of being intrinsically flawed and unable to control their illness. Beliefs about mental disorders as genetically determined and stable have shown to strengthen public perceptions of 'the mentally ill' as unpredictable, dangerous and untreatable, which tend to worsen stigma (e.g. by increasing people's desire for social distance) (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Rüsch, Todd, Bodenhausen, & Corrigan, 2010).

The point of reference for many when discussing ADHD and mental disorders, are the often stereotypical and sensationalized media portrayals of 'the mentally ill' as unpredictable, delusional, dangerous, immature, and in lack of willpower. Biogenetic models have shown to strengthen the tendency to associate dangerousness and unpredictability, which are strong predictors of stigma, with mental illness, despite that individuals with mental disorders are more likely to be the victims of, rather than the perpetrators of, violence and abuse (Angermeyer et al., 2011; Corrigan, 2000; Corrigan& Watson, 2002; Hinshaw et al., 2008).

2.2.2 Factors that contribute to the stigma of ADHD

Variables that contribute to the stigma of ADHD, are the public's uncertainty regarding the validity and reliability of the diagnosis itself, negative attitudes toward medical treatment of ADHD, and perceived dangerousness of individuals with ADHD (Mueller et al., 2012). Negative press about ADHD e.g. medication is common, and contribute to stigmatizing attitudes toward the assessment and treatment of ADHD, both in the public in general and among diagnosed individuals and their families (DosReis, Barksdale, Sherman, Maloney, & Charach, 2010; Mueller et al., 2012). The most common stereotypes about ADHD are closely tied to beliefs regarding over diagnosis, especially in children, and to perceptions of ADHD medications (stimulants) as dangerous, equivalent to illegal drugs, and/or unhelpful. Despite that ADHD medications have been thoroughly tested and used for decades, many news-stories and public debates fail to provide scientifically based information about stimulants. Public acceptance of unbalanced, uninformed, and/or stigmatizing debates serve as a way of legitimizing stigmatizing attitudes and practices, and reinforces individuals' fear of stigma.

The course of ADHD is heterogeneous across development, situations, and between individuals, meaning that the symptoms of ADHD are expressed differently and can lead to variable degrees of functional impairment, dependent on contexts and individual factors. This complicate the understanding of the diagnosis, and can open up for perceptions of its impairments as trivial, or caused by a lack of willpower or resistance to conform (Brown, 2009; Mueller et al., 2012). Accordingly, if not perceived as a 'real' disorder, a diagnosis of ADHD is also less likely to be met with sympathy and understanding, and might instead become subject to moral judgments and negative attitudes (Hinshaw et al., in press).

2.2.3 Consequences of stigma

The negative effects of stigma have shown to cause additional impairment and independently predict a poor outcome among individuals with mental disorders, even when initial levels of functioning and symptomatology are controlled for (Hinshaw et al., 2008). Consequences of stigma for individuals with ADHD include lowered quality of life, decreased sense of empowerment and self-efficacy, social isolation, and lowered self-esteem. Furthermore, the fear of stigma have shown to result in a reluctance toward pursuing a diagnosis of ADHD and/or seeking treatment, poor treatment responses, and increased symptomatology (Mueller et al., 2012;

Waite et al., 2009). In a study conducted by DosReis et al. (2010), 77% of parents of children with ADHD reported stigmatizing experiences, and Bussing, Zima, Mason, Porter, & Garvan (2011) have identified strong stigma concerns among adolescents with ADHD as a major predictor of treatment discontinuation, despite actual need for service usage due to significant functional impairment.

The fear of being labelled and stigmatized might increase as a function of the perceived legitimacy of public stigma (e.g. selective negative press coverage, lack of social sanctioning for those who express stigmatizing attitudes), and can result in social withdrawal and/or avoidance of diagnosis disclosure. Considerable efforts are required in order to hide and compensate for the symptoms of ADHD, and concealment also hinder individuals with ADHD from receiving important social support and recognition of their struggles (Mueller et al., 2012; Rüsch, Angermeyer, & Corrigan, 2005). Hatzenbuehler, Phelan, and Link (2013) define stigma as a fundamental social cause of health inequalities, based on the dependence of stigma on power; the harmful impact of stigma on individuals' health; and the disruption of stigmatized individuals' access to resources that could help reduce poor health outcomes. Consequently, Hatzenbuehler et al. (2013) highlight the importance of paying close attention to the existence and effects of stigmatization both in research and in the development of health promoting interventions.

2.3 Summary points

Recent explanatory models emphasize deficient response inhibition, executive dysfunction, and poor reward sensitivity as the main underlying causes of ADHD. A diagnosis of ADHD independently predict functional impairment and significantly increases the likelihood of developing psychiatric, social, and relational problems that lasts into adulthood, especially in individuals who are left undiagnosed and untreated. A significant number of girls and women with ADHD are assumed to remain undiagnosed, much due to limited knowledge and awareness regarding the occurrence and manifestation of ADHD in females. For girls, difficulties related to the disorder tend to get more salient as they reach puberty, and they often present with more symptoms of inattention, which commonly are misidentified as symptoms of other disorders than ADHD. A late or missed diagnosis of ADHD in women might prevent them from properly addressing and working on their problems, and women who are not diagnosed until adulthood are more likely to suffer from depressive symptoms, anxiety, substance abuse, and low self-esteem.

Symptoms and consequences of ADHD for women can make e.g. motherhood particularly challenging, and make it hard to live up to social gender norms expectations. Stigma of ADHD have shown to cause additional impairment for diagnosed individuals, including lowered quality of life, lowered self-efficacy and self-esteem and a reluctance toward pursuing a diagnosis of ADHD. Several variables contribute to the stigma of ADHD, e.g. selective negative press and the public's uncertainty regarding the validity and reliability of the diagnosis. The mechanisms that underlie and maintain stigma of ADHD needs to be better understood and targeted, in order to prevent its negative effects on an already impairing disorder.

3 Method and Data Analysis

"Experience without theory is blind, but theory without experience is mere intellectual play." (Immanuel Kant)

3.1 Background for the choice of a qualitative approach

Qualitative approaches provide the researcher with the opportunity to explore the complex set of interacting situational, relational, and individual variables that often underlie a phenomenon, and capture the essence of a phenomenon, which might be more inaccessible to quantitative methods. Based on the main objectives of this study, namely to explore and achieve a detailed and complex understanding of how ADHD and the stigma of the disorder is experienced by women with ADHD, I decided that the most suitable choice would be a qualitative research approach (Creswell, 2007; Finlay, 2009). Furthermore, it was important to have the interviewees feel empowered from sharing their stories and inform the research, and to minimize the power relationships that often exist between a researcher and the participants in a study. These central goals can be well attended to in qualitative approaches (Creswell, 2007). In further support of the utility value of a qualitative study of stigma, is the notion that *"(…) the gap in our understanding of how children and their families experience stigma may be due, in part, to the relatively few qualitative studies on this topic"* (DosReis et al., 2010, p.811).

The qualitative approach used in this study is informed by psychological/descriptive phenomenology, which slightly differs from hermeneutic phenomenology, in that the focus mainly is on the descriptions of how the participant's stories reflect their experiences with the phenomena under study, and less on the researchers own interpretations. Furthermore, it is a goal for the researcher to describe and then set aside own experiences and assumptions related to the topic under study, so that he/she can achieve a view of the phenomena under study that is as fresh and 'objective' as possible, in a process known as bracketing (Creswell, 2007; Finlay, 2009). Yet, as in hermeneutic phenomenology, the aim of psychological phenomenology is to describe and extract the essence of the shared experiences individuals' have of a phenomenon, including the meaning that these experiences hold for the individuals. Furthermore, this should be communicated in a way which allows other people to grasp the essence and 'get a personal feeling' of' how the phenomena under study is experienced (Creswell, 2007).

Qualitative accounts have the potential to enrich quantitative inquiries, e.g. by identifying variables that later can be measured quantitatively, or by providing existing statistics with situated 'real life' stories that give meaning and substance to quantitative information, and thus make it more comprehendible to people. It is a goal in the current study to present the research in a way that makes it available to a broad audience, based on a personal consideration of such availability as an important quality of research in general, and because ADHD is a topic of great public interest these days. Updated information and knowledge about the disorder should therefore be presented in ways that are comprehendible and of interest to individuals from all groups and levels of the society, regardless of scientific or academic background. Availability to a broad audience might also mean a more accurate assessment of the transferability of the study (described in part 3.3).

3.2 The Role of the Researcher in Qualitative Research

> *"A researcher's background and position will affect what he/she choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions." (Malterud, 2001, p. 484)*

It has been claimed that most qualitative approaches can be situated within a constructivist paradigm, because of the shared emphasis on understanding, describing, and/or interpreting dimensions of a social phenomenon, including the experiences of the individuals that are involved, and the wider social context in which the phenomenon exists (Postholm, 2005).

According to a constructivist view, human beings actively engage in the construction of their own and each other's realities (life-worlds), which they thus both shape and are shaped by, through means of social interaction. Consequently, concepts like 'knowledge' and 'reality' are understood as relative, in the sense that they represent the meaning and understanding of a phenomenon which individuals situated in a particular context, have created between them (Postholm, 2005).

Since qualitative investigations involve some form of social interaction between the researcher(s) and the research participant(s), the role and responsibility of the researcher as a subjective interpreter that actively takes part in a dynamic process of knowledge construction, is emphasized within a qualitative tradition. Instead of claiming objectivity, the researcher is encouraged to make an accurate account of how his/her subjectivity and position might have influenced the research process (Hiles & Čermák, 2007; Smith, Flowers, & Larkin, 2009). This

can inform the reader, as well as heighten the researcher's own awareness of such effects. Furthermore, the 'clarity' that this reflective process is meant to result in, can help the researcher to separate own experiences from the research participant's, which is especially important in the process of collecting, interpreting and analyzing research data. Useful information to include in this type of an account, include the background and knowledge the researcher has on the topic under study, the reason(s) for choosing to investigate it further, and those of the researchers personal beliefs and preconceptions that are likely to have shaped the interpretation and approach to the study (Creswell, 2007; Smith et al., 2009).

3.3 Trustworthiness, Rigor, and Ethics in Qualitative Research

Traditional validation measures like validity and reliability mainly apply to quantitative methods, and four 'alternative' procedures have therefore been developed for the assessment of trustworthiness and rigor in qualitative research. These include; credibility, transferability, dependability, and confirmability (Krefting, 1991), and are described below, along with the methods used to establish them in the current study.

Credibility ('internal validity') refers to the truth value of the study: how accurately does the method of data collection, and the interpretation and description of findings, capture and represent the research participants' life-worlds and experiences of the phenomena under study? I used several recommended strategies (Anderson, 2010; Krefting, 1991; Postholm, 2005) to enhance the credibility of the current study. These include prolonged time in the field (9 hours of interviews in total, follow-up emails, and former experience with a similar setting); member checks/respondent validation (before using the interview material in the thesis, I asked each interviewee to read, review, and validate the data from her respective interview); reflexive analysis (described further down); and theoretical triangulation (the use of multiple sources of theoretical and empirical material in the approach toward understanding and conceptualizing a phenomenon). The truth value of this study is further strengthened by what seemed to be genuine responses during the interviews (i.e. no apparent demand characteristics), and from the positive feedback I received from the participants regarding the topics and themes in the interview protocol, which they felt were representative of what they found important and relevant themselves.

Transferability ('external validity') refers to the degree of applicability of the research findings to other comparable settings, and thus to the overall utility value of the study as a whole.

The use of member checks is useful also for enhancing transferability, and according to Krefting (1991, p.216), *"(...) research meets this criterion when the findings fit into contexts outside the study situation that are determined by the degree of similarity or goodness of fit between the two contexts."* One way of assessing such naturalistic generalizability, is to provide a description of the phenomenon under study that is thick and detailed enough for others to be able to judge the degree of transferability, e.g. based on whether a person in a similar situation is able to recognize him/herself in the description (Postholm, 2005). The transferability of the findings from the current study is discussed in more detail in Chapter 5.

Dependability ('reliability') refers to the overall quality of the integrated processes of data-collection, data analysis, and – if applicable - theory generation, in terms of how consistently these processes are performed, and to how well the collected and analyzed data support and explain the research findings. The dependability of qualitative research is based on the degree to which variability in the data material is identified, addressed and explained, and on whether the researcher have described and made available to the reader the measures and procedures that he/she used during the research process (Anderson, 2010; Postholm, 2005). This way of addressing dependability is captured by the term transparency, which goes hand in hand with reflexivity and is described as *"(...) the need to be explicit, clear and open about the assumptions made and the methods and procedures used"* (Hiles et al., 2007). Transparency regarding method and procedure, interpretation, and analysis of the data give the readers of a research paper the possibility to follow and judge the whole research process, and to replicate the procedures that were used (Krefting, 1991).

Confirmability ('objectivity ') refers to the (degree of) freedom of bias in – or the neutrality of - the research procedures and results. Such neutrality is much dependent on the researchers' degree of awareness of potential influences of his/her subjectivity on the research process. Such awareness can be heightened through the researchers' use of reflexive analysis, which involve that he/she explicitly describe and systematically account for the effects of own subjectivity on the research process (Krefting, 1991; Postholm, 2005). Reflexive analysis is especially important in qualitative inquiries, because the investigator serve as a key instrument and thus an influence on all parts of the research process. One way of fostering reflexivity, and thereby prevent the researcher's subjectivity from serving as a bias that threatens the trustworthiness of the research, is to give an open report of the values; pre-conceptions; self-interests and beliefs that are seen as

pertinent to the inquiry, and to discuss the potential influence of these factors on the research process (Malterud, 2001). Furthermore, the researcher can enhance a study's confirmability by 'backing up' the claims and interpretations that he/she makes, with multiple independent sources of theoretical and empirical data (Krefting, 1991).

For me personally, it was mainly a positive experience to be diagnosed with ADHD, as it provided me with long awaited answers and strategies for managing a variety of challenges. Academically, I have continued to find the complexity and many aspects of ADHD both interesting and fascinating. I draw from several disciplines of psychology in my understanding of ADHD, including social- and community psychology, developmental psychology, developmental psychopathology, and health psychology. As I have learned more about the disorder through my own experiences, from the literature, and from the women who have told me about their lives, my own conceptualization of ADHD have become more complex. Much in terms of an increased awareness of the many factors and variables that underlie and influence the course and outcome of a diagnosis of ADHD in women. I find the interplay between social, environmental, and genetic factors especially interesting and also promising in relation to ADHD, as these processes can serve to modify and moderate the course and outcome even of a neurodevelopmental disorder with such strong heritability as ADHD, maybe particularly so when the symptoms are managed from an early age.

I find it very important that ADHD is recognized and taken seriously as a disorder. However, I'm also of the opinion that the way in which the implications of ADHD is communicated e.g. from the psychiatrist to the 'patient', might be of crucial importance for how a person will experience to get diagnosed and perceive the impact of ADHD on life and own functioning. In my understanding of it, taking ADHD seriously means a recognition of challenges and impairments, as well as of strategies for mastering and modifying these. I therefore find it essential to challenge the stigmas associated with ADHD, including portrayals of the symptoms as either trivial, unmodifiable or incompatible with a productive and/or fulfilling life.

Ethical and Methodological Considerations

After having reflected on the advantages and disadvantages of doing so, I chose to be open about my own ADHD diagnosis towards the research participants already in the Verbal Recruitment Script that was sent to all potential interviewees (Appendix 1). This decision was informed by ideals from phenomenology and community psychology regarding openness and a

degree of mutual trust and sharing. Moreover, it was driven by my wish to make the interviewees feel comfortable in sharing their stories with me, by reducing the potential risk that they would feel a need to 'hide' their true experiences and feelings, out of fear from embarrassment or negative judgment. I also worried that the efforts of 'hiding' my ADHD from the interviewees would require too much of my attention and thus hamper our interaction. Therefore, I concluded that it would be beneficial for the research participants, for myself, and for the overall quality of the study, that I openly positioned myself as an *insider researcher* (a researcher who is also a member of the group that he/she is studying).

Although a close relationship between the researcher and the research participant(s) is a hallmark quality of qualitative inquiries in general, the building of trust which is based on a sense of sameness and a common ground for understanding, opens up for an ever deeper level of information sharing, often at an earlier stage than what 'normally' might be the case. This, in combination with the insight and commitment to the field that comes with the insider role, have the potential to enrich and strengthen the quality of the research. Regarding the benefits of the insider role, and of qualitative approaches in general, Link et al. (2001) call it a shortage of research on stigma that *"(…) many social scientists who do not belong to stigmatized groups, and who study stigma, do so from the vantage point of theories that are uninformed by the lived experience of the people they study"* (Link et al., 2001, p.365).

However, the insider role can also increase the risk of what Krefting (1991) and Postholm (2005) refers to as *over involvement* from the researchers side. This involves that the researcher identifies with the research participants to the degree where (s)he loses the ability to separate own experiences from theirs, and to 'objectively' interpret the findings; both of which threatens the trustworthiness of the research. Again, active use of reflexive analysis can here be used by the researcher to increase the awareness of own preconceptions and beliefs, in order to 'set these aside', and thereby limit their influence on the research process.

For me, the reflexive process involved a strong focus on avoiding assumptions of identical feelings or experiences between myself and the research participants; to notice and emphasize unique and contrasting experiences equally strong; and to make sure that possible 'taken for granted' truisms were explored. In addition to this, I placed a strong emphasis on following ethical guidelines for research in a consistent and careful manner. This included that I thoroughly informed all the women about their rights as research participants (Informed Consent, Appendix

2), and explained that I was interested in their unique experiences, regardless of whether these would 'fit' the interview guide or not.

Because of the intimate setting that the data material was gathered in, and the personal importance of the topic to the interviewees, I found it particularly important to make sure that the interviewees felt comfortable with sharing their feelings and experiences; not only with me during the interview, but also as presented in my thesis. My use of respondent validation served this purpose by providing the research participants with the control of what information related to them, they felt comfortable with letting me share about them. Moreover, it was also an attempt to balance the unequal power distribution that inevitably takes place when information is given from the interviewee to the researcher.

3.4 Research Design: Semi-structured in-depth interviews.

To gather the detailed, personal accounts of the lived experiences of women with ADHD that I needed in order to reach an understanding of the phenomenon based on first-hand experiences, I chose to collect data by using semi-structured in-depth interviews. This method involve the examination of pre-defined themes through open-ended questions, and allows for directional changes during the study, e.g. based on new information and insight that emerges as the study proceeds. This can be an advantage when the aim of the research is to explore a phenomenon thoroughly and/or generate hypotheses for future investigation, and not to test any pre-determined hypotheses (Finlay, 2009; Smith et al., 2009). Importantly, and highly relevant to this study, in-depth interviews are also described as optimal for collecting data on individuals' personal histories, perspectives and experiences, particularly when sensitive topics are being explored (Creswell, 2007).

3.5 Practical procedures and recruitment of research participants

The data collection and most of the further work with this thesis was done at UC Berkeley, as a part of my Master of Science Degree in Cultural, Social and Community Psychology from NTNU.

In order to go through with my research, I needed to submit and have my research proposal approved at both NTNU and UC Berkeley, separately. After receiving approval from both Universities, I reported my project to the Regional Committees for Medical and Health Research Ethics in Norway (REK) and the Norwegian Social Science Data Services (NSD) for ethical

evaluation and approval of my research. Since I was going to interview American Citizens, I also needed to send an equivalent application to The Committee for Protection of Human Subjects (CPHS) at UC Berkeley. In addition to the approval from CPHS (Appendix 4), it was required from UC Berkeley that I completed a course in research ethics education (CITI Training Certificate, Appendix 5) before I could begin my data collection. It eventually turned out that approval from NSD and REK was unnecessary (Appendix 3), as I was going to conduct my research in the US, with American research participants.

Since this is a study of adult women with ADHD, it was a natural prerequisite for all the interviewees to be female, at the age of 18 or older, and previously diagnosed with ADHD. No requirement was made regarding age at the time of diagnosis. When the goal of a research project is to examine specific characteristics in detail, the recommended way of recruiting participants is the homogeneous type of purposive sampling, which refers to the selection of participants based on their sharing of a predetermined set of traits (Patton, 1990).

To get in touch with possible research participants, my US Advisor, Professor Stephen P. Hinshaw, provided me with the contact information of a woman who is part of a large network of adults with ADHD. I sent an email to her, where I explained the goals and nature of my research and asked whether she could think of any possible informants, where after she forwarded my request to a number of her contacts. I received positive answers from nine women with ADHD, of which five agreed to participate in an interview. That is described as a good sample size for a qualitative inquiry. I concluded that five interviews, each estimated to last between 1.5 and 2 hours, would provide me with sufficient data material for interpretation and analysis. Furthermore, that would also fit the time limits for this research project, as the work with both conducting and analyzing qualitative interviews is time consuming (Dalen, 2004; Smith et al., 2009).

Before conducting the interviews, I spoke with each woman individually via email and/or phone, to provide them with detailed information about my research, their role and rights as research participants, and the content of the informed consent form they were required to sign before we could go through with the interview. I thereafter arranged to meet individually with each woman, at the time and location that was most convenient for her. Two of the interviews took place in a private meeting room in a public library, while the other three interviews were done via Skype video calls, due to the long travelling distance between the respective interviewee and me. I had my concerns whether interviews via video calls would feel unnatural or impersonal for the

respondents and/or me, but it turned out to work well for both parties. In advance of the Skype interviews, I signed two copies of the Informed Consent Form and sent them by post to the respective informant, since it was required that they read, signed and returned one copy of the form to me, before we could go through with the interview. With the permission of the participants, all of the interviews were recorded on a digital audio recorder, but not stored anywhere else (e.g. PC), and only available for me to listen to and use.

I made the interview guide (Appendix 6) based on the theoretical and empirical literature presented in Chapter 2. It consisted of 26 open-ended questions that both my advisor and my sub-advisor reviewed in advance of my interviews. This list of pre-defined themes and questions helped me ensure that the same topics were covered in all my interviews, so that I could capture the participant's common experiences of the phenomenon under study (Postholm, 2005). At the same time, the participants were encouraged to elaborate on the topics that they found particularly relevant, yet within the thematic limits set by me in the interview protocol. To prepare each woman on the course and content of the interview, and include her in the research process, I gave her the chance to read through the interview guide just before we began the interview. At the same time, I made it clear that I was interested in her unique experiences, and didn't expect or want her to confirm or disconfirm any particular questions or hypotheses. I had the feeling that the interviewees were comfortable with this, as their stories and responses seemed genuine and honest both towards themselves and me, and not driven by any apparent efforts to answer in a particular and/or socially desirable manner (i.e. demand characteristics, see Krefting, 1991).

3.6 Description of Research Participants

The five participants were adult women in the age range 32 – 50 years (M=40.4 years), all diagnosed with ADHD in adulthood (M=35 years). In order to protect the participant's privacy and maintain their anonymity as best as possible, identifiable information has been removed from the data material. This include demographic characteristics (other than whether they are born in the US or not), details regarding their field of education and career, the exact number and age of children (when applicable), and the interviewees' real names, which are replaced by pseudonyms. As an extra precaution, the respondents' current age is given as age groups, either 32-40 years, or 41-50 years, instead of their exact age. Information regarding relationship/marital status, parental

status, educational level, employment status, and age when diagnosed with ADHD, is included in the data material.

Common for all the interviewees, is that they have completed a Higher University Degree; are married/in a relationship; have one or more close relative with ADHD; and either are or have been full time employees. Three of the women were born and raised in the US, while two of them moved to the US as young adults for career and educational pursuits. A more detailed presentation of the interviewees follows in the table below:

Name (pseudonym)	**Age group**	**Age when diagnosed**	**Children**	**Current employment status**
Amber	32-40	36	Yes	Working full time
Beth	41-50	43	Yes	Quit her job to be home with children
Christine	32-40	19	No	Working full time
Debra	41-50	48	Yes	Quit her job to be home with children
Emily	32-40	29	No	Working full time

3.7 Coding and analysis of data material

After having conducted an interview, I transcribed the respective audio recording successively, before conducting the next interview. The initial transcription of the audio recordings from all the interviews provided me with a total of 63 pages of raw material, which I imported into Atlas.ti (a computer aided data analysis tool designed for coding qualitative data) for content analysis and open coding.

In the first round of coding, I focused on identifying broad themes, subthemes, and categories in the data material, as such 'data reduction' aid an understanding of the meaning in a complex and comprehensive data material. I continued with reading and grouping the data material horizontally, i.e. after these initial themes and categories, so that I could make further comparisons and look for thematic patterns. This approach is in accordance with the Constant Comparative Method, in which common themes emerging in the data material create the basis for a grounded theory. Furthermore, the approach is inductive, since detailed reading and interpretation of the raw data material guide the selection of codes and focus on important themes. Yet, the analysis was

also partly deductive, since the coding of data as well as the collection of interview material was based on the research objectives that I had defined beforehand (Finlay, 2009; Smith et al., 2009; Thomas, 2006). More than 40 codes emerged from the first set of data analysis, of which several were later grouped together, based on their co-occurrence and similar meaning content. As I read and compared the codes, quotations, and data material in several rounds, many of the original codes were renamed or refined, as clearer thematic patterns in the material emerged.

After 8 rounds of increasingly specified coding, and exclusion of the material that didn't fit in under the scope of this project, I ended up with a total of 7 main themes and 10 defining 'sub-codes' which guide the structure of the presentation of findings in Chapter 4. Before I began describing the data further, I asked each interviewee to evaluate and give me feedback on the chosen quotes from her respective interview, which resulted in one name change (of a sports team, for anonymity sakes) and a couple of grammatical corrections. The presentation and discussion of results in Ch.4 is based on the study's problem formulations, and is divided into three content based sub-chapters, further specified by themes and codes. Due to the many references made by the interviewees to various aspects of self-esteem, I chose to devote one separate sub-chapter to self-esteem.

Overview of sub-chapters, and belonging themes and sub-codes

Chapter 1: ADHD in Women	
Theme	**Defining sub-codes**
The early symptoms and events that led to the ADHD diagnosis	
Today's main Symptoms and Challenges: Executive Dysfunction, and Worries, Rumination, and Anxiety	• Indecisiveness and disorganization. • Procrastination, motivational difficulties, and inattention. • Poor time management. • Emotion regulation and self-control. • Excessive worrying, rumination, and anxiety.
Personal conceptualizations of ADHD, and examples of what it's like to have ADHD	• Reactions towards receiving the diagnosis.

	• Could an earlier diagnosis have made a difference? • Examples and perspectives on how life is affected by ADHD.
Gender specific issues	• Hormones. • Social gender expectations, and motherhood.

Chapter 2: Self-esteem

Chapter 3: Stigma
Theme
Experiences/thoughts about stigma
To tell or not to tell: selective disclosure
Management of stigmatization and ADHD symptoms

4 Presentation and Discussion of Empirical Results

The following chapter is divided into three content-based sub-chapters, namely; "ADHD in Women" (4 themes, 10 codes), "Self-Esteem", and "Stigma" (3 themes), each organized after main themes, and sub-codes when applicable.

The first sub-chapter, "ADHD in Women", is the most comprehensive of the three, due to the broad scope of the title and its main relevance to the thesis, which is evident also in the number of related questions interview protocol. Because of the breadth of the data material included in its title, the chapter "ADHD in Women" is organized after both main themes and belonging sub-codes, in order to properly highlight and distinguish between the many nuances of the data material.

The interviews done in this study resulted in a very comprehensive data material, which unfortunately was too extensive to present in its entirety. Therefore, a careful selection of data was made, based on relevance to the research questions, and on recurrent themes as well as unique and surprising findings. The majority of the quotations have been shortened, but in cases where doing so would have been negative for the meaning content, I`ve chosen to keep the original length of the quote. Findings are presented, described and discussed consecutively. Thereafter, in the conclusive discussion in Chapter 5, main findings and key points are summarized and discussed in comparison to previous research.

4.1 ADHD in Women

4.1.1 The symptoms and events that led to the ADHD diagnosis.

"My own school years left a big scar, you know". (Debra)

Although none of them were diagnosed until adulthood, all the interviewees express clear memories of one or more early symptoms of ADHD, mainly in the form of inattention and concentration problems (e.g. *All my life I've known that I can't concentrate*); forgetfulness; motivational difficulties; procrastination; and resulting underachievement (discrepancy between intellectual capacity and educational achievement). Already in elementary school, inattention and daydreaming began to cause problems for several of the women, as it made it difficult to focus on homework and to pay attention in class. Yet, some of the women remember that they were able to focus on books and topics that they found particularly interesting:

"I spent a lot of time day dreaming in class when I was younger; I was not listening unless I was very interested in the subject, so I would have to study more later - I spent my week ends studying. The subjects that interested me were okay, I could focus on them, but it was difficult to read a book unless it really interested me." (Debra)

Debra points out that her struggles made it even harder to thrive in a school system that was already *"(…) brutal, very harsh, a very negative system that beats you up"*.

Because of inattention, more time and efforts than average were often required in order to keep up with schoolwork. Even though the girls both felt and were told that they were smart, their grades were often fluctuating and unrepresentative of their actual abilities. Additionally, as the often 'situational aspect' of inattention can open up for assumptions regarding the controllability of concentration problems, these tended to be attributed to laziness or a lack of effort, in the absence of a better explanation. Beth, who knew that she was smart and did her best to pay attention, couldn't explain to herself why she, in contrast to her classmates, still couldn't follow what was going on in school. In addition, she struggled noteworthy with motivational problems and procrastination:

"I tried to plan ahead and get things started earlier, but I just couldn't do it. It was as if I needed the panic of not understanding something, and knowing that I would get a test in it, to get the adrenalin going so that I could get it done. It's extremely stressful! Especially since you're also beating yourself up, because you're thinking "How dumb, and here I did it again, why can't I just do it ahead of time?" (Beth)

Like Beth, Amber couldn't explain to herself or others why she repeatedly failed to prepare in time, or how it was possible to fail easy exams while she got top grades in other, much harder classes. Still, she managed to complete her education with good results, but describe how her studies became harder to manage when academic and structural demands began to increase, and when she started working and had to perform continuously on a daily basis.

"I did better than most of my peers, but I've had bumps all along the way, you know. People would say 'you're so smart'; one guy told me that I was like an encyclopedia, that I knew everything about everything! But then, why couldn't I do better in life than people who supposedly were not as smart as me? It was like ups and downs all the time. I was struggling with structure, and with forcing myself to study on a regular basis, and not just on the day before an exam, right; that's what I would always do." (Amber)

Although inattention is the main predictor of academic difficulties and failure (Pingault et al., 2011), hyperactivity is the ADHD symptom that tend to be recognized and targeted by a child's immediate surroundings. Amber points out that inattention is an especially harmful symptom because it's so easily and commonly overlooked – especially in individuals who through great efforts manage to compensate for their symptoms and do well in school.

Christine have been told that she was 'kind of wiggly' as a child, and that her teachers would comment on her forgetfulness in school. Christine spent hours on homework from an early age, and managed to get very good grades all the way through high school, until they started falling all over in college, due to increasing academic and organizational demands.

In contrast to the four other women, Emily hasn't had any sort of academic difficulties, and always enjoyed and did well in school. She remember herself as a happy and well-adjusted kid, despite of some forgetfulness and social difficulties. One thing that she clearly remembers as problematic, and still struggles with today, is her problem with regulating her emotions:

"I remember losing my backpack and my homework in grade school. ADHD surely wasn't obvious in my grades; looking back, the signs of ADHD would be in many of my social interactions, and sort of in my struggles with picking up social clues. One of the things that I can look back to as a kid, are problems with regulating emotions. I remember having temper tantrums that would scare me, because I realized that I couldn't control them, and I didn't even know why I was so upset." (Emily)

Common for most of the women in this study, are their descriptions of how procrastination, motivational difficulties, and problems with planning and structuring work have presented them with academic as well as psychological challenges. In the absence of a better alternative, perceived personal flaws became the explanation for academic struggles, resulting in self-blame, and over time, to a negative self-image, which has followed several of the women into adulthood. It is both

interesting and important to note that they all describe early symptoms and challenges which are considered 'typical' for a diagnosis of ADHD, yet no such connection was ever made by anyone in the girls' surroundings.

The women were diagnosed as adults, when they self-referred for evaluations of ADHD, after having heard and read about ADHD (in women) for their own sake, or in relation to the diagnosis of own children, exemplified by Beth below:

> *"(…) my son's teacher suggested that I should get him evaluated for ADHD, and so I started reading some books on the topic. After doing that, I was not certain whether he had ADHD or not, but I was positive I did. I had thought about ADHD a lot, because I think I've always thought that it was me, but I mean…everyone is a bit like that." (Beth)*

When reading about adults and women with ADHD, some of the descriptions that the women recognized themselves in, dealt with relationship issues, time management problems, concentration problems, indecisiveness, and disorganization. Emily experienced that moving in together with a boyfriend for the first time brought a lot of tension, e.g. in terms of communicating together in general.

> *"I read an article that explained some common patterns in relationships between a person with ADHD and a person without ADHD, and some common tendencies in adults with ADHD, and while reading it I felt like I was checking off a checklist. I also struggled terribly with keeping a clean household at that time, and in my new job, there were things that I felt should be easier for me to learn and manage, but still I kept having problems with these silly little things. All of that sort of made me curious about what the reason could be that small things seemed harder for me than they should be, and harder than what other people did seem to find them." (Emily)*

Findings from Babinski et al. (2011a) suggests that romantic relationships become an area of impairment for women with ADHD first by adulthood, as experienced by Emily.

For Christine, things became more problematic when she turned 17-18, particularly in terms of time management problems and indecisiveness. She decided to seek help at the medical center in college, where they first thought that her problem was anxiety. Christine tells me that

because her time management problems were driving her crazy, she definitely had some anxiety issues going on. Eventually, at the age of 19, she was diagnosed with ADHD.

4.1.2 Today's main Symptoms and Challenges: Executive Dysfunction, Worries, Rumination, and Anxiety.

Indecisiveness and Disorganization.

"There is no more miserable human being than one in whom nothing is habitual but indecision." (William James)

Inattention often result in disorganization, and while indecisiveness and disorganization are involved in anxiety as well as depression, both concepts are also among the core features and consequences of executive dysfunction (Brown, 2009; O'Brien et al., 2010). All the interviewees tell me that they struggle with indecisiveness and the various problems it causes.

> *"When I was much younger, I would think that it would be nice to have a routine. Just to know what to expect, and feel like you could relax, because that does take a lot of stress away. The act of constantly having to make decisions is what you do when you don't have a routine; you constantly have to make decisions, and I think that my inability to get into a good routine sometimes causes anxiety." (Beth)*

> *"I often have a very hard time making decisions, especially if I have several options to choose from. I also have a tendency to make a decision, and then immediately second guess it and third guess it; I'll flip from one option to the other and drive myself and everybody else crazy." (Emily)*

> *"Sometimes it's easier if other people make the choice for me, but I also hate it when I defer to others and ask them to make the choice for me. I especially do that if I'm tired, and it's funny how easy it is for them to make a decision." (Christine)*

Amber tells me that she's having problems with planning and organizing everyday tasks, and that it can be an incredible effort for her to e.g. *"(...) actually make an appointment with a doctor, to go there on time, and to take the time off from work to do it"*. Beth uses the calendar and the reminder function on her phone to stay organized and to keep track of both minor and major

events, including monthly hormonal fluctuations. She explains that she doesn't see patterns; without a 'map' or clear instructions, everything is just noise.

Procrastination, Motivational Difficulties, and Inattention

Procrastination involve delaying the (previously) intended execution of important tasks and is understood as a form of self-regulatory failure. When the tendency to procrastinate become more of a trait than a state, it's associated with negative consequences for psychological health and well-being and on academic and professional performance, including feelings of guilt; underachievement; negative mood; and chronic stress (Steel, 2007; van Eerde, 2003). The majority of the interviewees tell me that they have struggled with procrastination from when they were children. Amber explains how her procrastination and indecisiveness have created problems for her academically, privately and at work. She tells me that she ended up not signing up for her health plan last year, because she postponed it too much.

> *"I always think that I need to read and learn everything about things before making a decision, and that takes a lot of time. So, things become such big tasks, and I keep procrastinating, thinking that I don't have the time, and suddenly it's too late."* (Amber)

Amber says that she's going to work without being able to work, and therefore get into trouble all the time. Despite the consequences, Amber feels unable to control her procrastination. Yet, in projects that she likes, she'll get motivated and do really well. Fluctuating performances is a significant concern for Amber, and she describes that her whole life is stress because she's doing everything last minute, which leaves her with a constant feeling of running out of time.

Christine explains how she's getting stressed out and end up in a bad mood, simply from thinking about boring and tedious tasks she has to do, because they seem so never ending. Furthermore, Christine describes how she dislike the feeling of 'being stuck' in something, along with a general tendency to easily get bored.

> *"I have this dream in my head that it would be great to have three careers at once, I don't like the idea of just doing one thing. A lot of people I talk to say that they want to be an*

expert in something, but I wonder if for me, that would mean that things would just become boring. I get bored easily." (Christine)

Difficulties with sustained focus and work efforts, and with going back to a task after an interruption, are by several of the women described as common challenges. Christine points out how problems with staying focused also can affect intimate situations: *"(...) like, it takes a while to get into something, and then you need to stay focused, and it's not a big deal I would say, but I wonder if other people have another experience with that, if focus is an issue for them."*

Beth tells me that it's very distracting to have kids, "(…) because it takes me so long to get focused on something, and they're constantly pulling me away, I feel like I can't think my own thoughts". Debra had the same problem before she began taking medication for her ADHD, which helped her multitask and stay focused. Furthermore, Debra explains that is was easier for her to work than to study, because it was interesting, structured and organized.

Like Amber, Christine describes how she experiences periods of 'hyper-focus', where she can work continuously for hours on projects she finds interesting. On the other hand, she's struggling with open-ended tasks, and both Amber and Christine emphasize that ('positive') pressure and structure is essential for motivation and productivity.

"The thing with ADHD is that if you lower your expectations, you'll lower your efforts, and then also do worse. I think that for ADHD people, pressure works. Short-term pressure works, lowering expectations does not. No matter how much you lower your expectations, you'll still have problems getting to work and finishing it on time." (Amber)

"I definitely feel that when my days are busier, I use my time more efficiently. I can almost get into this rhythm of being efficient, but if there's more open ended time with just one large task, it can be harder for me to use that time well. And also, if I have to do something on the computer that requires a lot of thinking, I find myself going on the internet as soon as I have to think extra for a second, and that's frustrating." (Christine)

Poor time management

Executive dysfunction in the form of time management problems (Brown, 2009) are presenting all the women with daily challenges, especially in terms of difficulties with estimating how much time that is required to complete various tasks, and in what seems to be a poor awareness of the passing of time, e.g. time escapes me, without me knowing where it went. The consequences of poor time management include frequent problems with getting to work and to social events on time, despite efforts to do so, and with making manageable plans for a day, which again results in self-disappointments and stress. Several of the women are sharing a feeling of constantly running out of time, and have received negative feedback for showing up late on various occasions.

> *"I think that I try to pack too much into my days, and I create pressure on myself by thinking that when I get home, I'm going to do like five things, but probably I'll just do one of them. I constantly underestimate how much time things will take, and then I end up feeling bad when I don't get them all done." (Christine)*

> *"I'm definitely not like a lot of other stay-at-home moms, who find a lot of time to do all these things and stuff, while I'm just able to maintain the home in order, and to make sure that the kids have places to study. I feel like I don't accomplish much, I'm not doing a lot of things and projects. There are a lot of things that I would like to do, but I don't have the time for it now, because it takes me so long to get to do things, but when I start doing them, I can do them real quick. It's just hard for me to do things consistently and to get into a routine." (Beth)*

> *"When I drop my daughter off at the daycare, I'm always late, and I can see what the teachers are thinking. People think you're a bad mother, right. I have friends who are constantly taking their kids to different classes and activities, but my kids aren't enrolled in any extra classes. I just can't deal with it." (Amber)*

Debra describes herself as disorganized and with a tendency to be late. Still, her rigid and structured childhood, has taught her strategies for managing her time and structuring her days. Her experience illustrate the possibility of learning time-management skills through efforts and practice, and from what all of the interviewees are telling me, the learning of such skills should be of great value to girls and women with ADHD.

Emotion regulation and self-control

Anger issues, poor emotion regulation (of negative emotions in particular), and a general fear of losing self-control are by several of the women identified as problematic parts of their ADHD-symptomatology. Amber points out that *"(...) there's a lot to ADHD, like anger. I have a lot of anger issues, and problems controlling emotions. It's not only problems with concentration and organizational skills".* Having read that environmental stressors can cause genetic changes and 'activate' ADHD-genes, Amber is worried about the effect that e.g. arguments with her husband, will have on their children. Both Debra and Beth experience that all the new distractions and responsibilities that came with motherhood, can result in stress which negatively affect their mood.

Emily, who struggled with temper tantrums as a child, says that she's developed more control as she's gotten older, but that she's still struggling with her hot temper. One of Emily's problems is that she'll realize that she's lost her temper only when it's too late, and she's therefore trying to find ways to stop herself earlier.

> *"If I get angry, I'll say exactly what's on my mind. I can say some very hurtful things to my boyfriend, or say something snippy or curt at work that can be interpreted by people in the wrong way, and sometimes I'm not even aware of it, or of the tone that I have when I say things to people. Or, even if I am aware of it, I will be over it the next day or the next hour, or ten minutes later, and don't understand why people are still hurt or angry with me." (Emily)*

Higher levels of emotion dysregulation have been found among adults with ADHD compared to controls (Mitchell, Robertson, Anastopolous, Nelson-Gray, & Kollins, 2012), and can be symptomatic of a more general self-regulatory failure, consistent with executive dysfunction and a deficit in response inhibition (Barkley, 1997; Brown, 2009). For several of the women, their mood and emotion regulation skills clearly suffer when the threshold for what they consider a manageable level of stress is exceeded. This threshold seems to be greatly influenced by distractibility and disorganization, and might therefore be lower for women who struggle with these issues as part of their ADHD symptomatology. However, Emily underlines that her hot

temper doesn't necessarily come from ADHD alone, as she's discussed with her family how they all are having trouble controlling their emotions.

Excessive Worrying, Rumination, and Anxiety

None of the women have a diagnosed mood or anxiety disorder, yet four of them struggle noteworthy with excessive worrying and rumination, as well as other symptoms of anxiety and/or depression. Following Quinn et al. (2004), worrying and rumination are common consequences of inattention in women with ADHD. Christine describes the cycling 'back and forth' nature of rumination, and its characteristic, often unconstructive "if" and "then" thoughts.

> *"I ruminate a lot, and I don't like that; there's a lot of traits that I wish I didn't have. Even thinking about my decisions in the past; it's not necessarily that I regret them - except sometimes I wish that I had worked harder because I feel that it would have provided me with more options-, but then again I feel that options are the biggest curse for me, so.. And if working harder would have meant not being able to do other things, maybe it wouldn't have been a good trade off. I wonder if other people think about these things as much as I do. I think it would be nice to have more of a balance." (Christine)*

Amber says that she's always worried, which has interrupted her sleep since from childhood. Her mother would tell her that she was thinking too much, which Amber says is true; *"(…) I think too much, and I've heard that I'm oversensitive."* She also describes periods of depression, and how she's come close to committing suicide on several occasions in her life. Feelings of unpredictability and lack of control regarding her life, and of not seeing a way out of her problems, seem to cause stress and reinforce feelings of anxiety and depression for Amber.

> *"Things can fall apart in a second; my whole life can fall apart. If I can't hold on to a job and an income, my whole life will fall apart – it's so scary. That is the reason I'm developing heart problems, because of the stress." (Amber)*

Like Amber, Christine has also been told that she's thinking too much, and explains how indecisiveness and feelings of being overwhelmed and not in control contributed to anxiety and disordered eating in college.

"In college I would get so overwhelmed that I'd freeze up, not knowing what to do. Or, I'd get so overwhelmed by the amount of work that I had to do, and end up not doing it. That was hard. I felt very out of control with myself, and in fact, I think that I could probably have been diagnosed with an eating disorder at that time. It wasn't necessarily that I wanted to get thinner, though I think that was a part of it, but I think it was more like I felt so out of control with my life that I was trying to control what I was eating. And by doing so, I was doing the opposite; I was even more out of control." (Christine)

Debra tells me that her vivid imagination tends to exacerbate what she describes as a general worry or fear e.g. that something could happen to her children. She's also struggling with public speaking, due to her difficulties with organizing her thoughts, particularly in settings that makes her nervous.

"It's hard for me to do public speaking; I've never felt awkward when I've had one on-one conversations, but when I have like conversations in a group – even now, if I have to speak in front of a group for a long time –; I become anxious. Public speaking can be a nerve wrecking experience for most, but for anyone inattentive, it might be more difficult and raise additional anxiety because you need to be able to organize your thinking." (Debra)

In Beth's experience, anxiety goes along with ADHD, and she describes how her fear of breaking social norms for female behavior can contribute to worsen her anxiety.

"I have some social anxiety, but my son (with ADHD) has none of that anxiety, because… it just comes down to that people expect different things from girls than from boys, and boys are not necessarily trying to fit in." (Beth)

Emily has not struggled with anxiety or depression, something she feels fortunate about, as she knows a lot of women with undiagnosed ADHD or who are finally diagnosed with ADHD, who are suffering from depression.

According to the women's descriptions, their worries, rumination and anxiety are much resulting from poor time management, indecisiveness, disorganization and resulting feelings of

lack of control and unpredictability on a daily basis. Factors such as a tendency to think too much, having trouble organizing and verbalizing thoughts, getting stressed and overwhelmed due to poor time management, and not being able to get into a routine, are described as important contributors to anxiety and other internalizing symptoms. Importantly, the consequences of ADHD symptoms that the interviewees describe are all in the form of internalizing problems and disorders, while no externalizing symptoms are emphasized. Christine describes her eating problems as a way of trying to deal with the fact that she wasn't externalizing her problems; *"(...) maybe eating is like this middle ground, sort of internal and sort of external"*.

4.1.3 Own conceptualization of ADHD, and examples of what it's like to have ADHD

Reactions towards receiving the diagnosis

The women's reactions to getting diagnosed with ADHD were mixed, varying from a sense of relief, to feelings of hopelessness.

> *"I think I had multiple reactions; in some ways it felt like a relief, because at least it means that I'm not lazy or stupid, and in that sense it was a relief. On the other hand I felt like it was an excuse, so even today I don't accept it a 100 %, because of the way it's diagnosed; it's not like it's a brain scan or something, or a DNA test, so since it's qualitative I wonder if it's really legitimately ADHD that I have." (Christine)*

> *"I kind of always thought that I did have ADHD, and when I was diagnosed and it was confirmed, I was relieved. I've always felt that it was something wrong with me, and it was! But it's not like it was something wrong in a bad or negative way, it was just that something was different, and I was actually dealing with something." (Beth)*

> *"It was kind of a relief to get diagnosed; it kind of confirmed what I already knew in the back of my head, but I also felt hopeless. Because now I know it's not me, it's not like if I work harder I can do better; now it's like I cannot help it, it's a sense of helplessness now. I'm at this point where I sometimes feel very depressed, because no matter what I do, this is like a bad disease that I can never cure." (Amber)*

On the positive side, all the women felt that the diagnosis made by a professional served as a validation of their struggles, which was helpful in itself. Emily explains that the diagnosis

provided her with a sense of being able to put a lot of pieces together. Furthermore, the women tell me that the diagnosis made it possible to relocate some of the feelings of guilt and shortcomings that previous problems had caused, to an 'external' cause. Yet, people's trivializations of the disorder, e.g. claims that ADHD symptoms simply are common problems or synonymous with laziness and lack of efforts, can exacerbate Christine's doubts concerning whether she really has ADHD.

For Amber, it was mainly a negative experience to be diagnosed with ADHD, as the thought of having a chronic disorder has left her with feelings of helplessness regarding the possibility to manage or get rid of her problems. Amber is concerned with heritability and epigenetics, and seems to feel little control over the influence of her ADHD symptoms on the course of her life. Emily has also experienced that it's more difficult to treat her ADHD than what she initially thought, yet she still perceives her symptoms as manageable through continuous efforts.

Could an earlier diagnosis have made a difference?

Because all the interviewees were diagnosed as adults, this question as well as their answers to it was naturally of a 'hypothetical nature'. Yet, it seemed like a suitable question to ask and reflect over.

> *"I was a happy and pretty well adjusted kid, and I did sports, so it's not that I suffered as a kid for not being diagnosed then, but I missed out on the chance to learn a lot of the things that I have to work on now, like organizational skills and time management, and things like that." (Emily)*

> *"I wish that I had been diagnosed earlier, because I think that would have helped me in high school. I went to a pretty rigorous and demanding high school and many of my peers were academically conscious, and everything seemed so easy for them. That's the feeling I've always had; things seem so easy for other people, like "why does everyone seem like they have all their stuff held together?" I think that if I had known a little bit earlier, maybe that would have helped me to make sense of why things seemed harder, at an earlier age." (Christine)*

> *"If I had known that I had ADHD when I was younger, then maybe I wouldn't have tried so hard. Because all my life I've tried very hard. People think that ADHD people are lazy, but I push myself very hard, and that got me a lot further than I could have come. I work*

for some of the biggest companies in the world, and sometimes I wonder, "How did I get here? I shouldn't have been here!" (Amber)

"I'm sure there's a reason why I came here (to the US), and that reason is probably my ADHD. I felt – and later discovered - that this country would be more open and friendly and less rigid, and I know that it wasn't a coincidence that I pursued that dream, or that I am where I am now. So, with medication, maybe I would have done better in school, but I probably wouldn't have been here in the US." (Debra)

Most of the women think they could have benefitted from an earlier diagnosis, yet neither Beth nor Emily feel that they have directly suffered from not being diagnosed earlier. Debra has felt some sadness when thinking about how an early diagnosis and treatment could have lessened her struggles in school, but she's mainly focusing on the positive parts of having ADHD and on the things that she has achieved, both despite of and as a result of her challenges.

Amber and Christine wonder whether they would have used an early diagnosis as a crutch or an excuse to work less hard, but Christine concludes that it probably would have been mainly positive for her.

Several of the women underline that self-esteem can be very damaged if ADHD isn't detected early. Debra emphasizes the importance of an early diagnosis for kids with ADHD, so that they can get the help and support they need in order to get through school, which might be one of the challenges that's associated with the most risk of failure and impairing consequences for individuals with ADHD. Sadly, Debra says, *"(...) many aren't diagnosed early and they fail school, and consequently a lot of them end up in prison."*

Examples and perspectives on how life is affected by ADHD

"For me, ADHD is like a processing disorder. The main problem is that I can't articulate what I think and feel. Before, I would go to conferences and I would feel things inside me, but it would never come out; it was almost as if I was mute. I was so scared of those conferences. And now, when I take medication and go to the same meetings, I'm so much more articulated and vocal. It's amazing! The last year I've felt more like "Yes, I can!", and that's so important for self-esteem and self-confidence. Actually I feel kind of good that I have ADHD; it's not something that's in my will, right, it's just the way I am." (Debra)

"I would describe ADHD as a way of being, as picking out the best parts of everything. I wouldn't want to be anybody else, and I've also had to sell it (ADHD) I feel, to my son. Not that he needs it, but I just want to make sure that he knows that there isn't something that's broken about him, and that the school system needs to work on how to teach things to him, because he has such potential that they are the only failures if he doesn't do well." (Beth)

"I think of ADHD as a part of the fundamental structure of how my brain works; it's not about what I think, and it's not about who I am, and it isn't who I am. It's a part of the framework that I see and live through. I think that assigning good or bad to ADHD can end up crippling your ability, or will, to make changes. If I think of ADHD in terms of habits that I've developed or need to develop, then it's something I can change and which it's worth trying to change even though it's hard." (Emily)

"When I read about the movers and shakers of society, the inventors or politicians who change things; they are often people who have ADHD. But I guess it's just that I don't have boldness; I have the impulsivity, but not the boldness, so it's like if I don't have that, I kind of wish that I didn't have the problem part as well. If it meant that I would be happy with my career and don't jump around so much, then I guess I wish I didn't have ADHD." (Christine)

"I'd like to say something positive about ADHD, but I just can't find anything positive about it. In the evening I will think that tomorrow I'm going to get up early and be at work by nine, but it never happens. Sometimes I try to think about the good things I do, and that I'm smart and that I did this and that, but it doesn't work." (Amber)

The interviewees' experiences of how ADHD is affecting life, are quite varied. In Amber's experience, ADHD is making it very hard to lead a normal life, and she describes the disorder as a curse. Yet, she assigns certain positive aspects to the diagnosis, such as her determination, adventurousness and willingness to take risks.

> *"At school, I had girls getting higher grades than me, but why are they not here? It's because I'm more adventurous, I can take risks. ADHD does that to you. You know, such a sheltered girl from a conservative family; I came here to the US all alone to study; how did I do that? I think it's part of the ADHD." (Amber)*

Beth and Debra are trying to focus on positive aspects of having ADHD, for their own sake and their children's. Debra does not think that ADHD should be called a disorder; she's concerned with identifying the strengths of individuals with ADHD, and perceive her son with ADHD as having a gift that other people don't have. She sees her own love of learning, her ability to easily get interested in and excited about new things, and her ability to connect different disciplines together, as positive aspects of her ADHD.

4.1.4 Gender specific issues in relation to ADHD

Hormones

A growing amount of research is focusing on the influence of female sex hormones on the functioning of the neurotransmitter systems in the brain that are involved in the neurobiology of ADHD, and thus the intensity of symptoms (Nussbaum, 2012). For my interviewees, hormonal influences on symptoms is not a significant concern, partly because most of them have not really considered the possibility of such a relationship. The one exception is Beth, whose Doctor informed her about the topic and helped her identify a pattern of premenstrual mood changes:

> *"The week before my period, I experience certain moodiness and anxiety, and I've often thought that I'm such a different person when I'm around my period, and I don't see how you could e.g. be the president of the USA and trust your judgment during that week. From one week to the next, I feel like night and day on some things. It's so stupid, it's this whole emotional thing that leads up, where I start thinking that I'm crazy, and then you get your period and you're like "oh, that was it!". You would think that knowing that would make the thoughts stop, but it's not that easy." (Beth)*

When looking back, Amber and Debra clearly remember how their ability to focus would change during their pregnancies (when they still were undiagnosed). Amber describe her periods of pregnancy and breast-feeding as the worst times of her life:

> *"During pregnancy my symptoms got really bad; I felt as if my brain wasn't working at all, I couldn't do any work. It got so bad that I couldn't complete the things I was working on, so I went on maternity leave without completing things, and my manager got very upset." (Amber)*

> *"During my pregnancies, I remember that my thinking became very slow; I felt like I couldn't understand anything. We were going through a big system change at work, which I had to take classes to learn, and I remember not understanding anything. It was going all over my head. I've never thought about that it could be related to ADHD." (Debra)*

Still, it is difficult to say whether these three experiences resulted from a combination of hormonal changes and ADHD, as they could also be representative of PMS (Beth), or simply be part of the normal symptoms of a pregnancy. Furthermore, since significant hormonal influences on ADHD symptoms are not emphasized by any of the women, there is no strong foundation for making any assumptions in that direction in this study.

Social gender expectations, and motherhood

Traditionally, organizational and structural skills have been considered 'innate feminine qualities', and women have had the main responsibility for running the household and organizing the life of children and the family as a whole. Although it is common that women today are working part or full time, the social expectations regarding mastery of traditional feminine responsibilities and qualities have not necessarily decreased. For women with ADHD, who often struggle with time management and organizational skills, it can be particularly difficult to meet the society's standards and expectations towards women (Hinshaw, 2009; Quinn, 2008). Christine share her frustration over (and experiences with) this gender specific aspect of ADHD:

"We've (women) been raised to take on a lot of responsibilities and make sure that things are okay, so I think that what I notice with my friends and my mom and other peoples' moms, is that when they come home tired from work, their workday isn't just over. There are so many things to think about, like even in the home, so home isn't necessarily a place to just like turn off your brain and relax. I think that boys are raised to have that feeling a little bit more, and I think that it can be extra challenging for women with ADHD, since women almost are expected to have an inborn ability to organize and maintain things in order. I've heard people say that if their house is a mess, then the in laws and the parents blame it on the woman, and that's completely unfair." (Christine)

Beth points out that in the media, you can find portrayals of male characters with traits that are consistent with ADHD (e.g. creativity, high energy, spontaneity), which they receive positive feedback for, while the more negative ADHD traits (e.g. disorganization) are judged less harshly in men than in women. Beth misses comparable female characters to look up to, and think that she'd have been met differently in her former job, had she been a man.

"It was very variable how well I would do at work; I would get all this big, challenging assignments - because everything that was a puzzle was interesting to me –, but when that puzzle turned into every day routine work, I couldn't do it. I actually think that if I was a man with the same talent, I'd be seen as a 'superstar', and people would just assign the routine work to someone else. I think women are expected to be able to do all the cleanup and routine work also, in addition to their 'main task' - and if they can't, they receive negative feedback - whereas a man in the same situation is more likely to be met with understanding attitudes." (Beth)

Christine has noticed that boys, in contrast to girls, are allowed to act a bit wild and run around without having to worry about social sanctions. She also notice that girls with ADHD try harder to act compliant and live up to social gender norms e.g. by faking that they're paying attention. Beth, who have a son with ADHD and a daughter with possible ADHD, have experienced how differently their teachers interpret the behavior of her children, and is worried that girls with ADHD don't get the support and recognition they need.

"When raising my son with ADHD, I felt free; it felt fine, non-judgmental; he was just a boy behaving like a boy should. He was also getting all this help and recognition, while my daughter - possibly with the same thing - isn't going to get any support, because she

looks like she's paying attention, even though she's not. I'm thinking what a shame it is, that my daughter - who is just as bright, creative, and capable as her class mates - are at risk of being judged by her teachers simply as being inattentive and just not as bright as the others." (Beth)

Beth, Debra and Amber experienced that motherhood brought additional challenges in terms of increased organizational and structural demands. Beth decided to quit her job when she had children, as the two roles became too hard to combine. Debra was working part time while also being a mother, a period which she describes as the most difficult time of her life. She eventually decided to quit her job, as she couldn't manage having one job during the day, and then coming home to the job of taking care of her child. Christine and Emily, who both are planning to have children one day, are aware of the potential challenges they can meet as mothers.

"I think that things became much harder for me when I became a mom. Because of the constant interruptions from my children, and I remember being exhausted by the end of the day; absolutely exhausted. There are so many things that you have to do when you're a mom. At work, it was much easier, because it was organized. If I had a problem, I would just call someone and get it fixed, while with kids you can't do that. So much responsibility lied on me as a mother, which was stressful." (Debra)

"I think about whether my children would have ADHD, and on whether my ADHD will impact my parenting; things like that. Other than that, I think I worry that school would be hard for them, and that organizing their time would be hard. Time is a very hard thing for me, and I worry that they would struggle with self-esteem. I also worry about like my own time management; I think that I almost come across like careless or selfish or something, so I wonder if like I had a kid, that others would think like "oh, she can't keep her act together"." (Christine)

"I know that it's likely that my child can have ADHD, and I know that it will make it particularly important for me to be able to teach routines. So it's definitely something that I'm aware of, and it's one of the main reasons why I want to continue to make changes and be more effective at those things. But it also just is, so it's not something that I need to worry so much about, it's just a fact that I need to be aware of. I know that my dad is and was a wonderful parent even though he has ADHD; that sort of calls for my optimism." (Emily)

Barkley (2002) underlines that there is a lack of studies that examine the impact of ADHD on child rearing. Debra experience the same, and appreciates the opportunity to talk about ADHD and parenting. Christine also misses more discussions about ADHD and parenthood, including the challenges associated with discontinuing medication due to plans of getting pregnant. The interviewees' experiences with negative feedback resulting from the conflict between symptoms of e.g. disorganization and poor time management, and social gender expectation towards women, are in support of Fedele et al.s' (2010) observation of certain ADHD symptoms as particularly challenging to women, as a mere interference with gender specific norms and values.

4.2 Self-Esteem

Self-esteem refers to a person's feeling of self-worth, and include the beliefs, judgments and attitudes a person holds toward his/her self. Self-esteem issues and their effects on well-being and experiences of ADHD and stigma were brought up on several occasions in all of the interviews, which is in accordance with results from previous research that identifies poor self-esteem as a serious and common problem among girls and women with ADHD (Biederman et al., 1994; Rucklidge et al., 1997).

The development of self-esteem begins at a young age, and Debra and Christine exemplify how early experiences of academic difficulties and underachievement, often followed by negative feedback and questioning of their efforts from their surroundings, contributed to lowering their self-esteem:

> *"In school I definitely felt that I wasn't smart enough, and that lowered my self-esteem. I was always told that I could do better. No one told me directly that I was stupid, but they asked whether I was working enough, and the comments I got were not positive at all, so I lost self-confidence." (Debra)*

> *"In grad school I felt that people could process information much faster than me, and in college I felt that people were learning the material themselves in class, while if I missed something, or spaced out and thought "I'll catch up with this later", it never really happened at a normal time run. I always felt that the other students could catch up quicker and could retrieve and talk about the material more quickly, and grasp on to things much faster." (Christine)*

Both Christine and Debra say that they are very hard on themselves, and struggle with accepting praise and positive feedback, which is symptomatic of a poor self-image and low self-esteem:

> *"It's very difficult to receive praise; I feel sad if someone says "oh Debra, you did so well, that was wonderful". I just feel sad, and I think that there's parts of me that I need to forgive. I have to forgive myself. I was never praised, I'm from the generation where girls were not really praised, but I also had bad grades at school, and that didn't help. I think I have to restore my sense of self-confidence, I'm working on that, because I have not really learned what it is." (Debra)*

> *"I remember in graduate school, when I got an A or A+, I'd immediately feel like "oh, that was because it was an easy class", whereas if I did poorly, I'd think "this I'm supposed to be able to do, but still I can't do it." (Christine)*

Debra specifically addresses that the most important topic regarding girls with ADHD, must be self-esteem, and underlines the need for more awareness about ADHD in girls so that they don't go unrecognized, as she did. Yet, while Debra on the one hand describes how her self-esteem has suffered over the years, she's also conscious about her strengths and achievements and focuses on the positive learning outcomes of her challenges.

> *"It did teach me to be really tenacious though; if I want something, I know I can get it. I know I'm smart, and probably smarter than many girls in my class. And in fact, I've probably achieved much more in my career, because my creativity helped me figuring out solutions. Maybe that's a good thing about ADHD; you have to find alternative solutions, and think creatively." (Debra)*

Christine feels that her current job has turned into routine work and doesn't challenge her anymore, which she says makes her feel stupid again: *"(...) I think that's why a fresh challenging start seems so tempting, where I feel like I'm using my brain. I'm not so dumb, if I'm using my brain."*

Amber grew up with a mother who abused her both psychologically (e.g. yelling, nagging, harsh criticism) and physically (e.g. pulling her hair, hitting her). She also struggled with living up

to her father's extremely high expectations, both of which might have influenced her self-esteem development. Amber reveals pervasive feelings of guilt for what she describes as having condemned her son with ADHD; a choice of words that both captures the intensity of her own negative experiences with ADHD, and a view of herself as a bad influence. Although Amber has told me about traumatic experiences and suicidal depressions earlier in the interview, it isn't until she starts talking about her feelings of guilt and worries regarding her children and their future, that she for a moment - in spite of her efforts not to – starts to cry.

> *"I feel so bad for my son, because I've condemned my son; my son got ADHD from me, and now he may face the same crappy life that my sister and I have had. I have seen academic difficulties with myself, with my sister, and now with my son. What is he going to do? What is he going to be? I don't see him getting into higher level studies; he can't even get through kinder garden. I don't think I could deal with the disappointment of having both my children having ADHD; I already feel guilty because of my son, and I'm like "How are they going to cope with life? How are they going to succeed in life?" (Amber)*

Emily tells me that she's always been a pretty happy and confident girl and woman, which she thinks has a lot to do with her growing up in a very loving, structured and open-minded family. Furthermore, she enjoyed school and played organized soccer from an early age, which provided her with social benefits, and feelings of mastery and self-esteem. Emily has also found a job that she really likes, and which takes advantage of her skills. While Emily had sort of a boundless self-confidence when she was younger, this has started to change as she is experiencing more challenges related to her ADHD, as she is getting older. That can be hard, but has also given Emily a more nuanced understanding of herself, which she feels is a good thing overall.

> *"I think that now that I'm in my thirties, I face new challenges that I didn't anticipate earlier. I find it tough to master a lot of the skills that goes into maintaining and building a good relationship, and I'm seeing the results of these difficulties more as I get older, and that certainly has an effect on self-esteem. One of the things that I'm learning as I get older and have to deal with more complicated and sophisticated cases at work, is to appreciate the benefit of preparing for things instead of just jumping into them. Whether it's professionally or personal, there are things that I have to work a little harder at now than I had to earlier." (Emily)*

4.3 Stigma

"Their image of themselves must daily confront and be affronted by the image which others reflect back to them." (Goffman, 1963, back cover)

4.3.1 Experiences and thoughts about stigma

The perceived legitimacy of stigma, reinforced by e.g. selective negative press coverage and lack of social sanctions for those who express stigmatizing attitudes, can increase stigma concerns among individuals with mental illness and ADHD (Hinshaw et al., 2008; Mueller et al., 2012). Beth describes that she was both shocked and surprised that the NYT chose to publish the piece "The Art of Distraction" (Kureishi, 2012), in which different aspects of ADHD is referred to in harsh and prejudiced terms by the author.

> *"The fact that this guy could write that "Ritalin boy" article and get it published in the NYT, baffled me. The article was so ignorant, and it was surprising that no one picked up on it until it was published, because I was really surprised when I read it." (Beth)*

Emily describes her perceptions of public stigma, and the resulting prejudice and discriminatory behavior that she's experienced.

> *"In terms of society in general and thinking about ADHD, I think there is some general sort of fear or lack of understanding and compassion about anything having to do with mental health. The New York Times print an article every couple of month that seems to wrap up the internet trolls about the problems with abusing stimulant medication, and I think that gets in the way of an actual helpful dialogue on what can help kids and adults with ADHD. Most of all, I think that ADHD is often still seen as a kids disease and for an adult to have it it's like "okay, grow up!". I think that there's this perception of adults having ADHD as being immature and choosing not to act like an adult. I think the stigmas are changing, but it takes time. I think there's a very strong stigma against taking medication to treat ADHD, and that's hard. It can be a daunting thing having to walk into a public pharmacy, and if there's a problem that isn't even your fault, but you then explain "here, this is what I'm getting prescribed" (stimulants), you feel that people suspect you of lying or cheating or breaking the law." (Emily)*

After the episode described above, Emily chose to switch pharmacy, which proved to be a positive experience in terms of a more professional staff.

In discussions about ADHD, Christine has heard people dismiss the severity of the disorder with jokes, or comments like *"Oh, I find it hard to start my work too", or "I get distracted too, no big deal. You just have to buck it up!"* Amber also points out that trivializations or reduction of symptoms into a 'moral deficit' makes it very difficult to get understanding and sympathy from others regarding ADHD. As a consequence, she's very hesitant to tell family or friends about her diagnosis.

> *"ADHD makes life very difficult, it's a disability that can't be seen, it's not as if your leg doesn't work or something. It can't be seen, and therefore you get no sympathy from people. I have this uncle who's a doctor, and he's very intelligent, but he's like "oh, ADHD! We all have periods of time when we can't concentrate! ADHD is bullshit!" Even my own parents think that it's bullshit. That it is just an excuse for people who cannot do well in life; that they blame it on their ADHD. People think that it is a fake disease. People with ADHD seem normal, right, and everybody have times where they procrastinate or can't concentrate, but it is not on the same level as for people with ADHD." (Amber)*

Trivializations of ADHD, misconceptions about the disorder, negative press and biased opinions about the medical treatment of ADHD are core elements in many of the interviewees' experiences with stigma of ADHD. These factors have been defined as important predictors of stigma of ADHD (Bussing et al., 2011; Mueller et al., 2012).

4.3.2 To tell or not to tell: Selective disclosure.

One common consequence of stigma concerns, is avoidance of labelling through concealment of one's diagnosis. Beth says that she can appear like the most organized person in the world, which makes it easy for her to 'hide' her diagnosis to others. Emily has told a few close people that she knows she can trust and felt needed to know, about her ADHD, so that they could better understand and support her emotionally, during and after the diagnostic process. Christine has told a few close friends about her diagnosis, yet she doesn't think that they understand the severity of the symptoms that comes with ADHD, such as procrastination, disorganization and indecisiveness. Debra makes a similar point, and says that she's quite highly functioning, and not hyperactive, and thus if she told people about her ADHD, *"(...) I think they'd look at me as if I*

was talking Chinese or something. I don't think that people understand - unless they have ADHD themselves – I don't think that they can understand what it is."

Amber tells me that she hardly tells anyone about her diagnosis *"(…) because people would just laugh at me. That's the tragedy of living with ADHD; nobody believes you have it."* She is also afraid that people would think that she is using the disorder as an excuse for failing in life.

Christine feels more comfortable talking about her ADHD at work, which she describes as a very mental health friendly place, than with her friends and family. Christine is under the impression that people generally find it easier to talk about ADHD compared to e.g. anxiety and depression, but also that ADHD by many is considered a less serious or valid disorder.

> *"I think people shy away from talking about emotions and feelings, and ADHD is considered more neurological. Yet, I think that people think ADHD is sort of a made up excuse for being unfocused and undisciplined, that it just takes self-control or something. I don't think that people think ADHD is as real as anxiety and depression." (Christine)*

In contrast to Christine, both Amber and Emily are clear regarding the presence of institutional stigma at their respective workplace, and the potential risks involved in disclosing their ADHD diagnosis.

> *"If I told my boss about my ADHD, I think they would just find a reason to lay me off, that's the way it is in the US. They're not supposed to lay off people like that, but they can always find excuses. You know, it's very cut throat here in the US." (Amber)*

> *"I don't tell anyone that I work with; while nobody would ever say that it would be a problem, there's too much stigma around ADHD for me to want to carry the torch at this point; I'm not there yet. I love my job where I am, and I don't know if people I meet through my work would have concerns, or just be really ready to see problems with me or my performance if they knew that I had ADHD. In my profession there's a stigma in general about mental health problems, to the point that when you're interviewed, you have to report whether you've ever received mental health care. It is in some ways a very old-fashioned profession." (Emily)*

In spite of her awareness about stigma of ADHD, Emily doesn't experience it as an emotional burden. However, she's thinking about the likelihood that her (future) children can have ADHD, and the possibility that they'll struggle more with dealing with the stigma if she's not open about or comfortable with her own ADHD.

> *"If I had a daughter or a son with ADHD, I wouldn't want them to feel that ADHD is something to be ashamed of, or something that he/she should hide or be afraid that other people would find out about. I do think that if I were to tell my daughter that, I would also have to be up front about having ADHD myself. If I want my child to have good self-esteem and believe me when I say "you're as great as anybody else, this is just a part of who you are. It doesn't matter if you have ADHD, and it doesn't matter if people know that you have ADHD", I would have to believe that for myself too." (Emily)*

4.3.3 Management of Stigmatization and ADHD symptoms.

Beth, Christine, and Emily tell me that they experience huge benefits from exercising, including improved sleep quality and concentration, enhanced mood, and a general increase of well-being. Debra has found mindfulness meditation to be very helpful in the management of anxiety symptoms, while Christine says that it's liberating to travel and go on vacations because that gets her brain out of its cyclical thought patterns, e.g. around career changes. Beth says that it's important for her well-being to try not to blame herself for things that she's not getting done, and describes how her life-quality increased simply from being diagnosed with ADHD, because *"(…) then I wasn't blaming myself anymore. There was a reason for my problems".* The diagnosis also provided her with a feeling of kinship with other people with ADHD.

Emily tells me that her boyfriend has made a lot of effort to educate himself about ADHD, and come with her to some support groups and classes, which has been of great importance to Emily in terms of emotional support. He's also encouraged her to try not to think about all her problems as part of or caused by ADHD, a perspective that she over time has learned to find helpful. Now, she rather thinks of her challenges in terms of habits that she needs to change, and underline to herself that everyone have things they need to work on with themselves, regardless of whether they have ADHD or not. Emily has also benefitted from seeing a coach and going to group meetings for people with ADHD, and describes several strategies that she's using to inspire and

motivate herself to follow through with her plans, as she's very good at starting things but bad at finishing them.

> *"I use different tools to stay motivated; it can be to build a habit of something, and I'm trying to keep my eye on the prize. I celebrate small steps and successes, and that helps me stay motivated because it makes me feel that I'm making progress. My boyfriend also helps me organize my dresser, and that motivates me to work for it myself. One thing that has helped me following through with my plans, is to make them more manageable. That's helpful with self-esteem too, because sometimes I would think "oh, I will change these dozen things and take all these steps", and then don't get them done, and then I'd feel like I'd let myself and everybody else down." (Emily)*

Emily finds it inspiring and useful to learn about the exact tools and strategies that other people with ADHD use to overcome the challenges associated with symptoms and stigma, and succeed in their life, *"(...) because even though I have my struggles, I still have to find a way of doing my job, just as people without ADHD has to."* Christine also likes it when people, e.g. celebrities, openly try to own up to their ADHD and give emphasis to strengths rather than limitations.

Amber has yet to find a way to manage her symptoms, and seems to struggle with pervasive feelings of helplessness, low self-efficacy, and of being controlled by her ADHD. In comparison to the other women, who tell me about social support from friends, partners, colleagues, and/or family members, Amber seems to have few people that she can open up to, or go to for advice and emotional support.

All of the interviewees have tried different kinds of stimulant medication at some point, and most of them are still using it. Their experiences of efficacy of medication vary between unhelpful, somewhat helpful, and very helpful.

> *"I definitely see a positive difference from when I take the medication and when I don't. The biggest thing for me was that with medication, I was able to articulate my thoughts. Before, I had like 50000 ideas in my head, so overwhelming and hard to articulate. Now it's like "wow, I can actually say what I think!", it's amazing! I also have less problems understanding new things; I think that for me, the medication helps me process information." (Debra)*

"I'm worrying a lot less on medication, it's kind of lifting me up from the ground, where I'm obsessing about little things and problems, what people might think about me and so on, and up in the real world, where I manage to see beyond those things and not care so much. The medication also helps me put thoughts into action; instead of looking at something and thinking, "I have to fix that", just to do something else instead or procrastinate, I actually fix it, there and then." (Beth)

Christine is not using any medication now, due to plans of getting pregnant, and finds it difficult to accurately evaluate and describe the effects of the medications she has tried. However, without medication, her thoughts are much more around the place, and she remembers that things generally felt easier when she used medication. Beth underlines that she perceives medication as eyeglasses and not as a complete treatment for ADHD. Similar to what Debra and Christine describe, Beth experiences that medication improves her ability to focus and take action, and that it is reducing her tendency to worry. Amber and Debra experience that medication increases their heart rate and thus enhance their anxiety, which made Amber discontinue her medication.

The factors and strategies that seem most effective for the women in their management of ADHD symptoms and stigma are self-empowerment, social support, exercise, mindfulness/mental relaxation and medication. Furthermore, it is helpful to read e.g. self-coaching books and to hear about how other people with ADHD have gone about establishing and maintaining routines and structure. Being diagnosed with ADHD was positive for the women's self-image, as it provided them with an explanation for their difficulties and thus improved their self-understanding. Furthermore, it gave them something concrete to work with, and a hope that improvement was possible.

However, the women have also learned that for them there is no quick fix for ADHD, such as one treatment strategy that works perfectly, or immediately solves all their problems. Amber expected a bigger jolt from medication than what was the case, while Emily initially thought that there would be more easily available tools to treat ADHD. Over time, all the women have learned that successful symptom management result from continuous work and efforts, and the use of several strategies combined. Babinski et al. (2011a) points out that there is a need for more research on effective treatment strategies for adults with ADHD other than medication, and that health care practitioners should become more familiar with effective interventions for ADHD.

5 Conclusion

In the current study, I have examined the different ways in which a diagnosis of ADHD influence women's lives and everyday functioning, with a particular focus on the role and influence of stigma. The following chapter is devoted to the summary of main findings and key points, which are discussed in relation to previous research. In addition to highlighting the most prominent challenges and difficulties described by the interviewees, attention is also given to their strengths and resources. Towards the end of the chapter, the negative effects associated with the stigma of ADHD are discussed in relation to the advantages of early identification of ADHD.

5. 1 Main findings

"Although the world is full of suffering, it is also full of the overcoming of it." (Helen Keller)

5.1.1 How are the everyday lives of (five) women affected by their ADHD?

Common for the interviewees, is that they are highly intelligent, resilient, determined and resourceful. Despite years of struggles and challenges related to their ADHD, all the women have succeeded academically, occupationally, and privately. Their stories represent an encouraging alternative to many of the more gloomy descriptions of the potential negative consequences and outcomes associated with a diagnosis of ADHD. In other words, the experiences of the interviewees in this study show that it is possible to succeed and live meaningful lives despite a diagnosis of ADHD. However, they have all experienced significant difficulties and adversity, continuing from they were children and into adulthood.

All the interviewees were diagnosed in adulthood, after self-referrals for a diagnostic evaluation. Their lack of external displays of hyperactive and interruptive behaviors in childhood might help explain their late diagnosis, as those symptoms that are the most likely to lead to referral for evaluation and treatment of ADHD (Hinshaw, 2002; Quinn et al., 2004).

The ADHD symptoms and problems most commonly described by the interviewees, include inattention; disorganization; indecisiveness; poor emotion regulation; anxiety; excessive worrying and rumination; procrastination; and poor time management. Indecisiveness and disorganization makes it hard to build and maintain structure and routines, which often results in unpredictability on a daily basis, ultimately causing and reinforcing anxiety (similar to what Solden (1995) has described). The women also feel that their indecisiveness and time management

problems can be annoying to people around them, while procrastination and motivational difficulties can get in the way of taking full advantage of their skills.

The women experience that many of their ADHD symptoms and associated challenges have become more salient as they have gotten older, much due to new and increased responsibilities and structural demands, as well as repeated negative experiences that they have not had any explanation for until adulthood. Findings that indicate that ADHD symptoms do not decrease as a function of age, but continue to cause significant psychological, vocational, and social impairment into adulthood, have been reported in previous research (Quinn, 2005; Rasmussen et al., 2008; Waite, 2009).

Most of the co-morbid problems that my interviewees emphasize, such as anxiety, poor self-esteem, depression and disordered eating, are all symptomatic of internalizing symptoms and disorders. Several of the women describe high levels of psychological distress, and frequently feels overwhelmed, and/or in lack of control of their lives. These problems seem to be linked with high levels of inattention and disorganization, and might have contributed to the general fear of losing control that some of them describe. Due to similar findings, Rucklidge et al. (2001) have previously stressed the importance of systematically addressing and targeting secondary psychological effects in women with ADHD.

Many of the symptoms and difficulties the women experience, are consistent with executive dysfunction and poor inhibitory control, and are thus in support of Barkley (2007) and Brown's (2009) emphasis on these as essential areas of impairment for individuals with ADHD. Nigg et al. (2005) have found indications that executive dysfunction mainly is related to impairments in the domain of inattention-disorganization, but not hyperactivity-impulsivity, which applies very well to the women in this study and their struggles.

Furthermore, my results are thus consistent with both Soldens' (1995) description of ADHD as a disorder of dis-organization, and of Volkow et al's. (2011) emphasis on dysfunction of the motivation and reward circuits in the brain in individuals with ADHD. The women perform very well and consistently at tasks that they find exciting, inherently reinforcing and/or externally structured, but also experience a dependency of those factors in order to have their 'motivation triggered', which has been apparent already since childhood. Several of the women are having more trouble with performing and/or learning simple routine tasks, than big and challenging assignments, and can experience a sense of paralysis associated with an uninteresting task or

project. Together, these findings seem to be indicative of poor sensitivity to reward and delayed gratification, and cause great problems and concerns, regardless of e.g. high intelligence, because *"(…) there's no point in being smart if you can't work like a worker bee, like other people do."*

Volkow et al. (2011) have found that impaired motivation also may enhance the severity of symptoms of inattention, as attentional deficits in individuals with ADHD are most evident in tasks that are boring, repetitive and considered uninteresting. Their suggestion is therefore that motivation-deficit should be part of the description of core-symptoms of ADHD. The results from this study are in accordance with previous research that link trait procrastination with poor time management, disorganization, low self-efficacy, high distractibility, weak impulse control, low intrinsic motivation, poor sensitivity to delayed reward, and proneness to boredom (Schouwenburg, Lay, Pychyl, & Ferrari, 2006; Steel, 2007).

The interviewees do not describe experiences of hyperactivity, impulsivity or sensation-seeking behavior. However, impatience can be interpreted as a manifestation of impulsivity and/or hyperactivity, as can hyper talkativeness, sudden directional changes in life, and a tendency to interrupt others or 'talk before thinking' – all of which are experienced by my interviewees, and described by Solden (1995) and Waite (2009) as common symptoms of impulsivity in women with ADHD. Impatience and a tendency to easily get bored can make it hard to settle down occupationally and vocationally, and to and to follow e.g. instructed activities over time, instead of unceasingly shifting to what one needs or wants at any given moment. Impatience can also be problematic occupationally, e.g. *"(…) where it'll be a real challenge for me to sit through a day-long meeting or negotiation. I'll reach a point where I only want to say like 'Let's just get on with this and get out of here!".*

A need for more specific and easily available information about various aspects concerning ADHD in women is expressed repeatedly. One of the women describes her experience of gender differences from a support group for adults with ADHD; *"(…) there were a lot of men there, and I just felt very uncomfortable. I thought that 'I don't have ADHD', because I just couldn't relate to them."* The interviewees register that women with ADHD face different challenges because of their diagnosis, than men with ADHD tend to do. One of the most prominent gender specific issue in relation to ADHD has to do with the conflict between ADHD symptoms and social gender norms (see also Fedele et al., 2010; Hinshaw, 2009; Quinn, 2008). According to my interviewees,

there is greater social acceptance of impulsive, disorganized, and energetic behavior in men, than in women. Furthermore, inattention tends to be overlooked or trivialized more often than hyperactive behavior, e.g. by teachers, which might affect girls with ADHD in particular as they often struggle more with inattention, and/or place a stronger emphasis on controlling their behavior.

Motherhood are experienced as particularly challenging to the women, as they already struggle with organizing their own time and daily activities, and find it very hard to organize the lives of their children on top of that. Moreover, their difficulties with focusing on and completing daily tasks and activities have become more salient, due to the combination of constant interruptions from their children and the women's problems with returning to a task after an interruption. Based on their own experiences, the interviewees are concerned that their children might struggle academically and with self-esteem and stigma. They are also worried about their own parenting skills, e.g. in terms of poor time management skills. However, positive experiences with own parents with ADHD have made several of the women feel more optimistic in that regard. They are also conscious about empowering their children, e.g. through focusing on strengths and positive aspects of having ADHD, and focus on learning good habits and strategies for symptom management, which they can pass on to their children.

After having blamed themselves for their difficulties most of their life, e.g. *"(...) you're also beating yourself up, because you're thinking "How dumb, and here I did it again, why can't I just do it ahead of time?"*, several of the interviewees struggle with deeply embedded feelings of lowered self-esteem and self-efficacy, and perceptions of self as lazy, dumb, or in lack of willpower. With one exception, all of the interviewees describe that their self-esteem began to suffer and develop in a negative direction from an early age. Furthermore, their repeated unsuccessful attempts at solving or avoiding academic problems, for which there were no apparent explanation for, might have resulted in learned helplessness. These problems can have long-lasting effects and be challenging to alter as adults; some of the interviewees describe that they now need to learn how to forgive themselves, and how to let go of self-blame. My findings, with support from previous research (Rucklidge et al., 1997) highlight the importance of addressing and targeting ADHD symptoms at an early age, to prevent self-esteem issues from developing.

The experiences of living with ADHD are described in terms of having a disability that cannot be seen. Because the impairments that the women experience as a function of their diagnosis are 'hidden', i.e. not of a physical kind, it is difficult to get sympathy and understanding from others regarding their problems. It can also be hard for the women to explain their challenges to themselves as well as to others, and they struggle with getting the severity of their symptoms recognized by others, who often assume that they only represent common everyday problems. While ADHD is associated with challenges, the women also attribute certain positive aspects to their diagnosis, such as high energy, creativity, adventurousness, willingness to take risks, and an ability to get easily excited about learning new things, as well as enjoying a wide range of interests.

5.1.2 What experiences do the women have with stigma of ADHD, and with public assumptions regarding their diagnosis?

All the interviewees have experienced stigma of ADHD, and observe its existence in the general society as well as among friends and family members. The women have registered that ADHD commonly is referred to as a fake disorder, made up as an excuse for being lazy, immature, and unwilling to conform. Symptoms tend to be perceived by many as moral problems, e.g., *"it just takes self-control"*, and not as signs of an actual disorder. Hinshaw et al. (in press) have previously noted that perceptions of ADHD as a fake disease may evoke negative attitudes instead of understanding. Mueller et al. (2012) highlight the public's uncertainty regarding the validity of the diagnosis of ADHD as one of the main contributing factors to the stigma of ADHD, which is in accordance with the current findings.

The women experience that the stigma associated with ADHD makes it harder to get the severity of their struggles understood and recognized by others. The most common consequence of stigma for the women is reluctance toward disclosing their diagnosis openly. Common public perceptions of what ADHD looks like include external displays of hyperactive, impulsive and 'messy' behavior, and the women tell me that because they don't fit into those stereotypes, they are quite certain that people wouldn't understand or even believe them if they were open about having ADHD. Some of the women are concerned that diagnosis disclosure would result in negative sanctions at work, which there might be a truth to, considering previous findings which show that individuals with a known history of mental illness are less likely to be hired (Corrigan, 2000; Hinshaw et al., 2008).

For some individuals with stigmatized characteristics, stigma awareness can represent the first step in what Corrigan and Rao (2012) refers to as the stage-model of stigma, where stigma awareness is followed by personal endorsement of negative public attitudes. This does not seem to be the case for the women in this study. However, it is difficult to determine whether e.g. perceptions of self as lazy or stupid, or feelings of guilt for having condemned own children with ADHD-genes, are indications of poor self-esteem or of self-stigma. Still, the most probable answer is self-esteem issues, as those appeared long before the diagnosis of ADHD for the women in this study. Some of the women in my study wonder whether they would have used an early diagnosis as a crutch or as an excuse to work less hard in school, which might indicate that they still, deep down inside, suspect that they are inherently lazy.

Stigma, along with misconceptions and faulty assumptions regarding the nature and validity of ADHD as a disorder, are experienced as frequently occurring at all levels of the society. Importantly, as one of the women describes, the many negative and opinionated media stories about ADHD gets in the way of a more constructive and helpful dialogue about ADHD. The feeling of not being taken seriously, or experiences having to 'defend' oneself when telling others about one's diagnosis of ADHD, serve as justifications of secrecy as a better and more self-protective option. The negative press, misinformed opinions and prejudiced attitudes against ADHD that exists in the society today, are experienced as difficult to overlook or avoid being exposed to, and represent an additional burden to the women. It can also fuel personal doubts concerning whether one really have ADHD, or if it's in reality just used as an excuse for something else. Ultimately, that might result in self-stigma, particularly in women who already struggle with self-esteem issues that are very similar to common stereotypes about ADHD as a 'disease of laziness and lack of willpower'.

5.1.3 Surprising findings

Numerous studies show that individuals with ADHD are at a heightened risk of academic failure, unemployment, co-morbid disorders, substance abuse, self-harm, and suicidal ideation, as well as social impairment, and hormonal influences on ADHD symptoms in women (e.g. Biederman et al., 2006; Chronis-Tuscano et al., 2010; Hinshaw et al., 2012; Mordre et al., 2012).Yet, many of those findings do not apply to the women in the current study.

Although nearly all the women mention symptoms of internalizing disorders, none of them is - or has ever been - diagnosed with or treated for e.g. anxiety or depression. Four of the women have struggled noteworthy academically, and report both underachievement and fluctuating performances, yet they have all managed to graduate with a higher University Degree.

None of the women have used/abused nicotine, alcohol or illicit substances, despite that academic difficulties and inattention are strong predictors of both nicotine use and illicit drug use, particularly among girls with ADHD (Pingault, Côté, Galera, Genolini, Falissard, Vitaro, & Tremblay, 2012). Different forms of fear and worries were among the factors that stopped the women from trying drugs when they were younger. Examples include avoidance of drugs out of fear that they would *"(...) actually fry brain cells or something",* or because they caused a feeling of not being in control, *"(...) and that feeling depresses me - the feeling of not being in control"*. Another reason for not trying drugs, was a fear of breaking social norms and gender expectations; *"(...) if there weren't such a strong social pressure on girl not to drink – my father would have killed me if he caught me drinking or doing drugs -; we'd be drug addicts and drunks too, like my male relative with ADHD. There is not so much pressure on boys not to drink."* Pingault et al. (2012) underline that symptoms of anxiety and depression can serve as protective factors against substance abuse, which might apply to the women in my study.

One of the interviewees experience it as very challenging to build and maintain romantic relationships, and to control her temper. However, she does not experience herself as having social difficulties in general, and neither does the other women. Only a few subtle social difficulties, mainly from childhood, are mentioned, such as problems with picking up on social cues, feelings of being awkward and out of place socially, or unintentionally saying things that were considered hurtful or inappropriate. Other issues in social interactions can be poor time management, and a tendency to interrupt others and talk too much.

Hormonal influences on ADHD symptoms are not prominent among the interviewees in this study, in contrast to what has been described in other studies (Nussbaum, 2012; Quinn, 2005). One factor that might have contributed to the few registered hormonal effects is that few of the women in my study have been aware of the possibility of a relationship between hormones and ADHD symptoms, or even knew that they had ADHD until late adulthood.

5.2 The negative impact of stigma versus the benefits of recognizing and treating ADHD in women: Conclusive comments and future directions.

There are several negative consequences associated with a delayed diagnosis of ADHD in women, including lost possibilities to properly address and work on problems and develop important mastery skills at a timely age, and the potential for deeply embedded self-esteem issues to develop. All of the interviewees initially felt relieved when they finally got diagnosed as adults, because the diagnosis provided them with an explanation for their problems, served as a recognition of their problems, reduced feelings of self-blame, and provided them with access to various treatment interventions. The potential benefits from an early diagnosis which are described, include possibilities to develop and practice on e.g. social skills, time-management skills, self-regulatory skills, and organizational skills. Furthermore, a diagnosis could have provided the women and their surroundings with more insight into why things seemed harder for them than for others, at an earlier age - which could have been positive for self-esteem and self-efficacy.

The findings from this study, and from previous research, leave little room for doubt concerning the importance of recognizing and targeting the significant challenges and consequences associated with a diagnosis of ADHD in women (see e.g. Goodman, 2007; Miller et al., 2007; Nadeau et al. 2002; Rasmussen et al., 2009; Waite et al., 2010). Furthermore, several studies point to the value of early identification and intervention for promoting health and positive development, and preventing global functional impairment. From a review of 36 relevant studies, Agarwal, Goldenberg, Perry, and Ishak (2012) conclude that an early diagnosis and pharmacological treatment have a positive impact on long-term prognosis and outcomes and quality of life in adults with ADHD. Mordre et al. (2012) underline that psychosocial functioning in childhood is a significant predictor of adult global functioning, and therefore stress the importance of identifying and targeting ADHD at an early age. Besides methylphenidate, motivational intervention and contingency management in school have been found to improve motivation and performance in individuals with ADHD (Volkow et al., 2011). This would have been relevant for my interviewees, whose main struggles include fluctuating performances and underachievement much caused by motivational difficulties and procrastination. Experiences of academic mastery in childhood can promote self-perceived scholastic competence, which to a

greater degree than actual academic achievement have shown to predict lower levels of adolescent internalizing behavior in girls with ADHD (Mikami & Hinshaw, 2010).

Overall, there are numerous valid arguments and research findings that underline the importance and long-term positive impact of an early diagnosis and treatment of ADHD. However, the negative effects of stigma of ADHD, along with an often unbalanced or incomplete understanding of the disorder among health-care professionals as well as nonprofessionals, complicate the discussion about advantages of an early diagnosis. How are a person's responses to being diagnosed influenced by prevailing public understandings of ADHD as a made up disorder and an excuse for being lazy and immature, or alternatively, as a biologically fixed flaw? And will an understanding of ADHD which involves an emphasis on the complexity of variables that together shape the course and outcome of ADHD, leave individuals feel more optimistic in terms of mastery, than an understanding influenced by ideas of genetic determinism?

Based on the findings from this study, the degree to which individuals experience it as helpful to be diagnosed with ADHD, and how they perceive their options for symptom management and mastery, greatly depends on how the disorder and its implications is presented to them by professionals as well as in the popular media. While ADHD should be recognized and treated as a valid and serious disorder, definitions of ADHD as biologically 'fixed' can lead to perceptions of it as equal to dysfunction and lost opportunities, and leave individuals feeling discouraged and helpless instead of relieved and determined on positive development. Overly negative outcome predictions and low expectations of improvement are examples of stigmatizing attitudes which have been found e.g. among health-care professionals (in relation to mental illness) (Heflinger et al., 2010), while biogenetic models have shown to possibly increase rather than decrease stigma (Rüsch et al., 2005).

The interviewees' conceptualizations of ADHD vary quite significantly, including in regards of how they perceive their own possibilities and capability for modifying and controlling symptoms. Personal experiences of mastery and self-efficacy can make challenges appear more surmountable, given that the diagnosis of ADHD is presented in a way which underline the possibilities for mastery. The majority of women in this study have repeatedly experienced a lack of control in different areas, which at times have overshadowed experiences of control and mastery. Challenges and failures have not resulted from a lack of efforts or capabilities, but are

explained by that they were never presented with the adequate tools for managing their challenges, due to the unidentified cause of their problems. Possibly because of the unpredictability of failures as well as of successes, several of the women seem to have attributed several of their many accomplishments to chance or luck, instead of to their own skills and qualities.

The different ways in which the women perceive and are affected by their ADHD, illustrates the value and importance of thoroughly informing children and adults with ADHD about the interplay between a variety of factors that influence the course and outcome of ADHD. An early diagnosis that is accompanied by an emphasis on strengths and the implementation of various treatment strategies can provide the individual with experiences of mastery, which potential long-lasting positive effects on self-esteem and on how later difficulties are dealt with. Learning how to manage symptoms at an early age, e.g. through the use of strategies for enhancing self-regulatory and motivational skills, can result in an experience based sense of trust in own ability to master and overcome challenges in general, and thus control the direction of own life. Furthermore, it might also protect women with ADHD from some of the common secondary psychological effects of the disorder, including learned helplessness, excessive worrying and rumination, internalization of stigma, and lowered self-efficacy.

Future directions. Based on the many examples of success and achievements among the women in this study, it would be interesting to further examine which factors that protect and contribute to positive outcomes for women with ADHD, despite challenges and hardship. More awareness about common challenges for women with ADHD, including motivation deficit, executive dysfunction, excessive worrying and rumination, are still warranted. Stigma of ADHD, including misconceptions and prejudiced information e.g. in the media, needs to be challenged and taken into account when informing individuals about the disorder. Furthermore, the impact of stigma is an important factor to include when trying to understand the implications of living with ADHD. More tools and strategies for symptom management seems necessary, and the potential effects of these on self-esteem and self-efficacy for women with ADHD, would be of great value.

5.3 What could have been done differently?

I chose to explore two very broad research questions, which resulted in an extensive data material. A more narrow scope could have made it easier and less time-consuming to analyze, organize and present the data material. At the same time, based on my aim of generating a

comprehensive data material that could provide the reader with a nuanced impression and understanding of stigma and ADHD in women, I felt that it was relevant to shed light on a complexity of interacting factors and variables. Furthermore, the thick and detailed descriptions that this resulted in, are important for the assessment of transferability of the research findings (Postholm, 2005).

I have become aware that my pre-knowledge might have been too evident in some of my question formulations in the interview guide, despite my efforts to avoid for that to happen. These questions, which should have been formulated less suggestive, include parts of question 8, 11, 15 and 18 from the interview protocol.

However, as described earlier, I absolutely had the impression that the interviewees in generally responded in accordance with their own personal opinions and experiences, regardless of whether these 'confirmed' or 'disconfirmed' the themes and questions, and then most likely also the formulations, in the interview protocol. Furthermore, the use of member checks, which gave the interviewees the chance to review the data material from their respective interview before it was analyzed and included in the thesis, did not result in any changes of content and/or removal of data from their side.

5.4 Transferability

The transferability of qualitative research findings involves the extent to which the research findings can be applied ('generalized') to other *comparable* settings. All the interviewees in this study were diagnosed as adults, and the experiences of these women, who grew up without any identified cause or explanation for their problems, nor access to any treatment strategies, might differ from the experiences of women who were diagnosed with ADHD in childhood or adolescence. The results from this study might therefore apply more specifically to other women with ADHD who also are/were diagnosed as adults. However, that might involve a large number of individuals, since it is so common that women with ADHD are diagnosed first as adults.

Because this is a qualitative study, where the aim was to explore selected individuals' experiences with a phenomenon without making generalizations to the whole population, it might be more meaningful to highlight sample characteristics than to discuss the representativeness of the sample. Moreover, since there's been done limited research on women with ADHD, and because many women with ADHD are assumed undiagnosed, it's even harder to determine the

representativeness of my sample. My interviewees described that their decision to volunteer for the study was much based on their personal interest in and commitment to the research topic. Their high educational level, occupational status, and lack of co-morbid disorders stand in contrast to previous studies that show high levels of academic failure, occupational impairment, and co-morbid disorders among women with ADHD. However, I do not have the results or the methods that would be necessary in order to define the women in this study as e.g. unique in terms of what they have accomplished. The interviewees' backgrounds are demographically very varied; a factor that is likely to strengthen the transferability of the findings regarding their experiences of ADHD and stigma, to other women with ADHD.

References

Agarwal, R., Goldenberg, M., Perry, R., & Ishak, W.W. (2012). The quality of life of adults with attention deficit hyperactivity disorder: a systematic review. *Innovations in Clinical Neuroscience*, 9, 5-6, 10-21.

Anderson, C. (2010). Presenting and evaluating qualitative research. *The American Journal of Pharmaceutical Education,* 74, 1-7. Doi: PMC2987281.

Angermeyer, M.C., Holzinger, A., Carta, M.G., & Schomerus, G. (2011). Biogenetic explanations and public acceptance of mental illness: systematic review of population studies. *The British Journal f Psychiatry,* 199, 367-372. Doi: 10.1192/bjp.bp.110.085563.

Babinski, D.E., Pelham Jr., W.E., Molina, B.S.G., Waschbusch, D.A., Gnagny, E.M., Yu, J., Sibley, M.H., & Biswas, A. (2011a). Women with childhood ADHD: Comparisons by diagnostic group and gender. *Journal of Psychopathology and Behavioral Assessment*, 33, 420-429. Doi: 10.1007/s10862-011-9247-4.

Babinski, D.E., Pelham Jr., W.E., Molina, B.S.G., Gnagny, E.M., Waschbusch, D.A.,Yu, J., MacLean, M.G…., & Karch, K.M. (2011b). Late adolescent and young adult outcomes of girls diagnosed with ADHD in childhood: An exploratory investigation. *Journal of Attention Disorders*, 15, 3, 204-214. Doi: 10.1177/1087054710361586.

Barbaresi, W.J., Colligan, R.C., Weaver, A.L., Voigt, R.G., Killian, J.M., & Katusic, S.K. (2013). Mortality, ADHD, and psychosocial adversity in adults with childhood ADHD: a prospective study. *Pediatrics*, 131, 4, 1-10. Doi: 10.1542/peds.2012-2354.

Barkley, R.A. (1997). Behavioral inhibition, sustained attention, and executive functions: constructing a unifying theory of ADHD. *Psychological Bulletin,* 121, 1, 65-94. Doi: 10.1037/0033-2909.121.1.65.

Barkley, R.A. (2002). Major life activity and health outcomes associated with Attention-Deficit/Hyperactivity Disorder. *Journal of Clinical Psychiatry,* 63, 10-15. Retrieved from: www.jclinpsychiatry.com/pcc/pccpdf/v04s04/v63s1202.pdf.

Barkley, R.A., & Peters, H. (2012). The earliest reference to ADHD in the medical literature? Melchior Adam Weikard's description in 1775 of "attention deficit" (Mangel der Aufmerksamkeit, Attentio Volubilis). *Journal of Attention Disorders,* 16, 8, 623-630. Doi: 10.1177/1087054711432309.

Biederman, J. (2005). Attention-Deficit/Hyperactivity Disorder: a selective overview. *Biological Psychiatry,* 57, 11, 1215-1220. Doi:10.1016/j.biopsych.2004.10.020.

Biederman, J. (2005). Attention-deficit/hyperactivity disorder: a selective overview. *Biological Psychiatry*, 1215-1220. Doi:10.1016/j.biopsych.2004.10.020.

Biederman, J., Faraone, S.V., Spencer, T., Wilens, T., Mick, E., & Lapey, K.A. (1994). Gender differences in a sample of adults with attention deficit hyperactivity disorder. *Psychiatry Research*, 53, 13-29. Doi:10.1016/0165-1781(94)90092-2.

Biederman, J., Faraone, S.V., Mick, E., Williamson, S., Wilens, T.E., Spencer, T.J., Weber, W., Jetton, J., Kraus, I., Pert, J., & Zallen, B. (1999). Clinical correlates of adhd in females: findings from a large group of girls ascertained from pediatric and psychiatric referral sources. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38, 8, 966-975. Doi:10.1097/00004583-199908000-00012.

Biederman, J., Monuteaux, M.C., Mick, E., Spencer, T.J., Wilens, T.E., & Klein, K.L. (2006). Psychopathology in females with attention deficit/hyperactivity disorder: a controlled, five-year prospective study. *Biological Psychiatry,* 60, 10, 1098-1105. Doi:10.1016/j.biopsych.2006.02.031.

Brown, T.E. (2009). ADD/ADHD and impaired executive function in clinical practice. *Current Attention Disorder Reports,* 1, 37-41. Retrieved from: www.drthomasebrown.com/pdfs/cmgarticle.pdf.

Bussing, R., Zima, B.T., Mason, D.M., Porter, P.C., & Garvan, C.W. (2011). Receiving treatment for attention-deficit hyperactivity disorder: do the perspectives of adolescents matter? *Journal of Adolescent Health,* 49, 1, 7-14. Doi: 10.1016/j.jadohealth.2010.08.014

Chronis-Tuscano, A., Molina, B.S, Pelham, W.E, Applegate, B., Dahlke, A., Overmyer, M., Lahey, B.B. (2010). Very early predictors of adolescent depression and suicide attempts in children with attention-deficit/hyperactivity disorder. *Archives of General Psychiatry*, 67, 1044-1051. Doi: 10.1001/archgenpsychiatry.2010.127.

Crichton, A. (1798). *An inquiry into the nature and origin of mental derangement: comprehending a concise system of the physiology and pathology of the human mind and a history of the passions and their effects.* Vol.1, book 2, Ch.2: On attention and its diseases, pp. 254-290. Retrieved from: http://books.google.no/books?id=XlRJAAAAYAAJ&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false.

Creswell, J.W. (2007). *Qualitative inquiry & research design: choosing among five approaches* (2nd ed.). Thousand Oaks, CA; SAGE Publications.

Corrigan, P.W. (2000). Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, 71, 48-67. Doi: 10.1093/clipsy.7.1.48.

Corrigan, P.W., &Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry,* 16-20. Retrieved from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1489832/.

Corrigan, P.W., & Rao, D. (2012). On the self-stigma of mental illness: stages, disclosure, and strategies for change. *Canadian Journal of Psychiatry*, 57, 8, 464-469. Retrieved from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610943/pdf/nihms363969.pdf.

Dalen, M. (2004). Intervju som forskningsmetode: en kvalitativ tilnærming. Oslo, Norge: Universitetsforlaget.

DosReis, S., Barksdale, CL., Sherman, A., Maloney, K., & Charach, A. (2010). Stigmatizing experiences of parents of children with a new diagnosis of ADHD. *Psychiatric Services*, 61, 811-816. Doi: 10.1176/appi.ps.61.8.811.

Eerde, W. van. (2003). A meta-analytically derived nomological network of procrastination. *Personality and Individual Differences,* 35, 1401-1418. Retrieved from: www1.fee.uva.nl/pp/bin/refereedjournalpublication2027fulltext.pdf.

Fedele, D.A., Lefler, E.K., Hartung, C.M., & Canu, W.H. (2012). Sex differences in the manifestation of adhd in emerging adults. *Journal of Attention Disorders,* 16, 2, 109-117. Doi: 10.1177/1087054710374596.

Faraone, S.V., Biederman, J., Weber, W., & Russell, R.L. (1998). Psychiatric, neuro-psychological, and psychosocial features of DSM-IV subtypes of attention-deficit/hyperactivity disorder: Results from a clinically referred sample. *Journal of the American Academy of Child and Adolescent Psychiatry,* 37, 185-193. Doi: 10.1097/00004583-199802000-00011.

Faraone, S.V., Spencer, T., & Montano, C. (2004). ADHD in adults: A survey of current practice in psychiatry and primary care. *Archives of Internal Medicine,* 14, 164(11), 1221-1226. Doi:10.1001/archinte.164.11.1221.

Faraone, S.V., Perlis, R.H., Doyle, A.E., Smoller, J.W., Goralnick, J.J., Holmgren, M.A., & Sklar, P. (2005). Molecular genetics of attention-deficit/hyperactivity disorder. *Biological Psychiatry,* 57, 1313-1323. Doi:10.1016/j.biopsych.2004.11.024.

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology and Practice,* 3, 1, 6-25. Retrieved from: https://ejournals.library.ualberta.ca/index.php/pandpr/article/.../15336.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity.* New York, NY: Simon & Schuster Inc.

Goodman, D. (2007). The consequences of attention deficit/hyperactivity disorder in adults. *Journal of Psychiatric Practice,* 13, 5, 318-327. Doi: 10.1097/01.pra.0000290670.87236.18.

Goldman, L.S., Genel, M., Bezman, R.J., & Slanetz, P.J. (1998). Diagnosis and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *The Journal of the American Medical Association,* 279, 14, 1100-1107. Doi: 10.1001/jama.279.14.1100.

Groenwald, C., Emond, A., & Sayal, K. (2009). Recognition and referral of girls with attention deficit hyperactivity disorder: a case vignette study. *Child: care, health and development*, 35, 6, 767-772. Doi: 10.1111/j.1365-2214.2009.00984.x.

Hatzenbuehler, M.L., Phelan, J.C., & Link, B.G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health,* 103, 813-821. Doi: 10.2105/AJPH.2012.301069.

Heflinger, C.A., & Hinshaw, S.P. (2010). Stigma in child and adolescent mental health services research: understanding professional and institutional stigmatization of youth with mental health problems and their families. *Administration and Policy in Mental Health and Mental Health Services Research,* 37, 61-70. Doi: 10.1007/s10488-010-0294-z.

Hiles, D.R., & Čermák, I. (2007). Qualitative research: transparency and narrative oriented inquiry. Paper presented at 10th European Congress of Psychology, Prague, CZ, July 2007. Retrieved from: http://psy.dmu.ac.uk/drhiles/pdf%27s/Microsoft%20Word%20-%20Hiles%20&%20Cermak%20_2007_%20QR%20-%20Transparency%20and%20NOI.pdf

Hinshaw, S.P. (2002). Preadolescent girls with attention-deficit/hyperactivity disorder: i. background characteristics, comorbidity, cognitive and social functioning, and parenting practices. *Journal of Consulting and Clinical Psychology,* 70, 5, 1086-1098. Doi: 10.1037/0022-006X.70.5.1086.

Hinshaw, S.P. (2009). *The triple bind: Saving our teenage girls from today's pressures and conflicting expectations.* New York, NY: Ballantine Books.

Hinshaw, S.P., & Blachman, D.R. (2005). Attention-Deficit/Hyperactivity Disorder in girls. In Bell, D.J., Foster, S.J., & Mash, E.J. (Eds.), *Handbook of Behavioral and Emotional Problems in Girls*, 117-147. 10.1007/0-306-48674-1_4. New York, NY: Springer US.

Hinshaw, S.P., Owens, E.B., Sami, N., & Fargeon, S. (2006). Prospective follow-up of girls with attention-deficit/hyperactivity disorder into adolescence: evidence for continuing cross-domain impairment. *Journal of Consulting and Clinical Psychology*, 74, 3, 489-499. Doi: 10.1037/0022-006X.74.3.489.

Hinshaw, S.P., and Stier, A. (2008). Stigma as related to mental disorders. *Annual Review of Clinical Psychology,* 4, 367-393. Doi: 10.1146/annurev.clinpsy.4.022007.141245.

Hinshaw, S.P., Owens, E.B., Zalecki, C., Huggins, S.P., Montenegro-nevado, A.J., Schrodek, E., & Swanson, E.N. (2012). Prospective follow-up of girls with attention-deficit/hyperactivity disorder into early adulthood: continuing impairment includes elevated risk for suicide attempts and self-injury. *Journal of Consulting and Clinical Psychology,* 1-11. Doi: 10.1037/a0029451.

Hinshaw, S.P., & Scheffler, R.M. (in press). The ADHD explosion and today's push for performance: Myths, medications, and money. New York, NY: Oxford University Press.

Hollon, M.F. (2004). Primary care evaluation and management of attention deficit hyperactivity disorder in adults. *Advanced Studies in Medicine,* 4(2), 79-86. Retrieved from: http://www.jhasim.com/files/articlefiles/pdf/journal_p79-86%28V4-2%29.pdf.

Kessler, R.C., Adler, L., Barkley, R., Biederman, J., Conners, C.K., Demler, O…. & Zaslavsky, A.M. (2006). The prevalence and correlates of adult adhd in the United States: results from the national comorbidity survey replication. *American Journal of Psychiatry,* 163, 716-723. Doi: 10.1176/appi.ajp.163.4.716.

Krefting, L. (1991). Rigor in Qualitative Research: The Assessment of Trustworthiness. *The American Journal of Occupational Therapy,* 45, 3, 214-222. Doi: 10.5014/ajot.45.3.214.

Kureishi, H. (2012, Feb.18). The Art of Distraction. *The New York Times.* Retrieved from: http://www.nytimes.com/2012/02/19/opinion/sunday/the-art-of-distraction.html?pagewanted=all&_r=0.

Lee, H. (1960). *To Kill a Mockingbird.* Philadelphia, PA: J. B. Lippincott & Co.

Link, B.G., & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology,* 27, 363-385. Doi: 10.1146/annurev.soc.27.1.363.

Mahone, E.M., & Wodka, E.L. (2008). The neurobiological profile of girls with ADHD. *Developmental Disabilities Research Reviews,* 14, 276-284. Doi: 10.1002/ddrr.41.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet*, 358, 483-488. Doi: doi:10.1016/S0140-6736(01)05627-6.

Mikami, A.Y., & Hinshaw, S.P. (2006). Resilient adolescent adjustment among girls: buffers of childhood peer rejection and attention-deficit/hyperactivity disorder. *Journal of Abnormal Child Psychology,* 34, 825-839. Doi: 10.1007/s10802-006-9062-7.

Miller, M., Ho, J., & Hinshaw, S.P. (2012). Executive functions in girls with adhd followed prospectively into young adulthood. *Neuropsychology,* 26, 3, 278-287. Doi: 10.1037/a0027792.

Miller, T.W., Nigg, J.T., & Faraone, S.V. (2007). Axis I and II comorbidity in adults with ADHD. *Journal of Abnormal Psychology*, 116, 3, 519-528. Doi: 10.1037/0021-843X.116.3.519.

Mitchell, J.T., Robertson, C.D., Anastopolous, A.D., Nelson-Gray, R.O., & Kollins, S.H. (2012). Emotion dysregulation and emotional impulsivity among adults with attention-deficit/hyperactivity disorder: results from a preliminary study. *Journal of Psychopathology and Behavioral Assessment*, 1-10, Doi: 10.1007/s10862-012-9297-2.

Mordre, M., Groholt, B., Sandstad, B., & Myhre, A.M. (2012). The impact of ADHD symptoms and global impairment in childhood on working disability in mid-adulthood: a 28-year follow-up study using official disability pension records in a high-risk in-patient population. *BMC Psychiatry,* 12, 174, 1-9. Doi: 10.1186/1471-244X-12-174.

Mueller, A.K., Fuermaier, A.B.M., Koerts, J., & Tucha, L. (2012). Stigma in attention-deficit hyperactivity disorder. *ADHD Attention Deficit Hyperactivity Disorders,* 4, 101-114. Doi: 10.1007/s12402-012-0085-3.

Nadeau, K.G., & Quinn, P. (2002). *Understanding Women with AD/HD.* Silver Spring, MD: Advantage Books.

Nelson, G., & Prilleltensky, I. (Eds.) (2010). *Community psychology: In pursuit of liberation and well-being.* (2nd ed.). Hampshire, Great Britain: Palgrave Macmillan.

Nigg, J.T., Stavro, G., Ettenhofer, M., Hambrick, D.Z., Miller, T., & Henderson, J.M. (2005). Executive functions and adhd in adults: evidence for selective effects on adhd symptom domains. *Journal of Abnormal Psychology*, 114, 3, 706-717. Doi: 10.1037/0021-843X.114.3.706.

NIH Consensus Statement Online (1998). Diagnosis and treatment of attention deficit hyperactivity disorder, 16(2), 1-37. Retrieved from: http://consensus.nih.gov/cons/110/110_intro.htm.

Nolen-Hoeksema, S. (2000). The role of rumination in depressive disorders and mixed anxiety/depressive symptoms. *Journal of Abnormal Psychology*, 109, 3, 504-511. Doi: 101037/10021-843X.109.3.504.

Nolen-Hoeksema, S., Wisco, B.E., & Lyubomirsky, S. (2008). Rethinking rumination. *Perspectives on Psychological Science*, 3, 5, 400-424. Doi: 10.1111/j.1745-6924.2008.00088.x.

Nussbaum, N.L. (2012). ADHD and female specific concerns: a review of the literature and clinical implications. *Journal of Attention Disorders,* 16, 2, 87-100. Doi: 10.1177/1087054711416909.

O'Brien, J.W., Dowell, L.R., Mostofsky, S.H., Denckla, M.B., & Mahone, E.M. (2010). Neuropsychological profile of executive function in girls with attention-deficit/hyperactivity disorder. *Archives of Clinical Neuropsychology,* 25, 656-670. Doi: 10.1093/arclin/acq050.

Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Beverly Hills, CA: Sage.

Pingault, J-B., Côté, S.M., Galera, C., Genolini, C., Falissard, B., Vitaro, F., & Tremblay, R.E. (2012). Childhood trajectories of inattention, hyperactivity and oppositional behaviors and prediction of substance abuse/dependence: a 15-year longitudinal population-based study. *Molecular Psychiatry*, 18, 806-812. Doi: 10.1038/mp.2012.87.

Pingault, J.B., Tremblay, R.E., Vitaro, F., Carbonneau, R., Genolini, C., Falissard, B., & Côté, S.M. (2011). Childhood trajectories of inattention and hyperactivity and prediction of educational attainment in early adulthood: a 16-year longitudinal population-based study. *American Journal of Psychiatry*, 168, 1164-1170. Doi:10.1176/appi.ajp.2011.10121732.

Postholm, M.B. (2005). Kvalitativ metode: En innføring med fokus på fenomenologi, etnografi og kasusstudier. Oslo, Norge: Universitetsforlaget.

Quinn, P.O. (2005). Treating adolescent girls and women with adhd: gender-specific issues. *Journal of Clinical Psychology*, 61, 5, 579-587. Doi: 10.1002/jclp.20121.

Quinn, P.O. (2008). Attention-Deficit/Hyperactivity Disorder and its comorbidities in women and girls: an evolving picture. *Current Psychiatry Reports*, 10, 419-423.

Quinn, P., & Wigal, S. (2004). Perceptions of girls and adhd: results from a national survey. *Medscape General Medicine*, 6 (2), 2, 1-16. PCMID: PCM1395774.

Rasmussen, K., & Levander, S. (2009). Untreated ADHD in adults: are there sex differences in symptoms, comorbidity, and impairment? *Journal of Attention Disorders,* 12, 4, 353-360. Doi: 10.1177/1087054708314621.

Rietveld, M.J., Hudziak, J.J., Bartels, M., van Beijsterveldt, C.E., & Boomsma, D.I. (2003). Heritability of attention problems in children: I. cross-sectional results from a study of twins, age 3-12. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 117B, 102-113. Doi: 10.1002/ajmg.b.10024.

Rucklidge, J.J., & Kaplan, B.J. (1997). Psychological functioning of women identified in adulthood with Attention-Deficit/Hyperactivity Disorder. *Journal of Attention Disorders*, 2, 3, 167-176. Doi: 10.1177/108705479700200303.

Rucklidge, J.J., & Tannock, R. (2001). Psychiatric, psychosocial, and cognitive functioning of female adolescents with ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 5, 530-540. Doi:10.1097/00004583-200105000-00012.

Rüsch, N., Angermeyer, M.C., & Corrigan, P.W. (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *European Psychiatry,* 20, 529-539. Doi: 10.1016/j.eurpsy.2005.04.004.

Rüsch, N., Todd, A.R., Bodenhausen, G.V., & Corrigan, P.W. (2010). Biogenetic models of psychopathology, implicit guilt, and mental illness stigma. *Psychiatry Research,* 179, 3, 328-332. Doi: 10.1016/j.psychres.2009.09.010.

Schouwenburg, H. C., Lay, C. H., Pychyl, T. A., & Ferrari, J. R. (2006). *Counseling the procrastinator in academic settings*. American Psychological Association. Retrieved from: http://elpub.bib.uni-wuppertal.de/servlets/DerivateServlet/Derivate-1229/conf05.pdf#page=79.

Sihvola, E., Rose, R.J., Dick, D.M., Korhonen, T., Pulkkinen, L., Raevuori, A., Marttunen, M., & Kaprio, J. (2011). Prospective relationships of ADHD symptoms with developing substance use in a population-derived sample. *Psychological Medicine,* 41, 12, 2615-2623. Doi: 10.1017/S0033291711000791.

Smith, J.M., & Alloy, L.B. (2009). A roadmap to rumination: a review of the definition, assessment, and conceptualization of this multifaceted construct. *Clinical Psychology Review,* 29, 2, 116-128. Doi: 10.1016/j.cpr.2008.10.003.

Smith, J.A., Flowers, P., Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research.* Great Britain: Sage Publications Ltd.

Solden, S. (1995). *Women with Attention Deficit Disorder.* Grass Valley, CA: Underwood Books.

Steel, P. (2007). The nature of procrastination: a meta-analytic and theoretical review of quintessential self-regulatory failure. *Psychological Bulletin,* 133, 1, 65-94. Doi: 10.1037/0033-2909.133.1.65

Thomas, D.R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation,* 27, 2, 237-246. Doi: 10.1177/1098214005283748.

Volkow, N.D., Wang, G.J., Newcorn, J.H., Kollins, S.H., Wigal, T.L., Telang, F… Swanson, J.M. (2011). Motivation deficit in ADHD is associated with dysfunction of the Dopamine reward pathway. *Molecular Psychiatry,* 16, 11, 1147-1154. Doi: 10.1038/mp.2010.97.

Waite, R. (2006). Women and attention deficit disorder: A great burden overlooked. *Journal of the American Academy of Nurse Practitioners,* 19, 116-125. Doi: 10.1111/j.1745-7599.2006.00203.x.

Waite, R. (2010). Women with ADHD: It is an explanation, not the excuse du jour. *Perspectives in Psychiatric Care,* 46, 3, 182-196. Doi: 10.1111/j.1744-6163.2010.00254.x.

Waite, R., & Ivey, N. (2009). Unveiling the mystery about adult ADHD: One woman's journey. *Issues in Mental Health Nursing,* 30, 547-553. Doi: 10.1080/01612840902741989.

Zahn-Waxler, C. Klimes-Dougan, B. & Slattery, M.J. (2000). Internalizing problems of childhood and adolescence: prospects, pitfalls, and progress in understanding the development of anxiety and depression. *Development and Psychopathology*, 12, 443-466. PMID 11014747.

Appendices

Appendix 1

Verbal Recruitment

Research Study

University of California, Berkeley

Department of Psychology

"WOMEN WITH ADHD: Effects on Everyday Functioning and the Role of Stigma"

My name is Mira Elise Glaser Holthe, and I am a student at UC Berkeley and at the Norwegian University of Science and Technology.

I am currently writing my Master Thesis in psychology at UC Berkeley, with Professor Stephen P. Hinshaw as my U.S Advisor. The study is about adult women with ADHD, and its focus is on gaining an in-depth understanding of how women are affected by their diagnosis, and of their experiences with stigma of ADHD. My interest in this area is largely due to the fact that I was diagnosed with ADHD as an adult myself, something that inspired me to learn more about the diagnosis in women, both privately and academically.

"The Committee for Protection of Human Subjects (CPHS)" at UC Berkeley has approved the project. As a part of the study, I will interview five women with previously diagnosed ADHD, in the age range 18 – 50 years. These will take place by the end of February 2013, either at UC Berkeley Campus, or alternatively in a location more convenient for the research participant.

I`m inviting you to participate in one of these interviews, which will last between 1.5 and 2 hours. You will not receive any financial compensation if you choose to participate, but each interview will be a valuable contribution to the work towards a better understanding of ADHD in women.

If you are interested in participating in an interview, you can contact me via phone (510 599 7988) or e-mail (miraglaser@gmail.com) for more information. Please don't hesitate to ask me if you have any questions.

Best regards,

Mira Elise Glaser Holthe.

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SAN FRANCISCO • SANTA BARBARA • SANTA CRUZ

CONSENT TO PARTICIPATE IN RESEARCH
"Women with ADHD: Effects on Everyday Functioning and the Role of Stigma".

Introduction

My name is Mira Elise Glaser Holthe. I am a Graduate Student from NTNU in Norway, currently working with Professor Stephen Hinshaw in the Department of Psychology at UC Berkeley. I am inviting you to participate in a research study. The reason for inviting you is that you are a woman who has been previously diagnosed with attention-deficit/hyperactivity disorder (ADHD).

Purpose

The purpose of this research is to gain increased knowledge and understanding of how ADHD affects the everyday lives of women with the disorder. The role of stigma of ADHD will also be investigated, to see what effects stigma may have on the life quality of women with the ADHD. The method to be used is an interview with women like you. I anticipate interviewing a total of approximately five women.

Procedures

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

I will conduct an interview with you at a convenient time and location. The interview will involve open-ended questions about what led to your diagnosis, how the symptoms of ADHD affect your daily functioning, how you experience being a woman with ADHD, the role of stigma surrounding ADHD (that is, society's negative attitudes about this condition), your coping strategies, and the effect of ADHD on your social relationships. It should last about 1.5 - 2 hours.
I expect to conduct only one interview with you. However, follow-ups may be needed for clarification after the interview. If so, I will contact you by mail or phone to request this. If such a follow-up is needed, I will make it as brief as possible, and not include any new questions. With your permission, I will make an audio recording and take notes during the interview. The goal is to accurately record the information you provide. The information will be used for transcription purposes only. If you agree to being recorded but feel uncomfortable at any time during the interview, I can turn off the recorder at your request. If you don't wish to continue, you can stop the interview at any time.

Study Time and Location

Participation in this study will involve a total of 1.5 - 2 hours of Interview of your time. I will transcribe your interview and then ask you to read and validate the information within March 2013, before it is included in the research paper. All study procedures will take place at a meeting room at the UC Berkeley Campus.

Benefits

There is no guarantee of any specific benefit for you by participating in this research; this is not a treatment study. Yet our hope is that the information gained from the study will contribute to an increased public understanding of ADHD in women, thereby making it easier for them to access proper treatment, information, and self-understanding. Existing research on ADHD in women is limited, and this study may lead to gains in scientific knowledge regarding ADHD.

Risks/Discomforts

Some of the research questions may make you uncomfortable or upset. You are free to decline to answer any questions you don't wish to, or to stop the interview at any time. As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk. If you should feel any discomfort or emotional distress after the interview, you are welcome to talk to me (Mira Elise Glaser Holthe) about any of your thoughts, feelings, and concerns.

Confidentiality

Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used.

To minimize the risks to confidentiality, we will do the following:

We will not maintain a link between your identity and the research data. Personal identifiers will be removed immediately – that is, after audio recordings have been transcribed. Also, your research records, including audio recordings, will be stored in a locked cabinet, in a secured building. Only my faculty advisors (main advisor and sub advisor) and I will have access to your study records.

Future Use of Study Data

The audio recordings will be transcribed and the tapes will be erased at the end of the study. The transcribed research data will be maintained for possible use in future research by myself or others. I will retain this data for up to three years after the study is over. The same measures described above will be taken to protect confidentiality of this study data.

Rights

Your participation in this research is completely voluntary. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

Questions

If you have any questions or concerns about this study, you may contact Mira Elise Glaser Holthe, at 510-599-7988 or miraglaser@gmail.com. If you have any questions or concerns about your rights and treatment as a research subject, you may contact the office of UC Berkeley's Committee for the Protection of Human Subjects, at 510-642-7461 or subjects@berkeley.edu.

Consent

You have been given a copy of this consent form to keep. If you wish to participate in this study, please sign and date below.

_____ _____

Participant's Name *(please print)* Date

_____ _____

Participant's Signature Date

_____ _____

Person Obtaining Consent Date

CPHS #

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
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			Deres dato:	**Deres referanse:**
			06.11.2012	

Vår referanse må oppgis ved alle henvendelser

Til Mira Elise Glaser Holthe

2012/1995 D Women with ADHD: Effects on Everyday Functioning and the Role of Stigma

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk i møtet 29.11.2012.

Prosjektleder: Mira Elise Glaser Holthe
Forskningsansvarlig: NTNU

Prosjektomtale
Kunnskap om hvordan ADHD påvirker og arter seg hos kvinner er i dag mangelfull, da forståelsen av diagnosen i stor grad er basert på forskning som kun har inkludert gutter. Symptomer på ADHD manifisteres og tolkes ulikt avhengig av kjønn, og problemer med å identifisere ADHD hos kvinner resulterer ofte i sen eller manglende diagnostisering.

Akademiske, psykiske og fysiske tilleggsvansker ses hos en stor andel kvinner med ADHD, og manglende adekvat behandling og forståelse av individene i denne gruppen viser seg å kunne resultere i omfattende helsemessige problemer. Redusert livskvalitet for kvinner med ADHD ses som følge av stigmatisering av diagnosen, et problem økt kunnskap kan redusere.

Formålet med dette prosjektet er å spre forskningsbasert og detaljert informasjon om påvirkningen ADHD har på kvinners hverdagsliv, innhentet gjennom kvalitative dybdeintervjuer av kvinner med diagnosen. Deres historier vil danne forståelsesrammen for dette prosjektet.

Prosjektet er en del av en masteroppgave i psykologi, og vil offentliggjøres i denne samt i artikkelform etter oppgaveinnlevering og sensur.

Komiteens vurdering
Hovedspørsmålet for komiteen i vurderingen av denne søknaden er hvor vidt dette er forskning som faller inn under helseforskningslovens geografiske virkeområde.

Forskningsprosjektet skal utelukkende gjøres USA, både når det gjelder rekruttering av forsøkspersoner og selve gjennomføringen av forskningsprosjektet. Slik dette er lagt opp, er komiteen av den oppfatning at prosjektet faller utenfor helseforskningslovens geografiske virkeområde. Prosjektet kan etter komiteens oppfatning inngå i en norsk gradsutdanning til tross for at det ikke er fremleggelsespliktig for REK

Etter komiteens oppfatning er det klart at prosjektet slik det er beskrevet er å regne som forskningsaktivitet som krever godkjenning i det landet hvor forskningsprosjektet skal gjennomføres – og informanter inkluderes. Det fremgår av søknaden at dette allerede er formalisert ved selvstendig vurdering av Professor *Stephen Hinshaw*, Department of Psychology, UC Berkeley, California og *Committee for Protection of Human Subjects*, UC Berkeley, California.

Besøksadresse:
Nydalen allé 37 B, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

For å gjennomføre prosjekter av denne typen trenges det ingen særskilt godkjenning fra REK. Det er institusjonens ansvar å sørge for på vanlig måte at tiltaket følger gjeldende reguleringer for behandling av helseopplysninger.

Ettersom prosjektet forutsettes gjennomført i samsvar med gjeldende reguleringer vil det ikke være noe til hinder for at resultatene kan publiseres. Hvis det er behov for dokumentasjon fra REK vil dette brevet bekrefte at prosjektet ikke er fremleggelsespliktig.

Vedtak
Prosjektet faller utenfor komiteens mandat, jf. helseforskningsloven § 3. Prosjektet kan gjennomføres uten godkjenning av REK.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK Sørøst D. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

Med vennlig hilsen

Stein A. Evensen
Professor dr. med.
Leder

Gjøril Bergva
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UNIVERSITY OF CALIFORNIA AT BERKELEY

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COMMITTEE FOR PROTECTION OF HUMAN SUBJECTS
OFFICE FOR THE PROTECTION OF HUMAN SUBJECTS
University of California, Berkeley
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FWA#00006252

NOTICE OF APPROVAL FOR HUMAN RESEARCH

DATE:	*December 21, 2012*
TO:	*Stephen HINSHAW, Psych* *MIRA ELISE GLASER HOLTHE*
CPHS PROTOCOL NUMBER:	*2012-10-4754*
CPHS PROTOCOL TITLE:	*"WOMEN WITH ADHD: Effects on Everyday Functioning and the Role of Stigma"*
FUNDING SOURCE(S):	*NONE*

A *new* application was submitted for the above-referenced protocol. The Committee for Protection of Human Subjects (CPHS) or Office for the Protection of Human Subjects (OPHS) has reviewed and approved the application by *expedited* review procedures.

Effective Date: December 21, 2012
Expiration Date: December 20, 2013

This approval is issued under University of California, Berkeley Federalwide Assurance #00006252.

If you have any questions about the above, please contact the Office for the Protection of Human Subjects staff at Tel (510) 642-7461; Fax (510) 643-6272; or Email ophs@berkeley.edu .

Thank you for your cooperation and your commitment to the protection of human subjects in research.

Sincerely,

Jane MAULDON
Committee for Protection of Human Subjects

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

HUMAN RESEARCH CURRICULUM COMPLETION REPORT

Printed on 09/21/2013

LEARNER	Mira Elise Glaser Holthe (ID: 3188196)
PHONE	5105997988
EMAIL	miraglaser@gmail.com
INSTITUTION	University of California, Berkeley
EXPIRATION DATE	11/12/2014

GROUP 2 SOCIAL AND BEHAVIORAL RESEARCH INVESTIGATORS AND KEY PERSONNEL

COURSE/STAGE:	Basic Course/1
PASSED ON:	11/12/2012
REFERENCE ID:	9103417

REQUIRED MODULES	DATE COMPLETED	SCORE
Introduction	11/12/12	No Quiz
Students in Research	11/12/12	10/10 (100%)
History and Ethical Principles - SBE	11/12/12	No Quiz
Defining Research with Human Subjects - SBE	11/12/12	5/5 (100%)
The Regulations - SBE	11/12/12	5/5 (100%)
Assessing Risk - SBE	11/12/12	5/5 (100%)
Informed Consent - SBE	11/12/12	5/5 (100%)
Privacy and Confidentiality - SBE	11/12/12	5/5 (100%)
Research with Prisoners - SBE	11/12/12	4/4 (100%)
Research with Children - SBE	11/12/12	4/4 (100%)
Research in Public Elementary and Secondary Schools - SBE	11/12/12	4/4 (100%)
International Research - SBE	11/12/12	3/3 (100%)
Internet Research - SBE	11/12/12	5/5 (100%)
Vulnerable Subjects - Research Involving Workers/Employees	11/12/12	4/4 (100%)
Hot Topics	11/12/12	No Quiz
Conflicts of Interest in Research Involving Human Subjects	11/12/12	5/5 (100%)
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research	11/12/12	3/3 (100%)
University of California, Berkeley	11/12/12	No Quiz

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Progam course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

SOCIAL AND BEHAVIORAL RESPONSIBLE CONDUCT OF RESEARCH CURRICULUM COMPLETION REPORT

Printed on 09/21/2013

LEARNER	Mira Elise Glaser Holthe (ID: 3188196)
PHONE	5105997988
EMAIL	miraglaser@gmail.com
INSTITUTION	University of California, Berkeley
EXPIRATION DATE	

SOCIAL AND BEHAVIORAL RESPONSIBLE CONDUCT OF RESEARCH : This course is for investigators, staff and students with an interest or focus in **Social and Behavioral** research. This course contains text, embedded case studies AND quizzes.

COURSE/STAGE:	Basic Course/1
PASSED ON:	11/19/2012
REFERENCE ID:	9103418

ELECTIVE MODULES	DATE COMPLETED	SCORE
Introduction to the Responsible Conduct of Research	11/13/12	No Quiz
Research Misconduct (RCR-SBE)	11/13/12	4/5 (80%)
Data Management (RCR-SBE)	11/13/12	5/5 (100%)
Authorship (RCR-SBE)	11/14/12	5/5 (100%)
Peer Review (RCR-SBE)	11/19/12	5/5 (100%)
Mentoring (RCR-Interdisciplinary)	11/14/12	5/5 (100%)
Using Animal Subjects in Research (RCR-Interdisciplinary)	11/19/12	7/8 (88%)
Conflicts of Interest (RCR-SBE)	11/14/12	5/6 (83%)
Collaborative Research (RCR-SBE)	11/14/12	4/5 (80%)
Research Involving Human Subjects (RCR-Interdisciplinary)	11/13/12	5/5 (100%)
The CITI RCR Course Completion Page	11/14/12	No Quiz

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Progam course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
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Appendix 6

INTERVIEW PROTOCOL

Introduction of the Informant

1. Current age:
   Age when diagnosed with ADHD:
2. Can you say something about what lead to your diagnosis? (*e.g. who first thought that you could have ADHD, when, and why?*)
3. Can you describe how you felt and reacted when being diagnosed? (*e.g. surprised, sadness, shock, relief, bitterness*)
4. What did you know about ADHD in women before you got diagnosed? *And what kind of information about ADHD in women did you get from your psychiatrist, from books, from the media? What other sources of information have been important?*
5. How was your understanding of yourself and events in your life affected after you got diagnosed with ADHD? *Please elaborate.*
6. How would you describe the impact of ADHD symptoms on you and your everyday life? Which main challenges does ADHD present you with?
7. If you were to describe to someone without ADHD how it is to live with the disorder, what would you say? *(e.g. are there some 'main points' you wish people around you and/or in general, knew (more) about regarding ADHD?)*
8. What disorders/problems have you dealt with, in addition to your ADHD?
9. What is the impact of your ADHD symptoms on your academic/work life?
10. What is the impact of the condition on your social relationships (*friends, family, romantic partners*)?

ADHD in Women

11. How does ADHD affect men and women differently?
12. What are your experiences with/impressions of the public knowledge about women with ADHD?
13. *Social gender expectations:* How do you feel that your symptoms of ADHD correspond with social expectations regarding `feminine` behavior and life style, and with responsibilities often given to women?

14. Have you experienced any hormonal influences on your ADHD symptoms and/or mood in general? *(e.g. in relation to puberty, PMS, pregnancy, breast feeding, hormonal contraceptives)*
15. What problems do you experience in organizing and structuring your life? What is the impact of these problems on your daily functioning?
16. Can you say something about how you perceive and manage stress? Can you tell me about your time management skills? *(e.g., remembering scheduled activities, planning/get through your day as planned, finishing projects on time)*?
17. How would you describe the intensity of your emotional life and emotional behavior/reactions, and your degree of control of these? *Please explain/give examples.*
18. How important is it to you to be in control of everything that is happening in your life? How do you handle it when things cannot be controlled very well / what does it mean to you not to be in control?

Stigma of ADHD

19. What do you think other people think about (individuals with) ADHD, and what are the reasons for your beliefs? *(e.g. things you have read, heard, experienced etc.)*
20. How is the way you perceive yourself affected by the way ADHD is portrayed in the media etc.? *Please give examples.*
21. Do you think that ADHD receives stigma, and have you experienced stigma yourself? *Why (not), how, give examples.*
22. Who (if any) do you tell about your ADHD diagnosis? How do friends/family/partners react when you tell them? What is important for you in order to feel comfortable with telling someone about your ADHD? (*e.g. the other persons knowledge, personality, position at workplace etc)*

Positive traits, coping and mastery skills, and stories of success

23. What are your key coping strategies that help you manage your ADHD symptoms? *(Do you have faith in your own capabilities of coping with and mastering challenges? Can you give examples of how you`ve overcome difficulties in your life?)*

24. What do you consider your strengths and capabilities? *(In what situations/settings are you most aware of these, and why?)*
25. Which types of treatment, special accommodations, information, and support have helped you manage your ADHD? How have they done so? Which treatments did not help, and why?
26. What are the ways that it`s possible to live a good life with ADHD? *Explain further.*

Clarifying and closing questions

- Debriefing
- Go through the interview and ask for details/clarifications if necessary
- Is there anything you would like to add (or remove, reformulate) before we finish the interview?
- Do you feel that any topics or questions important to you were missing? If yes, would you like to say something about them?
- How do you feel after sharing your information with me (If negative thoughts and feelings should occur, what can we do to reduce them)?