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Morality, temporality and neurobiology

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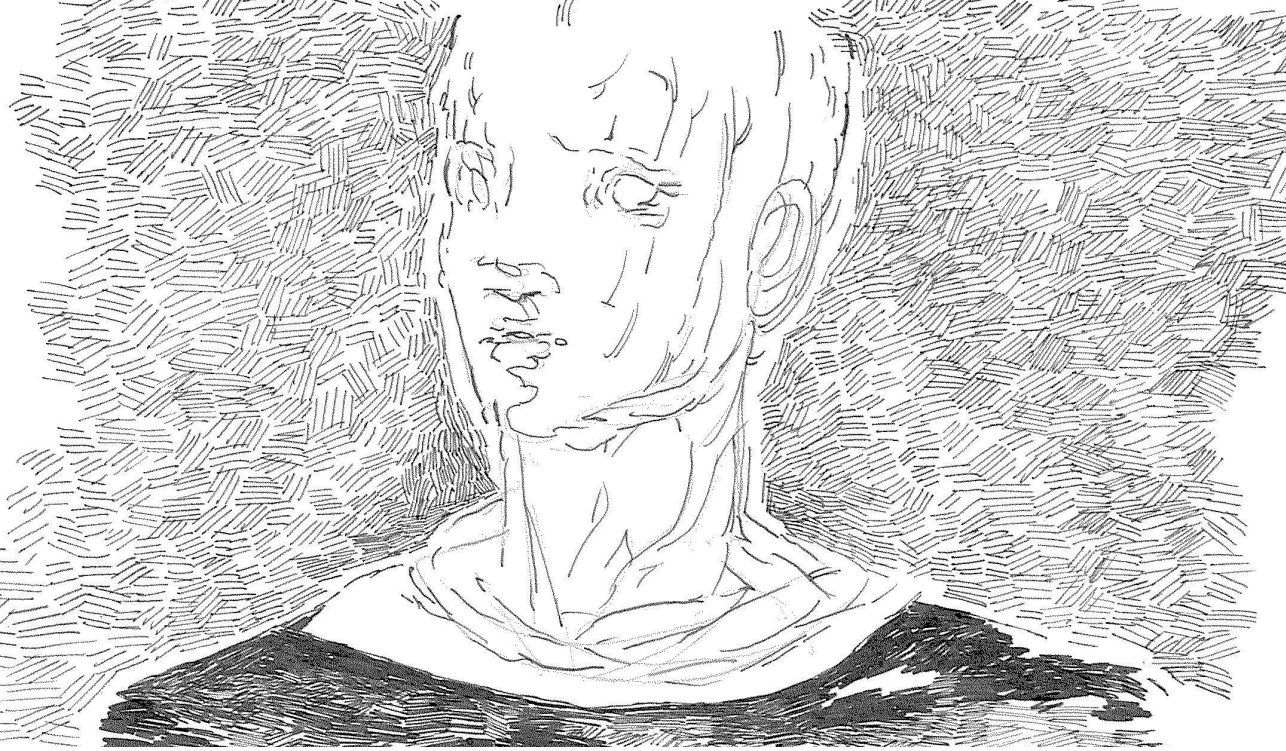
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EXPERIENCES OF ADHD IN ADULTS

MORALITY, TEMPORALITY AND NEUROBIOLOGY

**BY
MIKKA NIELSEN**

DISSERTATION SUBMITTED 2016



AALBORG UNIVERSITY
DENMARK

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MORALITY, TEMPORALITY AND NEUROBIOLOGY

by

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ENGLISH SUMMARY

This thesis is an examination of adults' experiences of ADHD. It is a study of life with ADHD, embodied experiences of ADHD, the implications of being diagnosed with ADHD, and ways of relating to the diagnosis. The number of people diagnosed with ADHD has increased within the last couple of decades and so has the number of prescriptions for drugs treating ADHD. We know, however, only little about the effects of diagnosing and about phenomenological aspects of ADHD. By analyzing how individuals experience symptoms of ADHD, interpret themselves through the diagnosis, and make use of the resources following the diagnosis, this thesis is a contribution to a limited literature on adults' experiences of ADHD.

The study is entirely qualitative. The analyses are based on data from interviews, conversations, and from time spent with 13 adults diagnosed with ADHD in adulthood (five men and eight women, ages 26-45); on observations at doctor's consultations; conferences for people diagnosed with ADHD, their relatives, and professionals working with ADHD; and finally from observations at online forums about ADHD. All research is conducted in Denmark. Following phenomenological and anthropological research on illness experiences, the study comprehends experiences of ADHD as embedded in social and cultural contexts. Hence, it is a general argument in the thesis that experiences of ADHD unfold in relation to social relationships, family struggles, cultural explanations of suffering, and contemporary expectations of being human. Within our specific culture and place in time, certain ways of being in the world and certain ways of understanding oneself are available. In this context, experiences of ADHD are intertwined with the desire of being a good parent, of wanting to navigate in society, of keeping a job, of maintaining friendships, and of being accepted.

The thesis is organized into ten parts: six chapters that set the introductory frame, three articles about adults' experiences of ADHD, and finally a conclusion.

In the first six chapters, the thesis presents different sociological, historical, and psychiatric perspectives on the emergence of ADHD as a diagnostic category, research on explanations of psychiatric diagnoses, and theories about medicalization of behavior and biologization of mental illness. A literature review of research on adults' experiences of getting an ADHD diagnosis demonstrates how being diagnosed with ADHD involves changes on the individual's self-understandings as well as ambivalence towards the diagnosis. Finally, a description of the theoretical, methodological and methodical background of the study is presented.

The first article "Structuring the self: moral implications of getting an ADHD diagnosis" examines the formative process of getting an ADHD diagnosis and how individuals diagnosed with ADHD use the diagnosis as a part of a self-evaluative

and self-constitutive project. The article illustrates how a diagnosis offers a certain narrative, into which the individual's life-trajectory is interpreted. Moreover, it is described how new everyday practices and routines are changed following the diagnosis, and how medical treatment changes the individual's way of perceiving and being in the world. These processes of understanding, making use of and experimenting with the opportunities offered by the diagnosis reflect different moral tasks, it is argued, concerning the act of taking responsibility, learning how to manage difficulties in life, and of striving to become a good parent, friend, and partner.

The second article "ADHD and temporality: a desynchronized way of being in the world" examines embodied experiences of ADHD. The article explores how to understand ADHD from a phenomenological perspective as a certain being in the world and as a matter of phenomenological difference in rhythm. It is argued that people with ADHD experience time differently than others, and when inner time accelerates in relation to outer time, a desynchronization occurs. This situation of desynchronization may result in discomfort and experiences of social clashes. The article emphasizes the intersubjective and intercorporeal aspects of ADHD and it is suggested that ADHD is not only an individual phenomenon, but symptoms of ADHD appear in relations, clashes, and interactions.

The third article "My ADHD and me: identifying with and distancing from ADHD" examines how individuals diagnosed with ADHD relate to ADHD. The study presents two positions of how people diagnosed with ADHD understand themselves and their actions based on neurobiological explanations of ADHD. The first position involves identifying with ADHD as a way of being human and a specific way of managing (and failing to manage) life based on certain neurological structures in the brain. The second position involves distancing from ADHD by separating the self from ADHD, transferring ADHD into an entity, explaining ADHD as caused by neurochemical impulses, and disclaiming behavior connected to ADHD. Lastly it is discussed how the neurobiological explanation of ADHD reduces comprehensions of how to live with ADHD and options for coping with the difficulties ADHD brings about.

DANSK RESUME

Denne afhandling er en undersøgelse af voksnes erfaringer med ADHD. Det er et studie af livet med ADHD, kropslige erfaringer med ADHD, implikationer af at blive diagnosticeret med ADHD og måder at forholde sig til diagnosen på. Antallet af mennesker diagnosticeret med ADHD er steget voldsomt de seneste årtier, og ligeledes er antallet af recepter på medicin til behandling af ADHD steget. Vi ved imidlertid ganske lidt om effekterne af at blive diagnosticeret og om fænomenologiske aspekter af ADHD. Gennem analyser af hvordan mennesker oplever at leve med symptomer på ADHD, hvordan mennesker fortolker sig selv gennem diagnoser, og hvordan mennesker gør brug af de ressourcer, der følger med en diagnose, bidrager denne afhandling til en begrænset litteratur om voksnes erfaringer af ADHD.

Afhandlingen er et kvalitativt studie af erfaringer med ADHD. Analyserne er baseret på data indsamlet via interviews, samtaler og samvær med 13 voksne diagnosticeret med ADHD i voksenalderen (fem mænd og otte kvinder i alderen 26 til 45 år), via observationer foretaget ved lægekonsultationer, på konferencer for mennesker diagnosticeret med ADHD, deres pårørende og professionelle, der arbejder med ADHD, og endelig via observationer foretaget i internetfora om ADHD. Al dataindsamling er foretaget i Danmark. I tråd med fænomenologiske og antropologiske undersøgelser af lidelseserfaringer er forståelsen i dette studie, at erfaringer med ADHD er indlejret i sociale og kulturelle kontekster. Et overordnet argument i afhandlingen er således, at erfaringer med ADHD udfolder sig i relation til sociale relationer, familieproblematikker, kulturelle forklaringer af lidelse og normative forventninger til mennesket. Der eksisterer særlige måder at være i verden på og særlige måder at forstå sig selv på i vores specifikke samtid. Ud fra dette perspektiv er erfaringer med ADHD forbundet med ønsket om at være en god forælder, kunne navigere i samfundet, kunne varetage et job, bevare venskaber og blive accepteret.

Afhandlingen er organiseret i ti dele: seks kapitler, som danner en overordnet ramme, tre artikler om voksnes erfaringer med ADHD og til sidst en konklusion.

I de første seks kapitler præsenterer afhandlingen forskellige sociologiske, historiske og psykiatriske perspektiver på opkomsten af ADHD som diagnostisk kategori, forskning om psykiatriske diagnoser og teorier om medikalisering af adfærd og biologisering af psykiske lidelser. En litteraturgennemgang af forskning om voksnes erfaringer med at få en ADHD diagnose demonstrerer, hvordan diagnosticeringen både medfører forandringer på individets selvopfattelse og ambivalens over for diagnosen. Endelig præsenteres en beskrivelse af det teoretiske, metodologiske og metodiske udgangspunkt for afhandlingen.

Afhandlingens første artikel "Structuring the self: moral implications of getting an ADHD diagnosis" undersøger, hvordan det er en formativ proces at få en ADHD diagnose, og hvordan mennesker diagnosticeret med ADHD anvender diagnosen som en del af et selvevaluerende og selvkonstituerende projekt. Artiklen illustrerer, hvordan en diagnose tilbyder et særligt narrativ, inden for hvilket individets livsforløb kan fortolkes. Ligeledes bliver det beskrevet, hvordan nye hverdagspraksisser og rutiner forandres i tiden efter diagnosticeringen, og hvordan den medicinske behandling forandrer individets måde at opfatte og være i verden. Artiklen argumenterer for, at den måde som voksne forstår, gør brug af og eksperimenterer med de muligheder, som diagnosen tilbyder, involverer forskellige moralske opgaver i forhold til at tage ansvar, at lære at håndtere vanskeligheder i livet, og til at stræbe efter at blive en god forælder, ven og partner.

Afhandlingens anden artikel "ADHD and temporality: a desynchronized way of being in the world" studerer kropslige erfaringer af ADHD. Artiklen undersøger ADHD fra et fænomenologisk perspektiv som en særlig måde at være i verden og som et udtryk for en fænomenologisk, rytmisk uoverensstemmelse. Der argumenteres for, at mennesker med ADHD oplever tid anderledes end andre, og at en form for desynkronisering opstår, når indre tid accelererer i forhold til ydre tid. Denne situation af desynkronisering kan resultere i ubehag og en følelse af sociale sammenstød. Artiklen betoner de intersubjektive og interkropslige aspekter af ADHD og foreslår, at ADHD ikke udelukkende er et individuelt fænomen, men at symptomer på ADHD opstår i relationer, sammenstød og interaktioner.

Afhandlingens tredje artikel "My ADHD and me: identifying with and distancing from ADHD" undersøger, hvordan mennesker diagnosticeret med ADHD forholder sig til ADHD. Studiet præsenterer to positioner, ud fra hvilke diagnosticerede med ADHD forstår sig selv og deres handlinger – begge baseret på neurobiologiske forklaringer af ADHD. Den første position involverer en identifikation med ADHD som en særlig måde at være menneske og måde at fungere (og mislykkes) i livet baseret på særlige neurologiske strukturer i hjernen. Den anden position består i en distancering til ADHD ved at adskille selvet fra ADHD, transformere ADHD til en entitet, forklare ADHD som forårsaget af neurokemiske impulser og frasige sig ansvaret for adfærd knyttet til ADHD. Til sidst diskuteres, hvordan den neurobiologiske forklaring af ADHD begrænser alternative måder at forstå, leve med og håndtere vanskeligheder forbundet med ADHD.

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CHAPTER 1. A PH.D. PROJECT ABOUT EXPERIENCES OF ADHD

“I am hyper on my speech” Karen says as on the first things when I meet her. Karen is 45 years old and was diagnosed with ADHD at 41. She has agreed to be interviewed by me about her experience of living with ADHD, how symptoms of ADHD affect her everyday life, and what changes the diagnosis has brought about. Karen is an enthusiastic storyteller, and just as she told me, Karen speaks from the moment I switch on my digital recorder till we say goodbye four hours later. From east to west, from one incident to another, and from yesterday’s laugh and back to some of the darkest times in her life, Karen takes me on a tour into her experiences of ADHD. Sometimes Karen loses track of her story and I need to remind her where she started, but my interview questions are almost unnecessary as Karen honestly, figuratively and humorously introduces me to her life with ADHD, a diagnosis she was given after numerous doctor appointments and nights of speculations. Karen has struggled most of her life: in school, with her family, and at work. She has never kept a job for a longer period of time, and she has been in more relationships than most people, she tells me. Karen’s story whirls me into a life of disappointments when expectations from other people have not been met, when misunderstandings have ruined relations, and when family fights have torn her to pieces, but it also tells me about a life of managing to keep a family together against all odds and about a life where she is slowly finding her footing.

I had just started my Ph.D. project a couple of months before I interviewed Karen, and since ADHD was still an unexplored field for me, I asked her how she would explain what ADHD is to someone who does not know about the diagnosis. The picture she painted of ADHD as a clash of expectations and a life of constant challenges has stuck with me throughout this project: “It’s like approaching a candy vending machine, putting a dollar in it, and pressing ‘Daim’ [chocolate bar]. And then you expect a Daim to snarf, but instead a boxing glove comes out, ‘boing,’ giving you a box on the ear.” To Karen, ADHD is about being different, about following a different logic, and about acting and speaking differently – and occasionally being knocked out for it. She once attended a seminar hosted by the Danish ADHD Association, where a presenter talked about speaking ADHD’ish, and she was thrilled to finally meet someone expressing so clearly what she had always believed: that she was somehow speaking another language. Life with ADHD is a constant encounter with clashes and misunderstandings when different ways of thinking and acting collide. Sometimes she manages to fit in and live up to the expectations of others. “I seem calm to you, right? But I can damn right promise you, I’m not,” Karen says, explaining how she twists her legs around the legs of the chair and keeps her arms crossed in front of her chest in order to keep herself restrained. “The whole body is locked.” She knows that her restless movement,

when she tries to ease her “craving for being hyper” is disturbing to others, and thus instead of moving her legs and fidgeting with her hands, she limits her cravings for movement by locking her body. At other times, life hits her like a boxing glove. Karen has the courage of her own convictions, and sometimes she stands firm on her way of doing things differently, unaffected by the consequences. Then she knows the boxing glove will hit. But occasionally, the boxing glove comes out of the blue.

Karen has always felt different from her peers, but only after her daughter was diagnosed with ADHD and Karen started reading about the diagnosis, did she realize why. Karen was in the middle of a dramatic and evaluative time in life when she was diagnosed and she was struggling to hold her family together and keep custody of her children. “I was tearing down and building up my life and I was reaching the point of being stuck, something needed to be done, but what the heck was I supposed to do?” After being rejected by several doctors who explained her difficulties as existential problems, Karen finally got the ADHD diagnosis. Karen describes herself as someone who has always developed strategies in order to manage her difficulties, but at this time in life, she needed new strategies. The diagnosis became the help she was longing for and it helped her understand herself in new ways. Medication following the diagnosis is a great help that gives her “calmness and breaks for me to learn,” and consultations (financed by herself) at a psychologist, who specializes in ADHD, helps her “because he puts things in to words.” “A handicap,” Karen tells me, “is when you don’t understand, when the surroundings don’t understand, and when no one is trying to explain.” The diagnosis is the explanation that mitigates the handicap. It does not eliminate every experienced problem, but it helps you understand the clashes of everyday life and develop strategies for limiting conflicts and experiences of failure.

Karen’s story is one of 13 life stories about ADHD I have listened to as part of this Ph.D. project. All the stories bear unique lives in them and ADHD plays a particular role in these 13 lives. A small glimpse into Karen’s story about ADHD illustrates elements of why and how some handle their problems through the help of a diagnosis and elements of what changes a diagnosis brings about. In this thesis, I examine different aspects of adult life with ADHD, embodied experiences of ADHD, the implications of being diagnosed with ADHD, and ways of relating to the diagnosis.

1.1. ASKING QUESTIONS AND FRAMING THE PROJECT

How can we understand experiences of racing thoughts, the head speeding, chaotic thinking, and bodily sensations of electricity running through the limbs? Experiences of thoughts jumping from subject to subject: from a friend in kindergarten, through reflections of a proper cemetery plot, and to the daily newspaper’s story about the first Danish astronaut in space? The American psychiatric association characterizes experiences like these as ADHD (Attention-

Deficit/Hyperactivity Disorder); it categorizes ADHD as a neurodevelopmental disorder; and it describes the disorder as comprising symptoms of inattention, hyperactivity and impulsivity. In large numbers, people are diagnosed with ADHD and adults increasingly receive the diagnosis that was previously considered a diagnosis for children. But how do individuals experience getting an ADHD diagnosis as an adult, and how is the diagnosis understood, used and acted upon? Examining questions about the bodily experiences of what we call ADHD and the experiences of getting the diagnosis is the purpose of this thesis. It is an attempt to delve into the phenomenology of ADHD and unfold experiences of a highly debated diagnosis from a first-person perspective and it is an attempt to understand these experiences within the context of our time, culture and ways of understanding the human being. ADHD is a complex phenomenon and a relatively new psychiatric diagnosis, and to understand what symptoms of ADHD feel like, why a growing number of people are diagnosed, why some people wish to be diagnosed, what explanatory force the diagnosis entails, and how it is received by the diagnosed, we need to address ADHD from multiple angles. In this thesis, my aim is to offer three different perspectives that each illustrate aspects of experiences of ADHD. Each perspective is presented in one of three articles, which form the main analytical arguments of the thesis.

The first perspective concerns *morality*. It examines experiences of getting an ADHD diagnosis and the moral implications following the diagnostic process. I argue that the process of being diagnosed entails different moral tasks such as creating meaningful self-narratives, crafting new skills, and experimenting with self-evaluation practices.

The second perspective is about *temporality*. It examines embodied experiences of ADHD and offers an analysis of ADHD as a rhythmic phenomenon. I explore how to understand ADHD from a phenomenological perspective as a certain being in the world – or more specifically, as a matter of a phenomenological difference in temporal experience and rhythm.

The third perspective deals with *neurobiology*. It examines how individuals diagnosed with ADHD explain and relate to ADHD and the implications of understanding ADHD as a brain disorder. I argue that my informants relate to ADHD by balancing between positions of identifying with and distancing themselves from ADHD – both positions drawing on neurobiological explanations of ADHD.

I wish to focus on stories about life with ADHD, about experiences of struggling with a chaotic mind and a restless being and about getting an ADHD diagnosis that describes these experiences. Hence, when studying experiences of ADHD, I refer broadly to a variety of experiences of ADHD, including both experiences of living with symptoms of ADHD and experiences of getting the ADHD diagnosis. Research

on adults' experiences of ADHD is limited (Andersen, 2009; Halleröd, Anckarsäter, Råstam, & Scherman, 2015; Young, Bramham, Gray, & Rose, 2008), and considering the amount of psychiatric literature on psychopharmacological treatment, prevalence and neurological aspects of ADHD and of sociological literature on medicalization and the emergence of ADHD as a diagnostic category, the lack of research on how people experience living with ADHD is striking. We know very little about the effects of diagnosing and phenomenological aspects of ADHD as a way of experiencing and being in the world. I hope this thesis can remedy this lack and contribute to reducing the imbalance in research on ADHD.

My analyses are based on data from interviews, conversations, and from time spent with adults diagnosed with ADHD (in adulthood). I have been invited into the homes of my informants and they have shared their life stories with me. They have explained me about life with ADHD and the process of receiving a diagnosis, and they have challenged me on my tentative ideas throughout the research process. Some of them have even invited me to join them at consultations with their doctor. I have also gathered data from observations at official conferences for both people diagnosed with ADHD and their relatives and professionals working with ADHD. Finally, I have followed different online forums about ADHD and kept myself updated on popular media coverage of the diagnosis. Attending the conferences has taught me about the official explanations for ADHD and ideas about coping with ADHD and discussions on the online forums have given me insights into the interests of people diagnosed with ADHD who use these forums for exchanging views and ideas. All data was collected in Denmark, but since the increased number of those diagnosed with ADHD in Denmark reflect a phenomenon that is spreading in most western societies, the context of my study includes larger cultural, medical, and scientific tendencies and practices.

The study is entirely qualitative. It takes a qualitative stance, as psychologist Jeanna Marecek (2003) describes as the characteristic of qualitative inquiry. Doing research that this way involves more than using specific techniques for collecting data, since it also entails a certain approach to the production of knowledge. What characterizes qualitative inquiry, according to Marecek, is how the researcher embeds the study in its historical, societal, and cultural context; resituates the informants in their social location; regards the informants as reflexive, meaning-making and intentional actors; and brings forward one's role as a researcher in the research process (Maracek 2003). Likewise, my methodological ambition is to examine experiences of ADHD as contextually shaped and to acknowledge my own stance as a researcher in the analysis and presentation of these experiences.

1.2. WHY STUDY EXPERIENCES OF ADHD?

There are various reasons why studying experiences of ADHD is relevant. Firstly, and most importantly, literature on experiences of ADHD is surprisingly limited, and especially literature on adults' experiences is almost non-existent, as pointed out in the section above. Researchers argue that diagnoses are far from only doctors' tool in clinical practice, but people actively engage with the diagnostic descriptions, interpret their symptoms through the diagnostic vocabulary, and turn to their doctor in search of a particular diagnosis (Brinkmann, 2016; Conrad, 2007; Hacking, 2007; Jutel, 2011). Hence, diagnoses not only function as entries for treatment and resources, but also as carriers of explanations and self-understandings. The voices of the people being diagnosed, however, are rarely examined, and there is an immense quest for research on first-person perspectives on living with a diagnosis in general and with ADHD in particular.

Secondly, the number of people being diagnosed with ADHD has been increasing rapidly since the diagnosis first entered the diagnostic manuals and so has the number of prescriptions for drugs treating ADHD. According to the Danish Health Data Authority, the number of people acquiring prescriptions for drugs treating ADHD in Denmark has increased from 2,901 people in 2002 to 35,554 people in 2011, corresponding to a 1,125 % increase (Statens Serum Institut, 2012). In particular, adults are representing a larger number in the statistics. While almost no adults were diagnosed with ADHD in 2001, 3,000 adults were registered as diagnosed with ADHD ten years later, and only within a three-year period, from the end of 2009 till the end of 2012, the number of adults receiving pharmaceutical treatment for ADHD has doubled (Statens Serum Institut, 2013). According to often-referenced psychiatrist Russell Barkley, prevalence studies of adult ADHD are few and the results are not clear, but estimates from longitudinal studies of the percentage of persistence of ADHD in children into adulthood show that the prevalence is approximately 3.3-5.3 of the adult population (Barkley, Murphy, & Fischer, 2008, p. 17).

Thirdly, ADHD receives great public attention. ADHD is treated in TV shows, in newspapers, and it is heavily debated among professionals and laypeople. The dramatic rise in prescribed Ritalin and other central nervous stimulants has hit the popular media, and headlines as the following has brought massive attention to the diagnosis: "New shock numbers: 38,000 are taking ADHD medication¹" (Ritzau, Politiken April 14th 2013) and "Explosion: Adults on ADHD medication has increased twentyfold²" (Cuculiza & Weber, Metroexpress, February 22nd 2016). In 2014, the headline "Non-treated ADHD costs nearly 3 billion kroner each year³" reached almost every Danish newspaper, the captions referencing a big research

¹ In Danish: Ny (sic) choktal: Nu får 38.000 ADHD-medicin

² In Danish: Eksplosion: Voksne på ADHD-medicin tyvedoblet

³ In Danish: ADHD koster ubehandlet 3 mia. kroner om året

project funded by The Rockwool Foundation, a big independent research foundation, which estimated a massive reduced tax income due to, among other things, difficulties keeping a job and risks of committing crime among people with un-treated ADHD (Rockwool Fonden, 2014). In January 2016, The Danish Council of Ethics⁴ launched a so-called ethical theme dealing with diagnoses focusing especially on ADHD, depression, and functional disorders. Other ethical themes from the council include abortion, euthanasia and cloning, but this specific theme raised questions about power relations, social services, stigma, and explanations for suffering. Based on workshops with invited professionals and patients, the council formulated selected ethical dilemmas in regards to diagnosing and even if the outcome of the project might not reach the broad public, the attention from the Council of Ethics illustrates how psychiatric diagnoses and ADHD have gained attention from authoritative institutions in Denmark. A TV show that managed to raise a lot of public attention was the program “Denmark on drugs,⁵” which critically portrayed the, according to the program, alarming increase in the Danes’ consumption of drugs prescribed for psychiatric diagnoses. A famous stand-up comedian diagnosed with ADHD hosted the program and revealed how he stopped taking drugs due to dramatic side effects. The program received 180 complaints from viewers who criticized the one-sided angle on pharmaceuticals and especially the coverage of antidepressants, but generally, the program reflected the massive attention towards psychiatric diagnoses and pharmaceuticals. A whole range of other programs, such as “That’s the crazy mind,⁶” “Mad or normal,⁷” and “Dad, mom and ADHD⁸” followed, all dealing with mental illnesses including ADHD.

Controversies over ADHD and questions about legitimacy, stigmatization, and medical treatment in public debates have aroused my interest in ADHD as a phenomenon, but it has also strengthened my curiosity towards everyday experiences of ADHD. While critics of ADHD and stories about the dramatic numbers of drug prescriptions often attract headlines in the media, the people diagnosed with ADHD share their experiences, frustrations, and hopes in parallel forums online, with their doctor, friends and families, and they hardly ever hit the headlines. I believe these experiences deserve more public and academic attention in order to nuance the debate about the increasing diagnosing of ADHD.

⁴ According to its webpage, The Council of Ethics is established “to provide the Danish Parliament, official authorities and the public with ongoing advice and information about ethical problems raised by developments within the national health service and the field of biomedicine” (etiskraad.dk).

⁵ In Danish: Danmark på piller

⁶ In Danish: Sådan er det skøre sind

⁷ In Danish: Gal eller normal

⁸ In Danish: Far, mor og ADHD

1.3. RESEARCH LAUNCH PAD: THE DIAGNOSTIC CULTURE RESEARCH PROJECT

My involvement in the Diagnostic Culture research group at Aalborg University has been significant for the development of my research throughout the process. The group has been a safe place for juggling ideas and receiving inputs and constructive critique, and the discussions within the group have guided my thinking. The overall ambition of the Diagnostic Culture project is to investigate the high prevalence of psychiatric diagnoses, using depression and ADHD as representatives of the expansion of psychiatric diagnoses. The research project asks if the increasing numbers of diagnoses are signs of genuine epidemics or if they reveal an immense pathologization of normal human behavior and sensations. By using a three-angled research strategy, the group wishes to contribute to the current discussion about psychiatric diagnoses. In the project's description, it is outlined that we wish to study:

- 1) How adults experience the process of receiving these diagnoses [depression and ADHD], and what it means for them to have their experience of suffering filtered through a diagnostic and psychiatric vocabulary;
- 2) How depression and ADHD are constituted in public discussions in media, films and television;
- 3) How these diagnostic categories have emerged and developed historically to become influential in many people's self-understanding (dc.aau.dk).

The intention of the project is to chart what we call a diagnostic culture, and my initial part in the group was to concentrate on ADHD and contribute to examining angles 1 and 2 and only briefly angle 3. I started collecting articles from newspapers and searching for ADHD in the public media. Presupposing that public discourses about ADHD affect adults' perceptions of ADHD and hence their experiences of getting the diagnosis, my aim was to examine not only media discourses but also how my informants positioned themselves in relation to the portrayals of ADHD in the media. Within half a year, a huge pile of articles rose on my desk with mostly critical articles in the Danish newspapers commenting on ADHD as a trending diagnosis and the rise of prescriptions for ADHD medicine. However, quite early on I realized that a discourse analysis of ADHD entailed some difficulties. Firstly, as I started interviewing people diagnosed with ADHD, I found that these stories could easily take up a whole Ph.D. project and I wanted to give them my full attention. Secondly, my supervisor became an influential voice in the public debate about psychiatric diagnoses, and to study the current debate would unavoidably be partly a study of our own research. That the work of the group appeared in the public debate did not make a discourse analysis entirely impossible, but in order to focus on my primary interest, which was individuals' experiences with ADHD, I chose to cut out the discourse analysis. The ambition of analyzing the interplay between individual

experiences and society, though, is still part of my project as part of the Diagnostic Culture project.

When I joined the Diagnostic Culture research group in 2013, it had already been working as a group for half a year and a first article was in preparation. This article, as well as the book “Diagnoser: perspektiver, kritik og diskussion”⁹ (Brinkmann & Petersen, 2015), which was published in 2015, contains a definition of a diagnostic culture. Pointing to the rising numbers of diagnoses in the psychiatric manuals; the use of diagnoses in other institutional settings than the psychiatric system when assigning social services; the growing number of people receiving psychiatric diagnoses; and the change in people’s perceptions of suffering that is increasingly interpreted through diagnostic categories, the concept diagnostic culture provides a “diagnosis of the culture and a cultural analysis of the diagnoses” (Brinkmann, Petersen, Kofod & Birk, 2014, p. 692, my translation). A diagnostic culture is “characterized by the circulation of psychiatric diagnoses and categories that not only professionals (doctors, psychologists, psychiatrics etc.), but also by laypeople and the public use in order to understand life problems and human deviance within many different social practices” (p. 693, my translation). Even in magazines diagnostic tests appear and TV series often portray characters with different psychiatric diagnoses. The diagnostic language infiltrates everyday language when we talk about being depressed, when we are sad or disappointed, being schizophrenic when we are having mixed feelings about something, and being manic when we are eagerly occupied with a task. Besides diagnosing our contemporary time and culture as a diagnostic culture and analyzing the historical and societal context for the development of such a diagnostic culture, the concept also involves an inherent critique of the pervasiveness of the diagnostic gaze. While the diagnostic language and the diagnostic comprehension of human suffering and deviance spreads, other ways of understanding the human being (social, existential, moral, religious etc.) become less influential and the overall palette of understanding but also importantly addressing human suffering narrows (p. 393).

My motivation for working with ADHD stemmed from my academic interest in the development of new psychiatric diagnoses and how diagnoses spread throughout history and within societies from my time as a student in medical anthropology. I was, however, even more interested in gaining insight into personal experiences of living with a psychiatric diagnosis and the possibility of examining a phenomenon as ADHD that is clearly situated in the midst of personal experiences and cultural practices and perceptions of the human being. The Diagnostic Culture project was my base and my initial entry into the field of ADHD, but along the way, I also realized that I needed to find my own path and academic standpoint in the group and that I had to balance between being critical of the medicalizing and pathologizing processes that were presented in the majority of the literature we were reading and discussing in the diagnostic culture research group (at least to begin with). This was

⁹ In English: Diagnoses: perspectives, critique and discussion

also a question of doing justice to my informants' stories as well as their common acceptance and great relief of receiving an ADHD diagnosis. I found it important that these stories were the foundation for my analyses and I wanted my informants to be able to recognize themselves in my text if they were ever interested in reading it. To use the critical literature and the discussions within the diagnostic culture group as my research launch pad became my strategy as I started to move into the complex jungle of restlessness, inattention, hopes, disappointments, and experiments connected to living with ADHD and getting an ADHD diagnosis.

1.4. AN ANTHROPOLOGICAL APPROACH TO ADHD

Medical anthropologists have pointed to the biological, cultural, and sociopolitical factors that underpin different illnesses (Lock & Nguyen, 2010) as well as to the medical reasoning that shapes experiences of illness (Good, 1994a). "In every culture, illness, the response to it, individuals experiencing it and treating it, and the social institutions relating to it are all systematically interconnected" (Kleinman, 1980, p 24), anthropologist and psychiatrist Arthur Kleinman states. Kleinman has had a massive impact on the emergence of medical anthropology as a field in his illustration of how beliefs about sickness, behavior exhibited by sick persons, expectations about treatment, and responses from practitioners (what he calls the clinical reality), are socially constituted (Kleinman, 1980, p. 38). From his fieldwork in Taiwan and China, Kleinman has demonstrated how individuals experience, exhibit and express symptoms differently across cultures and he emphasizes the need for having a contextual approach to illness. As a medical anthropologist, I follow Kleinman's way of understanding individual suffering and illness experiences as socially constituted, and that available resources, languages and treatments form the basis of how individuals and societies perceive illness. Pointing to the increasing psychiatric diagnosing of different types of suffering and to laypeople's use of the diagnostic language in everyday conversations, the Diagnostic Culture research project wishes to examine some of the many mechanisms that form our (western) ways of understanding mental illnesses. Hence, what makes the study of experiences of ADHD interesting from an anthropological perspective is the complexity and the social dimensions of illness and how individuals engage with and are shrouded in cultural understandings of illness. Even when studying experiences of ADHD, aspects of diagnostic practices and available treatment, conceptions of morality and responsibility are entangled with the individual's experiences of ADHD.

An anthropological study of ADHD could, however, naturally have taken many different directions. Anthropologists Nancy Scheper-Hughes and Margaret Lock (1987) point to three different perspectives from which the body may be studied, and a similar analytical differentiation can be used when studying ADHD. Examining the social body "referring to the representational uses of the body as a natural symbol with which to think about nature, society, and culture" (p. 7), could have

focused on ADHD as a symbol of the sick body representing a sick society; and studying the political body "referring to the regulation, surveillance, and control of bodies" (p. 7), could have addressed questions of medicalization and disciplining of the body when diagnosing and prescribing central nervous stimulants. My research, though, focuses on the individual body, "understood in the phenomenological sense of the lived-experience of the body-self" (p. 7) and the individual's experiences of living with ADHD. However, as Schepher-Hughes and Lock describe, the three approaches intersect and studying individual experiences of suffering implicitly equals studying the surrounding social and cultural norms and practices (p. 31). Societal changes have brought about transformations in the cultural idioms for communication of discontent, and traditional ways of expressing suffering are being replaced by a psychiatric understanding of human distress, Schepher-Hughes and Lock stress (p. 26). Similarly, the Diagnostic Culture project describes the mechanisms of how the diagnostic understanding of suffering has spread into layperson's vocabulary and self-interpretations. My aim in this Ph.D. project is to examine individual experiences of ADHD, shaped by and acted upon in a diagnostic culture. By investigating cultural explanations for ADHD, moral responsibility and moral crafting of the self, and intersubjective and phenomenological aspects of ADHD, I wish to contribute to the anthropological literature on illness with analyses of one of the most debated psychiatric diagnoses today.

1.5. ADHD AS EXPERIENCE AND DIAGNOSTIC CATEGORY

Throughout this thesis, I use the term ADHD to describe my informants' experiences of restlessness, speeding thoughts, inattention and what they portray as symptoms of ADHD as well as when I refer to the diagnostic category. I will elaborate on the psychiatric definition of ADHD specifically in chapter 2 and on anthropological perspectives on illness experiences more generally in chapter 4, but an initial explanation of my use of the term ADHD might provide some clarification.

I use the term ADHD instead of the term Hyperkinetic Disorder, which is ICD's¹⁰ term for symptoms of inattention and/or hyperactivity. Officially, Denmark follows the ICD's manual when diagnosing, but ADHD, which is a DSM-5 term, is widely used: It is used in guidelines from the Danish Health Authority, the Danish patient association calls itself The ADHD Association, all the official conferences I have attended refer to ADHD, the media talks about ADHD, and most importantly, my informants use the term ADHD. Since ADHD is used in any corner of the field I examine, I use the term ADHD as well.

Sometimes I write "what we call ADHD today" to underline the fact that ADHD is a contemporary term that defines and describes a specific set of symptoms in a specific time, but I have no intentions of deconstructing the diagnosis and I consider

¹⁰ ICD is WHO's standard diagnostic classification system.

ADHD to be real in the same sense as anthropologist Emily Martin describes bipolar disorder as real: namely, that the reality of the disorder “lies in the cultural contexts that give particular meanings to its oscillations and multiplicities” (Martin 2007, p. 29). Professionals, the public, and people experiencing the set of symptoms included in the diagnostic criteria all describe this phenomenon as ADHD, and they attribute certain characteristics to this description. Therefore, following the tradition in anthropology of using emic concepts, I use the term ADHD when I describe what my informants are suffering from. Martin uses the phrase “living under the description” of the diagnosis in order to reflect that people are given a diagnosis and she calls attention to the fact that the diagnosis is only offering one description of a person (2007). The phrase is useful to underline that ADHD is inscribed upon individuals based on certain criteria, which a phrase such as “people with ADHD” does not indicate. However, I prefer to use the phrase “people diagnosed with ADHD” when specifying that the individual is given a diagnosis to avoid what I perceive as an inferior position when talking about living *under* a description. From a stigmatization perspective, to be *diagnosed* with a diagnosis could have the same connotations as above, but since diagnoses are no longer only put on individuals, but are often demanded from people and perceived as a resource, I find this phrase more neutral.

All the people I have interviewed were diagnosed with ADHD when I met them, which means they already relate to the diagnosis and interpret their experiences through the diagnostic descriptions in different ways. Therefore, to separate illness experiences and the diagnosis is complicated if not impossible (a more detailed elaboration of the relation between illness experiences and the diagnosis will be dealt with in chapter 5). I examine ADHD as a certain being in the world and by that I recognize that the ADHD diagnosis covers a specific way of experiencing. I believe that the people I have interviewed suffer from many of the same problems and that these problems should be acknowledged and addressed. Experiences of illness are distributed along a qualitatively defined continuum and it is not a question of either-or but rather to what degree people experience symptoms of a particular diagnosis (Hvas, 2015; Jenkins, 2015). Whether the ADHD diagnosis and the following treatment is the right solution for people experiencing symptoms related to ADHD are not the focus of this thesis, but I pragmatically recognize ADHD as a diagnosis that describe certain behavior and sensations and that people relate to and interpret themselves through the diagnosis.

1.6. STRUCTURE OF THE THESIS

The thesis is structured into ten chapters. It has been a continuous experimental process to do this project and my thoughts and writings have taken many directions. This thesis is a product of that process and it is my ambition to communicate both my findings and the messy way that has led me to these findings. I present the different paths I have taken even if they led me to dead ends or were impossible to

follow – not to excuse the results of the choices I have made, but because I believe transparency about the process forms the best basis for assessing and critiquing what is written. In that way, this thesis is a collective description of the research process. Every person I have met: informants, professionals, and colleagues, are part of my data. They constitute what I have explored and how I have interpreted what I have met. I have been guided by all the different settings I have taken part in, and every process of my research has carried new opportunities and thoughts with it. The main contributions of this thesis are the three articles that each present different aspects of experiences of ADHD, but hopefully a description of the context to and the underlying premises for writing the three articles, provides a useful framework for reading and evaluating the articles.

In chapter two I introduce ADHD as a diagnostic category and outline psychiatric, historical, and sociological perspectives on what ADHD is and how the diagnosis has emerged historically.

Chapter three entails an introduction to relevant literature on explanations of psychiatric diagnoses, theories about the biologization of mental illness, and how we as individuals respond to being diagnosed.

Chapter four presents a literature review of existing studies of adult's experiences of getting an ADHD diagnosis, which reveals both advantages and disadvantages of being diagnosed with ADHD, and I position my research in relation to this literature.

Chapter five is where I account for my theoretical and methodological background. I clarify what I mean by the concept of experience and how I position my project within a phenomenological framework. I also present a theoretical perspective on the dynamics between individual experiences and diagnoses that have informed my research.

Chapter six contains a description of my fieldwork: how I recruited my informants; considerations about whose voices are represented in the project; a description of the sites for my observation studies; and how I have conducted my interviews. Finally, some of the ethical considerations in relation to my project are discussed.

Chapter seven consists of my first article about experiences of ADHD where the aspect of *morality* is analyzed. The article illustrates how getting a diagnosis is not only a clarifying process but also a formative process that shapes the diagnosed in certain ways. The process involves different moral tasks such as creating meaningful self-narratives, crafting new skills and experimenting with self-evaluation practices.

Chapter eight presents my second article, which deals with the aspect of *temporality*. Here I examine ADHD as impairment in the sense of time and a matter of a

phenomenological difference in rhythm. The article explores how to understand ADHD as a certain being in the world that is constantly out of sync.

In chapter nine I present my third article and last contribution to the investigation of experiences of ADHD, which is about the role of *neurobiology*. I examine how brain processes and mechanisms are perceived as causes of ADHD, and how people diagnosed with ADHD use this neurobiological explanation in different ways when relating to the diagnosis.

Chapter ten concludes the study. I outline the arguments and contributions in the thesis and point to avenues for future research on experiences of ADHD.

CHAPTER 2. A STORY OF ADHD AND MEDICALIZATION

One of the first tasks I decided to tackle after entering this project was to acquaint myself with literature on psychiatric diagnoses in general and on ADHD in particular and with research outlining the development of the DSM manuals and how comprehensions of mental illnesses have changed over the past 50 to 60 years. I wanted to know how ADHD became an official diagnostic category and understand the premise behind current discussions about the status of psychiatric diagnoses. The literature demonstrates different portrayals of ADHD, and while reading book after book about psychiatric diagnoses, I realized that I was moving into a field of complexity and controversies between disciplines' readings of how to understand ADHD. The heavy debates over ADHD are not only presented in the media, I learned, but the academic literature on ADHD likewise represents very different approaches to ADHD.

In this chapter I present relevant studies on developments in psychiatry, different explanations of the emergence of ADHD, and research on medicalization of behavior. The area of the review lies in an intersection between research traditions within psychiatry, sociology, history, and psychology, and illustrates in different ways how mental illness must be understood within its scholarly, social, historical and cultural context. I start the chapter, however, with a short introduction to the psychiatric definitions of ADHD and the official recommendations for diagnosing and treating ADHD in Denmark.

2.1. DIAGNOSTIC CRITERIA AND CLINICAL PRACTICE

ADHD is listed in the American Psychiatric Association's manual DSM-5 (The Diagnostic Statistical Manual, fifth edition published in 2013). The diagnosis is defined by symptoms of inattention, hyperactivity, and impulsivity and patterns of behavior are characterized as failure to pay attention to details, difficulty organizing tasks and activities, excessive talking, fidgeting, and inability to remain seated in appropriate situations. Criteria for getting the ADHD diagnosis is a positive response to a list of elaborate symptom descriptions such as: "often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities," "often fidgets with or tap hands or feet or squirms in seat," is "often 'on the go,' acting as if 'driven by a motor,'" or "often blurts out answers before questions have been completed." At least six (five for adolescents and adults) of the listed symptoms for inattention and hyperactivity-impulsivity respectively need to be present to a degree that is maladaptive and inconsistent with developmental level and the symptoms need to have persisted for at least six

months. Another fundamental criterion is the presence of the symptoms causing the impairment before the age of 12. Furthermore, the specific behavioral difficulties need to be present in multiple settings and there must be clinical evidence of significant impairment and performance issues in social, educational, or work settings (APA, 2013). The biggest change from the diagnostic descriptions of ADHD from DSM-IV to DSM-5 is the explicit inclusion of adults. Previous editions of DSM did not provide guidelines for diagnosing adults specifically, but as APA writes: “by adapting criteria for adults, DSM-5 aims to ensure that children with ADHD can continue to get care throughout their lives if needed” (APA, 2013). Hence, when introducing the DSM-5, diagnosing adults was officially authorized.

According to the clinical guidelines for diagnosing adults offered by the Danish Health Authority, diagnosis is given based on a questionnaire completed by the patient and a thorough interview with patient and relatives, both addressing experienced problems during childhood and adulthood. Anamnesis should contain systematically collected information about the individual’s development and psychiatric symptoms and accompanying difficulties from early childhood till adulthood and possibly substance abuse. Moreover, information about the individual’s health, social, and economic status and educational and occupational background should be collected (Sundhedsstyrelsen, 2015). In order to collect the preferred information, the tool ASRS (Adult ADHD self-report scale), a questionnaire that “in a structured way collects self-reported information about the patient’s symptoms” (p. 15, my translation), is recommended for initial assessment. Diva 2.0, which is a “semi structured interview guide (...) that systematically collects information about the patient’s symptoms” (p. 16, my translation), is recommended. The Danish Health Authority recommends treatment with methylphenidate or lisdexamfetamine, both central nervous system stimulants. According to the guidelines, evidence shows an effect on ADHD symptoms and functional capacity from pharmaceutical treatment and despite reports of unwanted side effects the advantages of the treatment are assessed to exceed the disadvantages (p. 23). If the patient is considered to benefit from it, medical treatment is combined with cognitive behavioral therapy. Psych education is listed as good practice (p. 41).

My informants describe very different experiences with the diagnostic process. While some were put through several tests and questionnaires, others describe the diagnostic process as a ten-minute conversation with a psychiatrist. Some were encouraged to bring relatives to the consultation while others were not. Only a few were offered additional treatment to the pharmaceutical treatment in the form of group therapy or psych education, but all were prescribed some type of drug.

2.2. A STORY OF ADHD AS AN EVER-PRESENT DISORDER

Scholars remain divided over the legitimacy of ADHD and while some scholars view ADHD as a genuine disorder with a long history others consider the diagnosis

as a form of social control. I will present both sides of the story of ADHD, starting with the first reading of ADHD as a disorder that can be traced back in history.

According to psychiatric scholars, behavior connected to what we call ADHD today is described as identified in children over the last couple of centuries, and books about ADHD tell an almost identical story of how different physicians have observed symptoms of hyperactivity in children throughout the history of childhood behavioral disorders. In the following section, I will outline the most common descriptions of how the history of ADHD is told. My intention is not to determine whether or not symptoms of ADHD have always existed, but rather to use this historical overview to illustrate how ADHD is commonly perceived as having emerged as a diagnostic category and how symptoms of what we call ADHD today have been treated throughout the last couple of centuries. Through changing medical discoveries and comprehensions of and explanations for deviant behavior, a review of the history of ADHD contributes to an understanding of how we have come to think about ADHD today or what Edward Comstock (2011) calls the proliferation of the “ADHD subject” and it illustrates the close-knit link between how we conceive this type of behavior and conceptions of how it should be treated.

2.2.1. THE INCAPACITY OF NECESSARY ATTENTION

In 1798, physician Alexander Crichton published three books on his clinical observations of mental illness, including the chapter “On Attention and its Diseases” (Lange, Reichl, Lange, Tucha, & Tucha, 2010, p. 242). Crichton expatiated on the nature of attention and the morbid alteration of attention, which he found in both children and adults (Crichton, 1798/2008). From personal observations, he identified what he called “incapacity of attending with a necessary degree of constancy to any one object” (p. 203). The people mentioned were easily distracted by extraneous stimuli and were incapable of keeping attention, they felt a mental restlessness and had “the fidgets” (p. 203). Uncommon at that age, Crichton took a medical and physiological approach to mental derangement issues and asserted that inattention was caused by an unnatural morbid sensibility of the nerves that a person was either born or that was caused by an accidental disease (p. 242). Hence, inattention was for the first time described in the literature as a pathological phenomenon – an understanding that has dominated both medical spheres and the general public since then. Whether Crichton actually described what we today call ADHD is debated and his research is only included in part of the literature about the history of ADHD. Firstly, Crichton did not mention hyperactivity in his accounts meaning that a comparison to ADHD can be criticized for being retrospectively strained and secondly, Crichton’s reflections on inattention are difficult to ascertain today as they are based on unspecified personal experience (Barkley, 2008, p. 206). Nevertheless, Crichton made some interesting deliberations on the etiology of inattention disorders that now, more than 200 years later, are still relevant in the comprehension of ADHD.

2.2.2. CHILDREN SUFFERING FROM IMMORALITY

While some consider Crichton to be the first to describe early symptoms of ADHD, others claim that the identification of hyperactivity, inattention and impulsivity in children, and a conceptualization of the symptoms as a medical phenomenon, has its roots in the early years of the last century. At that time, the behavioral sciences were influential and for the first time psychiatrists linked a kind of behavior that was never before subject to scientific knowledge to a medical discourse (Comstock, 2011, p. 48).

Doctor George F. Still is widely known as the first pediatrician who described children with abnormal incapacity for sustained attention and a distinctive fidgetiness. Still was interested in childhood diseases and was publishing and performing several lectures about his findings, including the most well-known series “Some Abnormal Physical Conditions in Children” from 1902. In these lectures, Still described his clinical observation of 20 deviant children who had all committed crimes or repeatedly transgressed moral boundaries and how he found that these children all had deficiencies in volitional inhibition. From his studies, Still was stunned by how these children repeatedly maltreated and inflicted pain on other children without feeling regret or were thieving needless things without any efficient motive. It seemed, Still noticed, that punishment did not have any deterrent effect, as the children could commit the same misdemeanor within a few hours after the punishment (Still, 1902/2006, p. 130). While the children’s behavior could be interpreted as symptoms of imbecile behavior this particular kind of behavior was not caused by intellectual shortage, according to Still. The differentiation between children suffering from mental retardation and the children from his observations was a central concern in his lectures and he repeatedly emphasized that these children were not necessarily less intelligent than other children of the same age. Instead Still concluded that the children were suffering from immorality or a “defect of moral control” (p. 130) defining moral control as “the control of action in conformity with the idea of the good of all” (p. 126). Hence, the children’s lack of moral control was due to “the overpowering of one stimulus to activity – which in this connexion is the activity contrary to the good of all – by another stimulus which we might call the moral idea, the idea of the good of all” (p. 127). Still did not consider this lack of moral control as an individual shortcoming, but rather a biological defect caused by a failure in development (Mayes & Rafalovich, 2007, p. 438). In a time influenced by evolutionary thinking and eugenics, Still was inspired by the contemporary currents and hypothesized that the moral ineptitude and failure in development was in accordance with the phenomenon of evolution. Following this evolutionary approach, moral control was regarded as the very highest product of mental evolution and a morbid limitation of moral control was therefore thought of as a developmental defect. Despite his insisting on biological and morbid causes for the children’s condition, Still was not suggesting medical treatment to the children but instead a careful training involving environmental accommodations since “moral

control can only exist where there is a cognitive relation to environment” (Still 1902/2006, p. 127). This relation to the environment needed to be strengthened so the children could develop their moral consciousness in order to be able to act within moral conformity.

Still’s focus on morality and the children’s constant violation of moral codes – as a discrepancy between the child and the environment – is still relevant in discussions of ADHD. Furthermore, Still identified some characteristics of the inattentive children that we still recognize today: namely that there is an element of heredity to the specific behavior, that the inattentiveness becomes visible between the ages of 7-12, that there is a marked overrepresentation of boys and that the children’s memory tended to be affected in a negative way.

2.2.3. MINIMAL BRAIN DAMAGE AND ANTI-SCHOOL BEHAVIOR

Another leading expert on mental impairment, Alfred F. Tredgold, who was conducting clinical observations of children with attention and concentration difficulties, was also explaining these children’s deviant behavior with a moral developmental deficiency. Tredgold introduced the term “minimal brain damage” (MBD) and was thereby following Still’s conviction that the children’s difficulties did not stem from character flaws or lack of discipline but from physiology (Mayes & Rafalovich, 2007, p. 438). According to Tredgold, the children suffered from an organic abnormality on the higher levels of the brain and he thus made a pioneering link between behavior and neurological impulses (p. 440). Tredgold and his medical research colleagues proposed many hypotheses as to what caused the impairment in the brain. Among other explanations, an epidemic of encephalitis lethargica in 1922 was thought of as causing neurological damages as clinicians began to encounter children with symptoms of impulsiveness, hyperactivity and irritability - similar symptoms to Still’s observations (p. 441). Tredgold was raising an essential awareness of how brain damages caused behavioral disturbances though he did it in light of evolutionism: shrouded in evolutionary thinking, he argued that the areas of the brain where the sense of morality was located were products of recent evolution and therefore more susceptible to damage (p. 440). That explained why the children were afflicted by their morality.

What is interesting about Tredgold’s findings today is his pointing towards the school as a revealing setting for the specific hyperactive and inattentive behavior. According to Tredgold, the children exhibited “anti-school behaviour” (p. 439), as the children’s shortcomings were most noticeable when the children were subjected to school demands. The argument about how the symptoms of today’s ADHD stay unnoticed until demands of education exposes them are widely acknowledged. Moreover, the linking of behavior and neurological impulses in the brain still dominates thinking about ADHD today.

2.2.4. A QUESTION OF NEUROLOGY: THE RISE OF MEDICAL TREATMENT

Many psychiatrists thereafter followed Still's and Tredgold's interest in children's inattentive and transgressive behavior. But the cluster of symptoms was not defined as a diagnostic category until 1957 when psychiatrist Maurice Laufer presented the diagnostic label "hyperkinetic impulse disorder" for children with an "organic drivenness" (Mayes & Rafalovich, 2007, p. 442). Laufer was employed at the Bradley home, a neuropsychiatric hospital for neurologically impaired children and headed by the psychiatrist Charles Bradley. The pediatricians at the home regarded the children's difficulties as a conflict in emotional development caused by anomalies in the structure of the central nervous system. In the early 1930s, a neurosurgical remedy in the form of a spinal tap was performed on some of the children as an experimental treatment but the quite drastic surgical procedure turned out to cause severe headaches (Mayes & Rafalovich, 2007). In response to surgery Bradley started clinical experiments in 1937 with the amphetamine Benzedrine on the so-called "problem children" showing restlessness, hyperactivity and distractedness. Bradley's research demonstrated how the children receiving the drug showed a decrease in their symptoms: they were not running around but behaving quietly, they lowered their voices, they did not rush into offensive discussions in the same manner, and they generally exhibited more "subdued behavior" (Bradley, 1950, p. 24). Another positive effect of Benzedrine was a "dramatic acceleration of their academic progress" (p. 25) and Bradley noticed that Benzedrine in its elimination of unwanted behavior was serving as a kind of performance optimizing drug. Suddenly drugs were not only used for curing diseases, but also for controlling specific behavior. However, the drug was only addressing the deviant behavior and not the psychological subject, Bradley believed, and Benzedrine did not change the children's character and the emotional conflict that caused the specific behavior but only the symptoms thereof (Comstock, 2011, p. 52).

With Bradley, it became practice to prescribe medications to children in order to regulate behavior and reduce the children's mind-addling disturbances. The professional view on the effect of the drugs changed during the 1950s from regarding drugs as a way to balance the children's behavior with the surrounding social norms to a genuine understanding of drugs as not only adjusting behavior, but also actually treating disorders (p. 53).

2.2.5. THE DSM-ERA

By the 1960s, the term MBD was challenged and accused of being speculative, since no solid empirical data could validate if organic lesions in the brain were the actual cause of the behavioral pattern of children exhibiting poor attention and hyperactivity. Instead focus shifted to behaviorally defined syndromes based on observations of children (Lange, Reichl, Lange, Tucha, & Tucha 2010, p. 251). The

DSM has included different versions of the diagnostic category. In 1968, DSM-II coined the label “Hyperkinetic reaction of childhood” and the concept of hyperactivity was incorporated in the official diagnostic classification manuals for the first time. In 1980, DSM-III renamed the disorder “attention deficit disorder” (ADD) and emphasis changed from hyperactivity towards inattention – a symptom that also showed the best response to stimulant treatment (p. 252). Hyperactivity, though, was included in a revised version of DSM-III and the diagnosis “Attention deficit hyperactivity disorder” (ADHD) was introduced in DSM-III-R in 1987. DSM-IV continued with the term ADHD, and the idea that ADHD was not exclusively a child disorder was tentatively presented in DSM-IV, as it included examples of workplace difficulties in the diagnostic descriptions. However, not until the release of DSM-5, as previously noted, did the diagnostic description explicitly present a diagnostic description for adults.

2.3. A ONE-SIDED STORY OF ADHD?

The above history of ADHD tells us a story of pathologization of certain patterns of behavior, and the development of a diagnosis based on contemporary perceptions of illness and treatment. Behavior that was not previously treated within the medical field was suddenly considered as pathological and requiring treatment. In spite of changing medical perspectives, similarities between the different categorizations of behavior and explanations are noticeable: The question of whether the disorder is caused by brain mechanisms has been persistent, and even if the MBD hypothesis was abandoned and focus shifted to observations of behavioral patterns, the assumption that a brain dysfunction causes the behavior exists in different versions among researchers and clinicians throughout the history of ADHD (Timimi & Leo, 2009, p. 2). Further, the tradition of prescribing stimulants to children with behavioral problems started years before the ADHD diagnosis was established, even if it did not become regular practice before Ritalin entered the market in the 1960s (Smith, 2013, p. 43). The idea that the children’s problematic behavior is caused by a dysfunction in the brain can be traced back to both Bradley and Still. Today, theories about hyperactivity and inattention seem to follow some of the same ideas about the dynamics between behavior, brain mechanisms and medical treatment: ADHD is a neurobiological disorder, because drugs are the most effective treatment, and drugs not only treat symptoms, but address the brain mechanisms that produce the symptoms (Comstock, 2011, p. 66).

Some researchers critique the story of ADHD for being selective, putting too much emphasis on specific types of behavior and leaving out factors that might tell a different story of the children in question in order to legitimize current conceptions of ADHD. According to historian Matthew Smith (2013), the stories of hyperactivity follow a similar pattern in the description of hyperactivity because they share the same purpose, which, according to Smith, is “to depict hyperactivity as a genetic and neurological condition that has been ever-present in humans and has

little to do with the social environment” (p. 23). A certain story about ADHD is told in order to verify that what we call ADHD today has always existed and to reject the position that ADHD as a diagnosis is a product of social and cultural conceptions of what is considered deviant. Moreover, Smith claims, the history “fits into the broader notion that modern medicine is a progressive, ever-improving enterprise” (p. 44). Instead, Smith advocates for a more nuanced historical analysis that contributes to the discussion of whether what we call ADHD today has always existed as problematic behavior or if the diagnosis is a product of our time and specific social arenas and medical regimen. Smiths’ historical analysis of ADHD is elaborated in the following section among other analyses of why the number of ADHD diagnoses has been increasing over the years.

2.4. A CRITICAL EXPLANATION OF ADHD

The world’s struggling children diagnosed with various psychiatric diagnoses are like canaries in a coalmine, teacher Chris Mercogliano (2009) writes in his analysis of children diagnosed with ADHD. The children’s behavior and suffering witness a polluted environment, in which diagnoses and medical treatment become the answer, and we need to recognize their so-called symptoms as reactions of distress and not as evidence of a neurological pathology, Mecogliano states. In this section, I present some of the critical literature on psychiatric diagnoses, diagnostic practices, pharmaceutical treatment, and medicalization of behavior.

2.4.1. MEDICALIZATION OF SOCIETY

Sociologist Peter Conrad is widely known and referenced for his thoughts on what he calls medicalization of society. Conrad (2007) points to the fact that the number of life problems defined as medical problems has increased immensely and he asks if there is an epidemic of medical problems; if the medical practice is better at identifying and treating already existing problems; or if a whole range of life’s problems are being diagnosed and subjected to medical treatment despite the dubious evidence of their medical nature (p. 3)? In Conrad’s analysis, the answer to the question lies in medicalization, which is “a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders” (p. 4). Diagnoses increasingly demarcate what is expected and acceptable and what is considered pathological, and behaviors and emotions that were once defined as immoral, sinful, or criminal, are now being diagnosed as medical problems, transferring them “from badness to sickness” (p. 6). Different drivers for medicalization can be identified, Conrad argues, but especially social movements and patient organizations, and not the least the pharmaceutical industry, have played a significant role in medicalization, promoting, and advocating for specific diagnoses (p. 134). Both group have an interest in medicalizing certain conditions for either the benefit of legitimization and access to resources or profit from selling drugs and they mutually support each other in their errand. The

American advocacy group CHADD (Children and Adults with Attention Deficit Hyperactivity Disorder), comprising patients and relatives, has become a strong supporter for diagnosing ADHD and for treating the disorder with pharmaceuticals. The organization, however, is supported financially by the pharmaceutical industry, and it is no secret that CHADD receives support from Novartis, the manufacturer of Ritalin (p. 139).

The main problem with medicalization, Conrad claims, is “its transformation of many human differences into pathologies” (p. 148). Medicalization narrows the range of what is considered acceptable and “diminishes our tolerance for and appreciation of the diversity of human life” (p. 148). Furthermore, medicalization locates the source of the problem in the individual rather than in his or her social environment and thereby “calls for individual medical interventions rather than more collective or social solutions” (p. 8). The individualization of social problems “obscure the social forces that influence well-being” (p. 152), and by expanding the medical jurisdiction, medicalization “increases the amount of medical social control over human behaviour” (p. 8), Conrad argues.

2.4.2. SOCIAL, POLITICAL, AND CULTURAL FACTORS BEHIND THE EMERGENCE OF ADHD

As briefly described above, two general stories about ADHD figure in the literature about the diagnosis. One is the story of how hyperactivity has been identified in children throughout the last couple of centuries; the other is the story of ADHD as emerging in a specific context in which political, environmental, and social factors have created conditions that either produce certain behavior or under which certain behavior becomes the focus of professional attention.

Smith is one of the researchers writing about what he calls “the controversial history of ADHD” (2012). Smith offers a historical account of hyperactivity and reveals how complex factors have come to shape our understanding of ADHD and the treatment thereof and why the increase in ADHD diagnoses happened during the post-war period. According to Smith, the rivalry between the USA and the Soviet Union, and the political climate following it, produced circumstances for ADHD to emerge. Fearing that the Americans were losing ‘the brain race’ against their rivals, new initiatives needed to be taken in order to improve the educational performance of the American population (p. 54). Whatever obstacle interfering with the goals of educational achievement was considered threatening to the overall aim of winning the race against the USSR, and politicians, educators, and researchers started analyzing where to deploy resources. The answer was the children. The post-war period had experienced a baby boom and overloaded classrooms together with a shortage of good teachers creating what Smith refers to as a crisis in education (p. 57). To meet this challenge, new educational strategies were developed. Education became the battlefield where the race was to be won and the relatively newly

established reform pedagogy was replaced by a stricter pedagogy that required great discipline (p. 60). Moreover, the school counselor entered the classroom in order to help the teacher identify children who were struggling academically and disturbing the lessons and subsequently referring the children to a psychiatrist for diagnosis and treatment (p. 55). These factors collectively created an educational milieu where hyperactivity, impulsivity, and inattention became associated with academic underachievement and intellectual shortcomings, thereby representing the fearful thought of the US lagging behind. Children's behavior became an important focus area, and with the increasing use of pharmaceutical drugs, the answer was obvious. The role of Ritalin, which Smith also points to in his analysis of the emergence of ADHD, will be dealt with in the following section.

Another critic of the neurobiological explanation for ADHD is psychiatrist Sami Timimi. Based on a review of the critical literature on ADHD, Timimi (2009) sets up two possible explanations for the increase in ADHD diagnoses: either there has been a real increase in ADHD-type behavior, which has led to greater scrutiny and concern about the behavior; or there has not been a real increase in ADHD-type behavior, but rather we have come to think about and deal with children's behavior differently. An interaction between both explanations might give a clearer picture of the causes for the increase in ADHD diagnoses, Timimi proposes, and we should therefore investigate these tendencies more intensely (p. 134).

Firstly, environmental factors play a crucial role. Like Smith, Timimi points to changes in the educational system, but emphasizes new teaching methods focusing on self-regulating and the highly stimulating environment in the classroom as key components for why children who have problems with organizing and attention are struggling under the new circumstances in school. Standard tests are introduced in class and energetic activities such as music and gym have been set aside, resulting in increased pressure on children's ability to concentrate on academic tasks¹¹ (Timimi, 2009, p. 139). Moreover, there has been a moral panic about boys underperforming in school, and whether or not boy's underachievement is a consequence of what some refer to as a feminization of the school that favors girls' behavior; there is a noticeable gender gap in ADHD diagnoses (p. 150). Similarly, Rosenfeld and Faircloth (2006) describe what they call "medicalization of boyhood" (p. 134) when explaining why boys comprise the majority of children diagnosed with ADHD. On the domestic front, Timimi argues, children are increasingly exposed to television and computers and a general "domestication of childhood" (Timimi, 2009, p. 138) has happened throughout the last couple of decades. Together with nutritious changes where processed food has brought significantly higher rates of sugar, saturated fat, and salt into children's diets, children's physical and mental health suffers. The growing literature investigating the link between dietary interventions

¹¹ In Denmark, the new primary school reform from 2013 includes more physical activities in school, and the inactive teaching model might be changing.

and reductions in symptoms of ADHD, however, show divergent results and the connection remain unclear (p. 136).

Secondly, Timimi points to changes in how we think of children's behavior and the role of parenting as a factor in the ADHD epidemic. As the state has become continuously more interventionist in family life, parents are more aware of their children's behavior and tend to leave guidance of the children to the expertise of professionals (p. 141). The so-called mother-blaming discourse accusing failed motherhood for children's deficiencies might also explain why mothers have actively demanded psychiatric diagnoses for their children, thereby transferring the cause from parenting skills to neurobiological causes (p. 148). Generally, patients have become more engaged in the diagnostic process and more demanding when it comes to demands for a diagnosis, Conrad (2007, p. 46), similarly claims.

Lastly, Timimi directs focus towards psychiatry and the pharmaceutical industry. According to Timimi, the number of psychiatric consultants in the UK has more than doubled in the past two decades and a similar increase in prescriptions to psychiatric patients are written (Timimi, 2009, p. 147). The pharmaceutical industry supports both patient activist groups and doctor's seminars at popular vacation sites, and the role of the industry in the emergence of new diagnoses should not be underestimated, Timimi argues (p. 145). Furthermore, the search for quick-fix solutions in the form of diagnoses and pharmaceutical treatment reflects a general societal attraction to technological advances that apparently make life easier, and in that respect, drug treatment fits in perfectly with our craving for efficiency and accuracy (p. 151). Family therapist Marilyn Wedge (2015) presents a similar analysis, criticizing the American psychiatrists for over-diagnosing and over-medicating children and drawing attention to France, where children are not equally diagnosed with attention disorders. According to Wedge, alternative guidelines for diagnosing together with strict parenting strategies explain "why French kids don't have ADHD," as she writes, and her analysis points to how culture within both family structures and medicine foster different circumstances for ADHD to spread.

2.4.3. RITALIN ON THE MARKET

Throughout the critical literature about ADHD, Ritalin is described as a central factor for the emergence of ADHD. Conrad (1976) even proposes that a cynical reading of the history of medicalization might be that "the label was invented to facilitate the use of a particular social control mechanism, in this case psychoactive drugs" (p. 15), and science journalist Robert Whitaker (2010) accuses the pharmaceutical company that produces Ritalin for misguiding their consumers when telling them that children with ADHD are suffering from low dopamine levels. The reason, Whitaker argues, that parents were told this story is because Ritalin stirs neurons to release extra dopamine, and the company therefore had great interest in promoting the theory of ADHD as a consequence of low dopamine levels (p. 77). By

identifying the mechanisms of a particular drug, the company transformed research about the effects into a theory of impairment, Whitakers states. Notwithstanding the level of cynicism, researchers point to the fact that Ritalin played a crucial role in the rise of the neurobiological explanation for hyperactivity. Because the drug promoted ADHD as a neurological problem and not an issue of improper parenting or unhealthy environments, parents and others involved in the children's development welcomed the drug. Parents got a legitimate explanation for their children's behavior, doctors got a concrete tool for treatment, and Ritalin thereby had the ability to generate a positive clinical encounter between patient, parent, and psychiatrist (Smith, 2013, p. 122).

Smith describes how Ritalin was first marketed for different conditions such as obesity, narcolepsy and depression, but its real success started when it was introduced as treatment for ADHD (p. 107). The company manufacturing Ritalin marketed the drug heavily in publications and films and they even organized meetings for parents and teachers about hyperactivity (p. 116). The advertisements were not only directed at doctors, they also spoke to parents¹² when infusing hope for getting happier and much calmer children. An advertisement from a medical journal in the 1970s illustrates Smith's point: On the one side is an angry boy, playing with a wooden toy, which he has torn apart. With teeth clenched and eyes closed, the boy is pictured unhappy, and the image is blurred as if the camera could not keep up with his movements. On the other side of the page, the child is much calmer, reading a book, and looking relaxed and quiet. Above the first picture, a caption states "how children with minimal brain dysfunction may be 'aggressive, destructive, easily frustrated' and 'can't concentrate'" (p. 101), while the second picture similarly has a caption declaring "how 'it may be that stimulants act on higher (cortical) centers of the brain and thereby "stimulate" greater conscious awareness'" (p. 101).

Researchers in neuroanatomy and social work respectively, Jonathan Leo and Jeffrey Lacasse (2009) also point to the link between the introduction of Ritalin and especially the advertising of the drug and the dramatic rise in the number of children diagnosed with ADHD. From the webpage ritalinla.com¹³, hosted by a pharmaceutical company, Leo and Lacasse found the text: "Studies show that the brains of children with ADHD may function differently than those of other children. These children may have an imbalance of chemicals in the brain that help to regulate behaviour" (p. 291). Another text informs us that: "While the specific cause has not been confirmed, brain imaging research using a technique called magnetic resonance imaging (MRI) has shown that difference exist between the brains of children with and without ADHD" (p. 289). Leo and Lacasse notice that radiological images of

¹² Smith's example is taken from an American context; DTCA (direct-to consumer-advertisement) is not legal in Denmark.

¹³ Leo and Lacasse found the texts on the webpage in 2008. From my browsing through the webpage in spring 2016, I found no similar text.

the brain have been used for marketing ADHD medications and that the consumers interpret the images as documenting a definable and visible neuropathological abnormality. The neuroimaging studies, however, “are plagued by a significant confounding variable” (p. 289), Leo and Lacasse argue, and like the theory of altered biochemistry of the brain is both complex and contested, parents and other recipients of the advertisements are not necessarily aware of the scientific reservations of the research. While the medical literature shows conflicting results and is based on a continuous questioning of its results, the advertisements portray the research in a simplistic way that leaves the consumer to think that evidence for the biological aspects of ADHD are unambiguous and clear (p. 308). Proponents of these kinds of advertisements directed at the consumers might propose that the advertisements increase disease awareness and therefore raise general public health and according to Leo and Lacasse, patients actually increasingly bring their concerns about potential symptoms to the doctor after seeing these advertisements (p. 287). The result of more people searching for answers to their experienced problems within a medical context, however, is that more people are getting the available answers within this context.

2.4.4. DIAGNOSING ADULTS WITH ADHD

How did ADHD, which for years was deemed a disorder of childhood, become a diagnostic category that also includes adults? Conrad (2007) describes what he calls a “diagnostic expansion,” entailing the process of how “once a diagnosis is established, its definition, threshold, or boundaries can be expanded to include new or related problems or to incorporate additional populations beyond what were designated in the original diagnostic formulation” (p. 47). Hence, the identification of ADHD in adulthood is a product of including new problems into a diagnostic category, and while childhood ADHD was a product of medicalization of behavior, adult ADHD is a consequence of medicalization of underperformance, Conrad argues (p. 64).

A combination of media portrayals of ADHD, popular books about adult ADHD, and lay organizations and the pharmaceutical industry’s advocacy for adult ADHD explains the proliferation of adults being diagnosed with ADHD. In the 1990s, popular books about ADHD in adulthood reached out to a big audience. In 1993, the self-help book “You Mean I’m not Lazy, Stupid, or Crazy?! A Self-Help Book for Adults with Attention Deficit Disorder” by Kate Kelly and Peggy Ramundo described how an ADHD diagnosis could bring a shift in responsibility among adults. The following year, Thom Hartman (1994) published his book “Attention Deficit Disorder: A Different Perception,” in which he, within a sociobiological framework, associates ADHD with an evolutionary adaptation to the environment and links ADHD to the quality of prehistorical hunting skills. That same year, Edward Hallowell and John Ratey’s book “Driven to Distraction” became a

bestseller. The two authors draw on their own experiences of living with ADD and promise their readers that life with ADD can be successful. They write:

The best way to think of ADD is not as a mental disorder but as a collection of traits and tendencies that define a way of being in the world. There is some positive to it and some negative, some glory and some pain. If the negative becomes disabling, then this way of being in the world can become a disorder. The point of diagnosis and treatment is to transform the disorder into an asset (Hallowell & Ratey 2005, p. xxxii).

The same year, 1994, the cover of Time Magazine asked: “Disorganized? Distracted? Discombobulated? Doctors say you might have attention deficit disorder. It’s not just kids who have it” (Conrad, 2007, p. 55). After reading and hearing about the benefits of the diagnosis, self-diagnosing became a widespread practice and adults increasingly demanded an ADHD diagnosis, fuelling “the social engine of medicalization (p. 59). Simultaneously, the two actors promoting medicalization of ADHD in childhood, CHADD and the pharmaceutical industry, also advocated for ADHD in adults to be recognized. CHADD organized several conferences about adult ADHD (p. 55), and the pharmaceutical company that produces Ritalin redefined ADHD as a lifetime disorder, drawing on arguments about ADHD as a genetic disorder (p. 57). In 2002, Strattera became the first drug specifically approved and promoted for treating ADHD in adults (p. 68), and as mentioned at the beginning of this chapter, DSM-5 explicitly included adults in the diagnostic descriptions.

Conrad’s analysis shows how the diagnosis is embraced and promoted by the people who receive it and how the widespread acceptance of diagnoses stimulates a diagnostic expansion. “The lay promotion of ADHD and predominance of self-diagnosis contradict some of the basic premises of labelling theory of psychiatric diagnoses,” Conrad says (p. 67) and the proliferation of diagnoses is not only a consequence of the pharmaceutical industry trying to expand their markets, but it is also a product of the “popularization of symptoms and diagnoses” (p. 67), spread through popular media, books, and lay organizations. This development points to a fundamental shift in how we as researchers need to examine the dynamics between diagnoses and the people receiving it, how to understand both the stigmatizing and legitimizing effect of diagnoses, and how to navigate in the paradox of both seeing diagnoses as agents of social control and acknowledging that people increasingly demand diagnoses and welcome medical treatment.

2.5. CONCLUDING REMARKS

The stories of ADHD presented in this chapter illustrate the complexity of understanding what ADHD is and how ADHD has emerged as a diagnostic category. ADHD is accepted as a psychiatric diagnosis and it has been included in

the diagnostic manuals for decades. Researchers within psychiatry widely believe that ADHD is caused by impairment in the executive functioning of the brain, and some claim that behavior connected to ADHD can be traced back in history and that it was identified in children centuries ago. Not everyone, however, accepts this story of ADHD and researchers state that psychiatric diagnoses such as ADHD are not indicators of objective conditions but rather products of socio-political factors. Psychiatric diagnoses are socially and culturally situated, reflecting, and reinforcing contemporary ideas about the human in general and mental illness in particular, it is argued. The consequence of diagnosis, therefore, is also debated and while some view the diagnosis and the following treatment as a source of help for people suffering from a medical condition, others consider the diagnosis a specious and damaging label, harming people who do not fit into our narrow conceptions of normality. As noted by Smith (2013), the different explanations of ADHD are interpreted by many, ranging from Thom Hartmann (1994), who contends that hyperactive people genetically are hunters who have been left behind in modern society, to people who believe that hyperactivity is a consequence of a high-performance and drug culture, continuously demanding more of people (Smith, 2013, p. 16f). What is alarming, Smith argues, is that “most hyperactivity theorists have been stubbornly unwilling to accept that hyperactivity is a complicated concept that can be justifiably interpreted in many different ways” (p. 17). Pluralism and acceptance of various explanatory factors behind ADHD are much needed. As sociologist Nikolas Rose (2015) also points out: only few would dispute that neurological processes are involved in how we think feel, act etc. (p. 33), but we also need to understand how mental illness is a matter of a living organism in its milieu.

In this Ph.D. project, it is my ambition to embrace the pluralism in the explanations of ADHD. I pragmatically recognize that all these different explanations exist, and I take them to be equally real, as I describe in the introduction. My interest is how people make use of these different explanations and what meanings they are inscribed with when used as ways of understanding oneself as I present in the article “Structuring the self: moral implications of getting an ADHD diagnosis” and in the article “My ADHD and me: identifying with and distancing from ADHD. In the article “ADHD and temporality: a desynchronized way of being in the world,” I explore the phenomenology of ADHD as a rhythmic being in the world, and I thereby acknowledge that some people experience symptoms related to what is categorized as ADHD. That does not entail, however, that experiences of restlessness, speedy thoughts, and difficulties with attention are not shaped by cultural circumstances. Rather I consider ADHD to be a complex phenomenon that needs to be examined from multiple angles and with an understanding of its historical, political, and social context.

CHAPTER 3. PSYCHIATRIC DIAGNOSES AND BIOLOGIZATION OF THE HUMAN

We have never been more aware of the arbitrary and constructed quality of psychiatric diagnoses, yet in an era characterized by the increasingly bureaucratic management of health care and an increasingly pervasive reductionism in the explanation of normal as well as pathological behavior, we have never been more dependent on them (Rosenberg, 2006, p. 417).

So far, I have presented literature dealing with explanations of mental illness and the emergence of the ADHD diagnosis. But what is a diagnosis? What role are diagnoses playing in contemporary health care? And how is a diagnosis ‘acting’ and being acted upon? Obviously, a diagnosis is the clinician’s tool for classifying disorders and arranging treatment. As historian Charles E. Rosenberg writes in the quote above, diagnoses are fundamental for managing health care, notwithstanding the arbitrary quality of diagnoses. Similarly, Rose (2015) lists numerous ways diagnoses have come to function in our contemporary society: A diagnosis is a condition of treatment and for financial coverage of its costs; a diagnosis gives access to social services; in clinical settings, a diagnosis is a central feature of patients’ records; and for researchers, diagnoses make it possible to make estimates and predictions of incidence and prevalence (p. 18f). Besides the structuring function in institutional settings, researchers also point to how diagnoses become fundamental for people’s interpretation of themselves and their suffering or difficulties. In this section, I present different perspectives on what a diagnosis is and how a biologization of the human has changed our conception of the human being in general and of mental illness in particular.

3.1. CREATING MENTAL ILLNESS

In his book “Creating Mental Illness“ sociologist Alan Horwitz (2002) criticizes what he calls diagnostic psychiatry for not differentiating between genuine mental diseases and culturally expressions of distress. From his 25-year study of mental disorders, Horwitz identifies a change in both mental health professionals’ and patients’ comprehensions of mental illness and he directs his critique towards the publication of the DSM III, which marked a “revolution of thinking about mental illness” (p. 2). What happened with the DSM III was a change from a holistic, etiological approach to diagnosing people, often based on psychoanalytic theory, into a symptom based approach in which certain clusters of symptoms are said to indicate distinct underlying diseases, Horwitz writes. No biomarker exists for

identifying mental diseases, and psychiatry is bound to diagnose patients on the basis of clinical observations of symptoms, however, “although diagnostic psychiatry is officially agnostic about the variety of factors that lead people to develop mental diseases, the medicalized system of classification it uses emphasizes underlying organic pathologies” (p. 3). The primary problem with diagnostic psychiatry, therefore, is how “biological models seek the primary causes of mental diseases in genetic and biochemical factors and so locate the pathological qualities of psychological conditions in the physical properties of brains, not in the symbolic systems of minds” (p. 3). According to Horwitz, genuine mental diseases are “conditions where symptoms indicate underlying internal dysfunctions” (p. 15), while mental illnesses refer to “whatever a particular social group defines as such” (p. 15), and to address the two similarly is mistaken. Mental diseases such as schizophrenia, bipolar disorders and other psychoses fit the premise of a diagnostic psychiatry, since they clearly show dysfunctions in mechanisms regulating perception and thinking, but mental illnesses do not fit into the schema because of their cultural dependency (p. 13). That does not mean people are not suffering from mental illnesses, Horwitz emphasizes, but rather that they need to be understood as ontologically different than mental diseases.

The reason for the success of the diagnostic psychiatry is manifold and only by taking political, economic and social factors into consideration, it is possible to explain why the idea of specific disease entities has become so influential, Horwitz argues. In an article co-written with Rick Mayes he elaborates further on the issue: For one thing, research oriented psychiatrists needed specific cases to study and therefore embraced a system that allowed them to more clearly demarcate different mental disorders, to compare cases and to generalize beyond research sites (Mayes & Horwitz, 2005, p. 256). In the clinical room, psychiatrists needed specific categories to obtain reimbursements for their services (Horwitz, 2002, p. 74). Politically, it suited the administrative climate to focus more on specific illnesses with specific treatment options rather than on broad complex social problems (ibid, p. 77), and insurance companies increasingly demanded diagnoses and treatment that were demonstratively effective and financially accountable (Mayes & Horwitz, 2005, p. 254). Similarly lay advocacy groups, fighting for the rights of people with mental illnesses, welcomed the idea that mental illnesses are brain-based disorders caused by biological factors, since it rejected the theory that mental illness are caused by poor parenting and traumatic experiences, which has haunted families experiencing mental illness (Horwitz, 2002, p. 77). And last but not least, psychiatry was facing a major dilemma, as psychotherapy was not only growing in popularity, but also increasingly performed by psychologists who undercut them in price, and psychiatry had to decide how to demonstrate the legitimacy of their profession if they were leaving psychotherapy to other professions. The diagnostic psychiatry with its focus on neurobiology and drug treatment was the solution to strengthening psychiatry as a profession (Mayes & Horwitz, 2005, p. 257). Overall, with the DSM III, psychiatry shifted from a dynamic understanding of mental illnesses to a

biological understanding that stresses brain chemistry and drug treatment and supersedes the psychosocial understanding of mental illness that had dominated for decades.

The proliferation of mental illnesses “illustrates the spread of a medicalized disease framework to encompass many sorts of problematic psychological conditions” (Horwitz, 2002, p. 5), and too many of the conditions represented in the DSM are not mental diseases nor specific disease entities, but rather the illnesses “reflect expectable reactions to stressful conditions, culturally patterned forms of deviant behaviour, and general human unhappiness and dissatisfaction” (p. 15). People who become depressed or anxious “react in *appropriate* ways to their environments” (p. 14, italics in original), and they will not be mentally disordered if the symptoms disappear because of changes in their social circumstances. In the end, the entry of the diagnostic psychiatry, Horwitz argues, has led to an overestimating of the prevalence of mental disorders and improper treatment of people experiencing mental distress. Like Conrad (2007), who describes what he calls “diagnostic expansion,” Horwitz points to the continuous inclusion of new types of distress into the diagnostic manuals and he critiques the increasing comprehension of all kinds of suffering as caused by biological dysfunctions in the brain. As part of this argument, Horwitz points to a central concern, namely that even if people’s reactions to stress vary only slightly across time and place, the meaning people ascribe to these reactions, notions of what causes the reactions, and the help people seek to ease the suffering has changed dramatically within the last couple of decades.

In the case of ADHD, as I outlined in the previous chapter, ADHD is said to be a consequence of medicalizing of behavior and underperformance rather than a genuine mental disease. Following Horwitz, ADHD might reflect an expectable reaction to the changing conditions in modern life, as also noted by Timimi, and people experiencing symptoms related to ADHD might react in appropriate ways to the challenges they meet. If expectations in school, at work, and changes in level of activity favor certain kinds of behaving, ADHD related behavior intensifies. And if we at the same time witness a diminishing of tolerance for and appreciation of the diversity of human life, as Conrad notices, this kind of behavior becomes inappropriate and will eventually be subjected to medicalization.

3.2. PUTTING A NAME TO IT

Like Mayes and Horwitz (2005), Rosenberg (2002) describes the change in psychiatry when focus shifted from etiology to symptoms and the discipline started to understand various forms of human suffering in terms of specific diagnostic categories. From his analysis of technological breakthroughs in medical history, Rosenberg outlines the dilemma in what he calls disease specificity and the idea that idiosyncratic human beings can fit into constructed and constricting ideal-typical diagnostic categories. This disease specificity is based on the notion that diseases are

entities existing outside their manifestation in particular individuals, and the context, in which the symptoms appear, as Horwitz also states, is neglected. “It helps makes experience machine readable” (p. 257), Rosenberg notes, pointing to the standardization of experiences that diagnoses represent that transforms experiences into categories, charts, and boxes within institutions. Diagnoses function as a way of systemizing experiences in institutional settings, but diagnoses also affect the individual whose experiences are systemized. Diagnosing is “a ritual of disclosure,” when “a curtain is pulled aside, and uncertainty is replaced – for better or for worse – by a structured narrative (p. 255). What used to be diffuse bodily sensations or emotional difficulties are analyzed, categorized, and labeled within a diagnostic framework that offers a specific narrative to the suffering. Rose (2015) similarly describes how a diagnosis enables the doctor to organize the patient’s history into a treatable condition and how the diagnosis reframes troubles into an illness, thus providing a framework for understanding the past and for orienting to the future for the patient (p. 20). The built-in narrative in the diagnosis renders a much more concrete way of understanding and talking about suffering possible, and even if a diagnosis sometimes predicts a life with chronic illness, it is welcomed by many because of its ability to transform experiences into a comprehensible entity. Diagnoses have become “indisputable social actors, real inasmuch as we have believed in them and acted individually and collectively on those beliefs” (Rosenberg, 2002, p. 240). Diagnoses ‘act’ on people and despite their constructed quality, they have real, social implications.

A researcher who advocates for the development of a “sociology of diagnosis” is Annemarie Jutel (2011). Jutel argues that diagnoses are social constructions that provide “a cultural expression of what a given society is prepared to accept as normal and what it feels should be treated” (p. 3). Overall, three circumstances determine if a condition is classified as a disease and listed as a diagnosis: Firstly, it must be recognized as undesirable, secondly technology needs to be able to discern it, and lastly, a collective will to assimilate the condition into the spectrum of diseases needs to be present (p. 35). That diagnoses are constructed, however, does not mean that they are not real, but rather that their existence is bound to what is defined as problematic. In that perspective, diagnoses are concepts formed by biology, technology, the social, the political and the lived, Jutel emphasizes (p. 13). Diagnoses capture a reality despite their fluid nature of that reality, and to exemplify her point, Jutel refers to an illustrative description by Mirowsky and Ross (1989) saying that diagnoses are like star constellations in the sky. These formations are truly present, but the meaning of them is shaped by how we assemble them in recognizable patterns (Jutel, 2011, p. 61). Like constellations of stars, symptoms are linked together to create a diagnostic pattern, and “a collective cultural position determines which symptoms we will see, which we will brush off as insignificant, how we make sense of what is there, and what social consequences the diagnosis will convey” (p. 61).

While a diagnosis provides structure and distinguishes the pathological from the normal, a diagnosis also rearranges identity. From her own experience of being diagnosed, Jutel describes how the diagnosis came to play an important role in the way she understands her life and illness. The diagnosis conferred a new identity, as she, in the moment of the diagnosis, “became someone with an autoimmune disorder” (p. xii). To be that someone may remove the individual from the isolation of his or her suffering and provide the person with a new collective identity together with others suffering from the same. “Being diagnosed gives permission to be ill,” Jutel argues, referencing Talcott Parson’s notion of the sick role, and once diagnosed, the suffering person is no longer blamed for failing social expectations, but is instead treated for a disease (p. 11). A diagnosis, thus, can both stigmatize and legitimize conditions dependent on how the diagnosis is commonly perceived. As an example, people diagnosed with fibromyalgia often ambiguously welcome the diagnosis. For one part, receiving the diagnosis is relieving because it validates the suffering and gives a sense of credibility, for the other part, the psychiatric diagnosis does not cover what the patients believe to be a physical disease (p. 78). Hence, the legitimacy of the diagnosis relies on whether it corresponds with what society and the patient recognize as a legitimate disease and whether the patient accepts the narrative offered by the diagnosis. Similarly, the degree to which the diagnosis is incorporated into and rearranging identity depends on whether the diagnosis is accepted by the patient. The fact that diagnoses potentially offer identities, legitimacy, and access to resources, explains the gravity in the battle over diagnoses. As also noted by Conrad (2007), Jutel points to lay social movements’ advocacy for specific diagnoses in search for explanation and legitimization as an illustration of how diagnoses have become the center of battles not only inside psychiatry but also in society. The submissive patient has become a minority among patients pursuing diagnoses (Jutel, 2011, p. 69), and diagnoses have increasingly become the subject of negation and disputes of recognition.

As I will show in chapter 4, adults diagnosed with ADHD often welcome the diagnosis as a legitimization of their experienced problems and an official explanation of their difficulties. In research, we might point to the arbitrary construction of the diagnoses and emphasize diagnoses as pragmatic tools for treating suffering, but from the patients’ perspective, diagnoses become much more than that. As my first article: “Structuring the self: Moral implications of getting an ADHD diagnosis” will illustrate, an ADHD diagnosis brings about new ways of understanding oneself and of managing everyday practices. As noted by Rosenberg, diagnoses structure experiences by offering a specific narrative to the suffering and in this article I analyze how this structuring effect unfolds in my informants’ lives and engagement with the diagnosis.

3.3. A NEUROCHEMICAL ERA

While the theory of a chemical imbalance in the brain as the cause of mental illness has been subject to critique and is now widely rejected, a general biologization of mental illness still strongly prevails and research on ADHD also reflects a tremendous interest in the neurobiological mechanisms of the disorder. Neuroscientists are now examining subjects that traditionally have been studied from psychological, anthropological, philosophical, and religious angles and the humanities are increasingly inspired by neuroscientific knowledge about how human nature is shaped by the structure and functions of the brain (Rose & Abi-Rached, 2013, p. 1).

The question of how neurobiological knowledge changes the way we think about the human being in general and of (mental) illnesses specifically is extensively discussed within a wide range of research disciplines. The debate provokes questions about how we as laypersons engage with this type of knowledge and if it has produced a shift in everyday conceptions of the self. In an article reviewing empirical investigations of how neuroscientific knowledge affects lay understandings of personhood, psychologists Cliodhna O'Connor and Helene Joffe (2013) conclude that neuroscientific ideas become integrated in our understandings of selfhood and that especially people who have been through a diagnostic process adapt the neuroscientific knowledge. According to the review, some of the most dramatic research reveals that neuroscientific insights "will fundamentally alter the dynamic between personal identity, responsibility and free will" (Illes & Racine, 2005, p. 14); that "neuroimaging has contributed to a fundamental change in how we think of ourselves and our fellow persons" (Farah, 2012, p. 75); and that neuroscientific knowledge is "propelling humanity toward a radical reshaping of our lives, families, societies, cultures, governments, economies, art, leisure, religion – absolutely everything that's pivotal to humankind's existence" (Lynch, 2009, p. 7). O'Connor and Joffe, however, also conclude that the effect of neuroscientific knowledge on people's conception of selfhood is sometimes overestimated and that neuroscientific knowledge is assimilated into our existing social and psychological ideas about selfhood in ways that "perpetuate rather than challenge existing modes of understanding" (O'Connor & Joffe, 2013, p. 262). Other studies examining the impact of the neurobiological explanation for ADHD in public and private discourses come to similar conclusions (Bröer & Heerings, 2013; Danforth & Navarro, 2001; Horton-Salway 2011). Sociologists Christian Bröer and Marjolijn Heerings (2013) find that a neurobiological discourse dominates public discourses about ADHD in Holland, while personal discourses encompass more various descriptions of ADHD ranging from sociological to spiritual portrayals of the disorder. Researcher in discursive psychology Mary Horton-Salway (2011) finds two overall repertoires representing stories about ADHD in the UK newspapers: 1) A biological repertoire that describes ADHD as a brain disorder and justifies medical treatment for ADHD and 2) a psychosocial repertoire that support moral

judgments about poor parenting and the so-called sick society and criticizes medicalization processes for the diagnostic labeling of bad behavior. Generally, it seems that, parallel to the two main explanations for ADHD in the scientific literature on ADHD, research in public discourses likewise identifies both a position explaining ADHD as a neurobiological disorder and a position explaining ADHD as a product of social and cultural factors.

3.3.1. A SHIFT IN THINKING ABOUT THE HUMAN

Rose and Abi-Rached (2013) outline how the social sciences have shifted back and forth between a biologization and a psychologization of the human being. In the eighteenth-century's racial sciences, a biologization of the human being dominated scientific understandings of human nature, but the period was followed by an intense psychologization of the human throughout the first half of the twentieth century. And now, paradoxically, we witness a return to the biological explanation of human nature in the form of the influence of neuroscience. Horwitz (2002) makes a similar analysis, stating that "the current emphasis on the biological foundations of mental disorders is a *re-emergence* of earlier biological thinking in psychiatry" (p. 132). Especially after the second world war, the biological theories became associated with eugenic programs and reactionary political thoughts and the theories were discredited, and a period of what Horwitz calls dynamic psychiatry came to dominate psychiatric thinking (202). Moreover, the anti-psychiatry wave in the 1970s, represented in popular culture with movies like "One Flew over the Cuckoo's Nest" (1975), criticized biological psychiatry for "creating the forms of damages and disordered selfhood that it claimed to explain" (Rose & Abi-Rached, 2013, p. 113). Today, the scientific landscape has changed again, and "the study of brains and of genetics now dominates psychiatry" (Horwitz, 2002, p. 133). The accusations against psychiatry, however, have not gone silent and researchers such as Whitaker (2010), psychiatrist David Healy (2012), and in a Danish context Peter Gøtzsche (2015), critique the pharmaceutical industry for doing more damage than good and for incorrectly explaining mental illnesses as consequences of a chemical imbalance in the brain. But generally, a "regime of futurity" (Rose & Abu-Rached, 2013, p. 14), in which science wishes to govern the future, prevent illnesses, and tackle the burdens of mental disorders, has come to form our way of thinking.

So what does this neurobiologization of the human entail? Rose and Abu-Rached claim that non-conscious neural processes are considered as constituents of moral action and that especially researchers and professionals working with mental health consider the brain as a target of self-improvement (p. 219). The concept of the brain's plasticity, however, is central. Since we know that the brain is plastic, we acknowledge that "human brains are both shaped by and shape their sociality" (p. 22) and the neurobiological understanding of selfhood has not eliminated or rejected psychological understandings of selfhood, but the two approaches exist concurrently. Knowing that the brain is plastic and is shaped by its sociality, we are

expected to take moral responsibility for nurturing and optimizing it in the best possible way (p. 223). The brain becomes the subject for interventions of various kinds. As Rose and Abu-Rachid put it:

We extend our hopes and fears over our biological bodies to that special organ of the brain; act upon the brain as on the body, to reform, cure, or improve ourselves; and have a new register to understand, speak and act upon ourselves – and on others – as the kinds of beings whose characteristics are shaped by neurobiology (p. 223).

3.3.2. THE SELF IN MEDICAL TERMS

Rose's analysis of "the neurochemical self" (Rose, 2003) and how modern individuals have come to understand themselves in terms of their brains and bodies is highly referenced in sociological research on contemporary biomedicine. Inspired by Foucault's notions of governmentality, Rose claims that the active and responsible citizen is obliged to constantly monitoring his or her health and improving oneself in response to society's requirements and that pharmaceuticals have come to be the tool for these self-disciplining practices (p. 59). Pharmaceuticals "are entangled with certain conceptions of what human are or should be" (p. 59) and taking drugs becomes a practice of adapting to the specific norms that are inherent in the drugs. While Rose talks about neurochemical selves, anthropologist Janis Jenkins (2010b) analyses what she calls the "pharmaceutical self." Since the primary source of psychiatric treatment is psychopharmacology and because aggressive marketing of pharmaceuticals shapes the perception of subjects in need of treatment, we have become pharmaceutical selves, Jenkins claims. Based on her research on treatment of psychoses, she examines the dialectic between what she calls the pharmaceutical imaginary, which is the dimension of culture oriented towards pharmaceuticals as potentials for human life, and the pharmaceutical self, which is the aspect of the self oriented toward pharmaceutical drugs (p. 23). According to Jenkins, individuals adopt the pharmaceutical imaginary of mental illnesses as caused by chemical imbalances and interpret themselves and their problems in light of this imaginary. Subjectivity is not only a feature of individual experience, Jenkins states, and it cannot be distinguished from its surroundings, but the self must be understood as "the sum of processes by which the subject is oriented in the world and toward other people" (ibid). As patients incorporate and take the idea of schizophrenia as a consequence of a chemical imbalance, schizophrenia as a form of subjectivity can only be understood as strongly intertwined with the idea of restoring the balance with psychopharmacology. Thus, both Rose and Jenkins address consequences of neurobiological explanations for disorders on not only decisions about treatment but also on how we think about ourselves. Similarly, a study conducted by anthropologist Joseph Dumit (2003) examines the role of brain images experienced by people suffering from mental

illness. Dumit describes how brain images have altered people's understanding of their body, or what he calls their "objective self," which consists of:

our taken-for-granted notions, theories, and tendencies regarding human bodies, brains, and kinds considered as objective, referential, extrinsic, and objects of science and medicine. That we "know" we have a brain and that the brain is necessary for our self is one aspect of our objective-self (ibid, p. 39).

We are confronted with scientific images of the brain on a daily basis and we are convinced that these images can tell us who we are.

ADHD is illustrative for how we have come to think about human behavior as shaped by neurological processes. As I outlined in chapter 2, comprehensions of inattention and hyperactivity have changed throughout the past couple of centuries, but the neurobiological explanation has roots in the very early descriptions of children's disruptive behavior. Even if no biomarkers or brain scanning reveal ADHD, the biologization of ADHD is widely accepted, and as noted by Jutel and Conrad among others, patient organizations intensively advocate for the neurobiological explanation of the disorder. In my third article: "My ADHD and me: Identifying with and distancing from ADHD," I will illustrate how understanding ADHD as a neurobiological disorder opens up a number of interpretations and ways of relating to the diagnosis. The neurobiological explanation forms what Rose calls the register for people diagnosed with ADHD to understand, speak, and act upon themselves, and in this article, I analyze how the pharmaceutical imaginary, in Jenkins's words, affects the pharmaceutical self.

3.4. CONCLUDING REMARKS

The degree to which we have become neurochemical selves and how neurobiology has changed the way we think of the human and of human suffering is debated. Rose is criticized for overstressing the argument about people exclusively understanding themselves in terms of neurobiology, claiming that psychological and social explanations for suffering exist parallel to the neurobiological explanations (Bröer & Heerings, 2013; O'Conner & Joffe, 2013). Rose and Abu-Rached (2013), however, emphasize that "we are not seeing personhood replaced by brainhood, but the emergence of a new register or dimension of selfhood, *alongside* older ones – a dimension in which we can understand and take care of ourselves, in part, by acting on our brains" (p. 223). Rose might have nuanced his argument himself and the critique seem to accuse Rose for a rigid argument he is not presenting (any longer). Notwithstanding the level of neuroscience's influence on our perception of self, the idea that we increasingly understand ourselves in biological terms is widely acknowledged.

Psychiatric diagnoses are constructions or selective symptoms clustered together in order to differentiate between different kinds of suffering and coordinate treatment accordingly. Nonetheless, we often think of diagnoses as existing in themselves, independent of the individual's history and the social circumstances in which the individual suffers. Diagnoses give access to resources and are central for people organizing, demanding legitimization of their experienced problems, and in that sense diagnoses become powerful tools for the fight of social rights. Moreover diagnoses rearrange identity by offering a specific narrative and grouping the individual with others suffering the same. But maybe most notably, if the way we explain and think of diagnoses affects expectations of how to react to suffering and decisions of treatment, these explanations are immensely powerful.

CHAPTER 4. EXPERIENCES OF AN ADHD DIAGNOSIS: A LITERATURE REVIEW

Academic literature on adults' experiences of getting an ADHD diagnosis and living with symptoms of ADHD is limited. Historical and sociological literature contextualizing the diagnosis in macro societal developments dominate the investigations of ADHD within the social sciences and the few studies taking a first person perspective on ADHD all call for more research. Considering the increased number of adults diagnosed with ADHD, the absence of qualitative studies investigating adults' experiences of being diagnosed with ADHD is striking. I previously introduced some of the literature dealing with how diagnoses in general affect people's self-understanding, but in this section, I present studies that specifically investigate adults' experiences of receiving an ADHD diagnosis and the consequences thereof based on interviews with adults diagnosed with ADHD and a single study analyzing online narratives on Internet blogs by adults diagnosed with ADHD. I chose to include research that either focuses on experiences of getting a diagnosis and the consequences following the diagnosis or on how individuals cope with and experience symptoms of ADHD.

4.1. BEING DIFFERENT AND LIVING IN CHAOS

The most referenced study in investigations of adults' experiences of getting an ADHD diagnosis is conducted by psychologist Susan Young and her colleagues. Based on interviews with adults diagnosed with ADHD, the study evaluates the psychological impact of receiving an ADHD diagnosis and examines how diagnosis and drug treatment change the individual's self-perception (Young, Bramham, Gray, & Rose, 2008). The study lists three overall themes: how the diagnosis makes the individual review the past, how the diagnosis is followed by an emotional reaction and readjustment process, and finally how a diagnosis brings considerations about the future. In the first theme, the interviewees describe their feeling of being different from others. Throughout their lives, the participants have experienced negative judgments from family members, teachers, and friends who told them they were stupid, lazy, and disruptive, and while some ignored the feedback, others accepted it, which negatively affected their self-esteem (p. 496). Narratives about feeling different appear in the majority of literature about experiences of ADHD and reviewing the past as problematic and full of failure are common characterizations. From their interview study with adults diagnosed with ADHD psychologists Sheila Jones and Morten Hesse (2014) report how the interviewees have never felt like their peers and often experience a lack of social skills (p. 4), and Michelle Toner, Thomas O'Donoghue and Stephen Houghton (2006) demonstrate from an interview study with adults diagnosed with ADHD, how the interviewees have always felt different from the rest of the world (p. 252). The latter study describes the feeling of

being different as part of being socially isolated and lists the narratives of differentness together with the experience of failing in school, a history of frequently changing employment and a lack of self-esteem under a category they call “chaos.” According to the study, the participants regularly describe their lives as “chaotic,” “unsettled,” and “turbulent,” and the authors conclude that “chaos” as a concept “captures the notion that the starting point of people with ADHD is disorder and that they must work to achieve order in their lives” (p. 251). Thus, the diagnosis becomes a tool for ordering life, understanding one’s differentness, and working on how to cope with the differentness. As the literature also shows, however, the diagnosis and the following treatment paradoxically both help eliminate the feeling of being different and enforce it.

4.2. RECONSTRUCTING SELF-PERCEPTIONS AND LEARNING NEW WAYS OF MANAGING

The second theme listed in the analysis made by Young and colleagues (2008) describes the process of psychological adjustment following the diagnosis, which falls into three stages. Firstly, the participants describe an initial sense of relief because the diagnosis is accepted as the long waited explanation for their difficulties. The diagnosis provides the opportunity for relocating blame for previous failures, and “it enabled them to shift from an internal attribution that they were solely responsible for their problems to an external attribution whereby ADHD was an explanation for their difficulties” (p. 496). The relief, however, is often followed by feelings of confusion about how to understand themselves in light of this new diagnosis as well as anger over not being diagnosed earlier (p. 497). Lastly, the final stage of the adjustment consists of acceptance of ADHD as part of their life and who they are and it marks the end of the ruminations that had previously been experienced in relation to the diagnosis (p. 497). That an ADHD diagnosis gives a sense of relief is consistent in the research I found. Hesse and Jones report that most of their participants were relieved to get the diagnosis and that the diagnosis affected their self-worth positively “because it filled a blank spot in their self-understanding” (Hesse & Jones, 2014, p. 6). However, as also mentioned by Young and colleagues, Hesse and Jones find that the initial relief is often followed by both disappointment for not being diagnosed earlier, as the interviewees believe it could have shielded them from previous frustrations and problems in life, and by anger towards professionals by whom they had felt misunderstood (p. 6). Likewise, Halleröd and colleagues demonstrate the ambiguous state of, on the one hand, welcoming the ADHD diagnosis as an explanation for the individual’s academic and social shortcomings and for the experience of feeling different and on the other hand being sad about “the lost years prior to diagnosis” (Halleröd, Anckarsäter, Råstam, & Scherman 2015, p. 4). Toner and colleagues (2006) describe the process of getting a diagnosis as a process of gaining control in a chaotic life. According to the study, the diagnosis offers a new awareness of the reasons for the individual’s difficulties, and even if he or she might always have known about their differentness, “the

answer was given to them with the naming of their condition” (p. 254). After being blamed and blaming themselves for whatever problems they have encountered in life, which is often experienced as being beyond his or her control, the participants recognized that the problems were “not their fault” (p. 254). Knowledge of their disorder brought acceptance of themselves; “they were able to allow for their weaknesses and give themselves permission to fail” (p. 254). Moreover, the diagnosis made it possible to explain their behavior to family and friends and to “arm themselves with all the knowledge they could about the disorder that was shaping their lives” (p. 254).

In her Ph.D. thesis, social worker Maja Lundemark Andersen (2009) examines “how an ADHD diagnosis is filled with meaning and used in a meaningful way by the informants in terms of living their daily life” (p. 268), based on interviews with adults diagnosed with ADHD. Like the above studies, Andersen describes how an ADHD diagnosis puts a name to the individual’s difficulties and transforms the difficulties into a treatable phenomenon. The diagnosis offers a professional explanation and the individual thereby gains an understanding and acceptance of oneself (p. 119). At the same time, a diagnosis legitimizes the individual’s experiences and functions as a box into which the individual systematizes his or her experiences (p. 113). Andersen further argues that what has previously been interpreted as the individual’s fault can be deconstructed and reconstructed into an interpretation of ADHD as the fault (p. 110). ADHD becomes a category that recapitulates the individual’s experiences and the diagnosis is used as the knot that binds together the past, the present, and future possibilities. In that way, to get an ADHD diagnosis is a process of reconstructing self-perceptions as focus shifts from an unfounded differentness and failures to an official deviance that is evidence of a diagnosis (p. 264).

In a study based on online narratives from adults diagnosed with ADHD on blogs and webpages dedicated to strategies for coping with ADHD, Fleischmann and Fleischmann (2012) find a certain narrative structure in the stories told by adults diagnosed with ADHD. The narratives often fall in two stages. The first stage, lasting from childhood to the time of the diagnosis, focuses on how the narrators did not understand the reason for their difficulties and therefore blamed themselves for their failures. The second stage, beginning after the diagnosis, focuses on how awareness of ADHD turned their life around. People recall how they as undiagnosed found it difficult to cope with their everyday difficulties because they did not know about the reasons for their misbehavior and thus could not obtain the appropriate help (p. 1489). The ADHD diagnosis, as the narratives illustrate, changed this situation of helplessness and self-blame. After being diagnosed, the narrators researched ADHD on websites, books, online blogs, turned to psychologists and coaches for help and started pharmacological treatment. Reading others’ autobiographical accounts of life with ADHD derived knowledge and consolation and the narrators developed the belief that it is possible to cope with ADHD. They

were taught tips about how to organize their time better, prevent procrastination, and avoid distractions, and thereby learned how to improve their ability to perform different tasks. “Armed with information these narrators realized that difficulties originated in ADHD” (p. 1490), and by knowing the difficulties were possible to cope with, the narrators “began to view their present and future in a more positive light”(p. 1491).

4.3. AMBIVALENCE TOWARDS THE DIAGNOSIS

Research on adults’ experiences of getting an ADHD diagnosis describes different feelings of ambivalence towards the diagnosis. Besides using knowledge about the disorder to positively reconstruct self-perceptions, some people experience doubt and conflicting thoughts following the diagnosis. Andersen’s study reveals how ADHD is associated with handicap and disability categories, which are not perceived as attractive or relevant to the participants. While an ADHD diagnosis is experienced as liberating because of its ability to offer explanations for the individual’s difficulties, it is also constraining because it offers only a limited set of roles for the individual to hold (p. 121). Therefore, the participants try to navigate between, on the one hand, accepting the diagnosis and its symptoms descriptions when understanding themselves and, on the other hand, insist on maintaining individual characteristics and being different in their own specific way (p. 122). According to Andersen, the dilemma arises because the ADHD diagnosis is based on an essentialist understanding of the human. Even if the individual requests the diagnosis based on its symptoms descriptions, the essentialist descriptions collide with the individual’s self-descriptions. The participants do not “buy the whole ADHD package” and do not accept the stereotypical roles connected to ADHD (p. 122). The diagnosis might mediate understandings and offer explanations, but the participants only partly accept the ADHD role. They chose ADHD as the headline for understanding themselves, but they write the content of the text themselves, as Andersen states (p. 137).

Halleröd and colleagues list different reasons for having ambivalent feelings about getting an ADHD diagnosis. Firstly, some of the interviewees raised questions regarding the actual existence of ADHD as a diagnosis and expressed thoughts about not adapting to modern society rather than having a psychiatric diagnosis or that symptoms considered as ADHD were caused by childhood or environmental conditions (Halleröd, Anckarsäter, Råstam, & Scherman 2015, p. 4). Secondly, some of the interviewees did not see themselves as fitting into the stereotypical conception of a person ADHD or they did not feel resemblance with others diagnosed with ADHD and therefore questioned the accuracy of their diagnosis (p. 5). Thirdly, some of the interviewees expressed feelings of insecurity concerning identity following the diagnosis and feared that the diagnosis might interfere with their identity. According to the study, the concern was expressed as to “whether one could remain the same person after having been assigned a diagnosis of ADHD” and

“how much of an individual’s characteristics and behaviour could be explained by ADHD” (p. 7). Some were afraid that the diagnosis could turn into a self-fulfilling prophecy if their possibilities in life were underestimated because of the diagnosis and if knowledge about difficulties associated with ADHD would result in loss of self-confidence and lack of courage to explore new possibilities. “One could lose one’s freedom and start living according to the diagnosis, letting the diagnosis guide one’s choices and thereby avoiding things which are considered difficult or impossible for people with ADHD” (p. 9). And lastly, even if the diagnosis was a great help to many in terms of giving access to resources and knowledge about themselves, their reactions and opportunities for managing situations in new and more strategic ways, some interviewees also reported disappointment with being left without the expected help after being assigned the diagnosis (p. 8). Young and colleagues report a similar disappointment following not only the diagnosis but also specifically the medication. Though the medication had a positive impact on the interviewees’ ability to function more successfully in their everyday lives, diagnosis and treatment with medication were not sufficient to overcome their experienced difficulties (Young, Bramham, Gray, & Rose, 2008, p. 498).

4.4. CONCERNS ABOUT STIGMATIZATION

The last main subject presented in the literature about adults’ experiences with being diagnosed with ADHD deals with concerns about stigmatization. Young and colleagues list the issue as part of their third theme about considerations of the future and describe how the participants were concerned that others may perceive them differently following the diagnosis (p. 497). Similarly, Andersen describes how the interviewees are afraid that others will connect the ADHD diagnosis to categories of being mentally ill and unstable and that the diagnosis will be used against them in that respect (Andersen, 2009, p. 111). Again, Andersen points to the dilemma between demanding the diagnosis in order to get relief and clarification and accepting the role offered by the diagnostic category that is associated with handicap and disability and potentially stigma (p. 118). Halleröd and colleagues refer to fear of discrimination because of the diagnosis as a big concern in the study. Some of the interviewees expressed worry that others, including authorities, would judge them by the diagnosis and treat them differently, resulting in difficulties with relationships, employment, insurance, and even getting a driving license (Halleröd, Anckarsäter, Råstam, & Scherman 2015, p. 9). To be able to pass, as Andersen describes it using Goffman’s concept, becomes important to adults diagnosed with ADHD in order not to be stigmatized due to their diagnosis. Toner and colleagues demonstrate that participants keep the diagnosis a secret from most people because they feel a lack of understanding about it as well as an unsympathetic attitude towards the disorder in society in general and in the media particularly (Toner O’Donoghue & Houghton, 2006, p. 257). The participants “pretend to be ok,” “winging it” (p. 257), and choose to hide the ADHD diagnosis, resulting in what Toner and colleagues describe as leading a double life.

4.5. THE CONTRIBUTION OF THIS THESIS TO THE EXISTING RESEARCH

The current research on adults' experiences of getting an ADHD diagnosis informs us of both positive and negative consequences of being diagnosed with ADHD. The studies show quite concordant results and are primarily performed as interview studies, except Andersen's study, which also includes observation studies and Fleischmann and Fleischmann's study, which examines online narratives. I read these studies concurrently while doing my own research and I found that most of my findings were confirmed by these studies. Similar to the existing research, my informants told me about feelings of being different, experiences of failure, and about how the diagnosis helps them manage practices in more productive ways and not least how the diagnosis reduces blame and reconstructs new self-perceptions. My informants strategically chose whom to inform about the diagnosis, but generally, concerns about stigmatization are not dominant in the stories I was told about life with ADHD. Since my informants have experienced stigma in various degrees and ways throughout their life because of their differentness, the diagnosis is described as reducing stigma rather than enforcing it. The consequences of taking drugs, however, carry ambivalence due to experiences of radical changes in ways of perceiving, thinking, and acting. Receiving a diagnosis and drug treatment is a complex process that requires conditioning and experimenting with new opportunities.

The existing research deals less with everyday life with ADHD, experiences with medication, understandings of the disorder and generally how adults engage with the diagnosis when interpreting themselves through the diagnosis. Psychologist Iina Singh (2007; 2011; 2013) is one of the leading researchers studying children diagnosed with ADHD and their understanding of the diagnosis. From her fieldwork in UK primary schools, Singh (2011) draws attention to "ADHD as a lived experience in local contexts" (p. 889) and argues that the disorder not only resides in the child or is a consequence of narrowing surroundings that pathologizes certain behavior, but the disorder unfolds somewhere in the nexus of the two. Singh illustrates how children strategically use the ADHD diagnosis as a resource in order to explain behavior and morally disclaim responsibility, but also how they mobilize opportune behavior based on certain conceptions of what ADHD is. "Uncovering the social and moral dimensions of ADHD" (p. 890) in the spaces and relations in which it is expressed and negotiated is one of Singh's agendas, and she demonstrates how children negotiate and consciously inhabit the diagnosis. Inspired by Singh, I wish to contribute to the existing literature on adults' experiences of ADHD by examining how my informants creatively relate to and understand the diagnosis and how they experiment with practices and new ways of handling everyday problems following the diagnosis. From my longitude fieldwork and my analyses, the aim is to bring new perspectives of moral, bodily, and phenomenological aspects of life with ADHD to the existing literature.

CHAPTER 5. THEORETICAL AND METHODOLOGICAL BACKGROUND: STUDYING EXPERIENCES OF ADHD

“Is it a phenomenological project or is the project inspired by phenomenological perspectives and analyses?” a reviewer of one of my articles asked. I suddenly was not sure. Neither if I could subscribe to a specific scientific paradigm nor what the difference between a phenomenological and a phenomenology-inspired project was. I was studying experiences of ADHD and I was taking a first person perspective in my examination of ADHD. I was asking how we can understand the bodily experiences of what we call ADHD and the experiences of getting the diagnosis. Experience was a central concept, and following the anthropologist Michael Jackson (1996) who states that “phenomenology is the scientific study of experience” (p. 2), and that phenomenology seeks to describe “human consciousness in its lived immediacy” (p. 2), I considered my project a phenomenological project. I knew, however, that the concept of experience is intricate. Despite being a key concept in anthropology, the concept of experience is often taken for granted and it has remained largely unquestioned and unexamined (Throop, 2003). My use of the concept entails a broad spectrum of experiences ranging from bodily experiences of what we call ADHD to experiences of getting the diagnosis and using it as a tool for self-understanding and self-interpretation and I realized, after pondering over the reviewer’s question for a while, that I had to be more specific about the status of my project and about my conception of experience.

In this section, I try to clarify what I mean by the concept of experience and how I position my project within a phenomenological framework. The following is not meant to be an exhaustive discussion of the notion of experience within anthropology and philosophy, but rather a selective excerpt of some of the central traditions and debates. According to anthropologist Kirsten Hastrup (1995), the notion of experience in anthropology is used both in the sense of the informant’s lived experience, comprising thoughts, desires, and words, and in the sense of the ethnographer’s shared experience with his or her informants as the initial step towards anthropological knowledge (p. 79). Studying experiences, then, entails attention to the informant’s lived experience as well as to the intersubjective process of studying experiences. I use this differentiation of how to understand experience and how to study experiences as my first approach to the concept. Lastly, I outline the theoretical perspective offered by philosopher Ian Hacking that has informed my thinking about the dynamics between diagnostic categories and individual experiences.

5.1. HOW TO UNDERSTAND EXPERIENCES?

Jackson (2013) describes how entire domains of human experience were assigned to other disciplines in the formative years of establishing anthropology as a science. In the attempt to follow demands of objectivity from the natural sciences, the social sciences created an image of objectivity by reducing individuals to functions, roles, obligations, performers of rituals, and followers of rules and thereby deducting experience from people's lives (p. 4). Today, however, anthropologists no longer see it as their task to discover hidden causes, structures, and meanings, but rather, inspired by phenomenology, to examine individuals as experiencing beings. The phenomenological turn calls for detailed descriptions of "how people immediately experience space, time, and the world in which they live" (p. 12), and to give ontological priority to what Husserl calls the lifeworld (*Lebenswelt*) over the world of theoretical thought and explanatory ideas. The task for anthropology, Jackson (1996) argues, is "to recover the sense in which experience is situated within relationships and between persons if the lifeworld is to be explored as a field of intersubjectivity and not reduced to objective structures or subjective intentions" (p. 26). Individual experience is embedded in various contexts of interaction, recognition, and relationships, and if we only look at the individual as a product of social structures, we miss the chance of understanding human experiences. In my examination of ADHD, I am interested in understanding experiences of ADHD and not in explaining ADHD as a consequence of either medicalization of behavior or of neurological processes in the brain. My aim is to understand how experiences of ADHD unfold within various social contexts, and I thereby concur with the phenomenological ambition of examining experience.

Phenomenology as a tradition is often portrayed as founded by Edmund Husserl and his ideas about human consciousness and experience as lived and embedded in the world. Husserl wanted to study the human as actively creating and being in the world instead of reducing the human to an object in the world (Jacobsen, Tanggaard & Brinkmann, 2010, p. 187). One of Husserl's phenomenological successors is philosopher Maurice Merleau-Ponty who describes phenomenology as "an attempt to provide a direct description of our experience such as it is" (Merleau-Ponty, 1945/2012, p. Ixx). According to Merleau-Ponty, "phenomenology involves describing, and not explaining or analysing" (p. Ixxi), and the phenomenologist therefore needs to return to things themselves and not indulge in theoretical speculations. "Everything that I know about the world, even through science, I know from a perspective that is my own or from an experience of the world without which scientific symbols would be meaningless" (p. Ixxii), Merleau-Ponty argues. Science, from this perspective, is "the second order expression" (p. Ixxii) and simply an explanation of the world. To return to things themselves, therefore, is to "return to the world prior to knowledge" from a descriptive rather than an explanatory ambition.

Phenomenology conceives of the human as ontologically existing and experiencing in the world, which is captured by the concept of “being in the world.” The human being is immersed and shrouded in the world, and it makes no sense to differentiate between the world as it is and the world as it appears to human perception. As Merleau-Ponty writes:

The world is not an object whose law of constitution I have in my possession it is the natural milieu and the field of all my thoughts and of all my explicit perceptions. Truth does not “dwell” in the “inner man”, or rather, there is no “inner man,” man is in and toward the world, and it is in the world that he knows himself (p. Ixxiv).

The individual is not a solipsistic subject, but the individual is experiencing in the world and experiencing with others. According to the phenomenological analysis, the subject is not only for-itself, it is also for-others and aspects of both subjectivity and of things in the world are always related to the other (p. Ixxv). Referencing Heidegger, Jackson (2013) describes how “our own world (eigenwelt) is inextricably tied up with the world of others (mitwelt) and the physical environment of which we are also vitally a part (umwelt)” (p. 5). As individuals we “live intentionally and in tensions with others as well as with the world” (p. 5) in what is described as an intersubjective being in the world. Our relationships with the world and with others are relations of “inter-est” and “inter-existence” (p. 5), Jackson emphasizes, and we are therefore not a stable set of pieces with established essences or identities, but we are constantly changing and formed through our relationship with the world and others. The term intersubjectivity points to the notion of the subject as continuously in dialogue and the term thereby, as Jackson writes, invites us to explore

the subtle negotiations and alterations of subjective experience as we interact with one another, intervocally or dialogically (in conversations and confrontations), intercorporeally (in dancing, moving, fighting, or competing), introceptively (in getting what we call a sense of the other’s intentions, frame of mind, or worldview) (p. 5).

Even if phenomenology calls for a first person perspective when studying experiences, experiences, from this perspective, are conceived as intersubjectively and intercorporeally embedded. Experiences are contextualized, situated and social, as well as shared with others and emerging out of engagement and interactions with the world and others.

5.2. EXPERIENCES OF SUFFERING IN MEDICAL ANTHROPOLOGY

The social dimension of experience is often emphasized in anthropological literature, and Hastrup (1995) even proposes using the concept ‘social experience’ as

a replacement of 'lived experience' since experience is always mediated by a socially based interpretation (p. 84). I, however, stick to the term experience, implicitly recognizing the intersubjective character of experience.

Within medical anthropology, research on illness experiences also points to the social aspect of experiences. Medical anthropologists "explore the organization of sentience, of experience, as well as the object of experience, the contours of the world as experienced and responded to, as well as the organization and shaping of experience," as anthropologist Byron Good writes (1994b, p. 37). According to Kleinmann, Brodwin, Good and Good (1994), for example, "the experience of chronic pain is fundamentally intersubjective" (p. 9). Chronic pain not only affects the suffering individual, but chronic pain also has a profound effect on the lives of the relatives and friends, who in turn "shape the experiential world of the sufferer" (p. 9). Therefore, to simply look at etiological mechanisms eschews what is essential in experience of pain, namely the "relationship between neurobiological and social psychological processes" (p. 9). Likewise, Jenkins (2015), referencing Hallowell's notion of experience as culturally constituted, argues that conditions of mental illness must be understood as engaging fundamental human processes, formed by culture, biology, and psyche (p. 2). Mental illness exists in families, in romantic relations, and at work and manifests itself as a struggle, thwarting expectations and desires to navigate in these relations (p. 88). Therefore, in order to understand experiences of mental illness, we need to comprehend the social and cultural premises for experiences. From her research on mental illnesses, and especially experiences of psychoses and trauma, Jenkins argues that "there is no such thing as individual pathology insofar as the sociocultural milieu profoundly affects the formation of subjective experience" (p. 71). Situations of mental illness are "constituted by intersubjectivity, social and economic conditions of possibility and constraint, and the shaping of cultural expectations of persons in relation to gender, mental, and political status" (p. 3). Describing how informants diagnosed with schizophrenia conceive of their disorder, Jenkins illustrates that "cultural conceptions of mental illness play a role in shaping how illness is experienced" (p. 38-39). As an example, her research shows that while Euro-Americans conceive of their disorder as a product of a chemical imbalances in the brain, African-Americans are more likely to speak of their disorder as a product of bodily instability and imbalance connected to social problems and family struggles (p. 37). "The metaphor has penetrated into the lived experience" (ibid, p. 39), Jenkins writes, pointing to the relation between cultural conceptions of illnesses and how experiences are shaped. As noted by Lakoff and Johnson (1994), metaphors both express and structure our perception of the world and way of navigating in it, and in Jenkins's description, concepts and metaphors both reflect and shape experiences of illness.

Jenkins' cultural approach to comprehending experiences of mental illness resembles Kleinman's (1994) emphasis on human suffering as embedded in "local moral worlds" (p. 172), understood as the microcontext that mediates the

relationship between societal and personal processes. According to Kleinman, local moral worlds are “particular, intersubjective, and constitutive of lived flow of experience” (p. 172). Experiences of illness, constructed in local moral worlds, are only partly subjective, since the experiencing individual continuously orients him or herself in the world based on a moral sensibility to the local world (p. 173). Universal situations of for example death, disaffection and disease, are experienced as particular forms of bereavement, pain and suffering. Jenkins’ and Kleinman’s analyses both teach us about the intersubjective aspect of experience, but they also encourage us as researchers to examine the local context of the experiencing individual. “To understand what chronic pain signifies, what its experience is like, ethnographers must work out a background for understanding of local knowledge and daily practices concerning the body and the self, and of misfortune, suffering and aspiration generally” Kleinman (1994, p. 173) writes. Hence, how we conceptualize and understand the concept of experience involves specific ways of examining experience.

In my fieldwork, I came to learn that experiences of ADHD were intertwined with the desire of being a good parent, of wanting to navigate in society, of keeping a job, maintaining friendships, and of being accepted. Taking drugs and experiencing a newfound calmness when reading bedtime stories for one’s children render the quest for being a good parent possible, as I describe in the article “Structuring the self: moral implications of getting an ADHD diagnosis.” Experiences of restlessness and having the feeling of being socially out of sync with people around you provoke the feeling of being different and misunderstood, as I describe in the second article: “ADHD and temporality: a desynchronized way of being in the world.” And experiencing ADHD as both a way of being human and as an entity to distance from, illustrate how scientific and public explanations of ADHD form ways of understanding oneself, as I describe in the third article: “My ADHD and me: Identifying with and distancing from ADHD.” Whether I examine bodily experiences of ADHD or experiences of getting and relating to the diagnosis, experiences of ADHD are socially embedded. My informants orient themselves in the world based on expectations from themselves and others and their experiences of ADHD are shaped by and situated within relations to others. Certain ways of being in the world and certain ways of understanding oneself are available within local contexts, and experiences of ADHD exist within these particular circumstances. In my analyses, it has been my ambition to focus on my informants’ particular experiences, understanding these experiences in relation to social relations, family struggles, and cultural explanations of suffering, and expectations of being human without understanding these experiences as simply products of social and cultural dynamics but rather in constant relation to these.

5.3. HOW TO STUDY EXPERIENCES?

While the above perspectives on experience focus on the intersubjective aspects of experience, the debate over how or whether we can even study and understand experiences is almost inevitable, and I will continue by briefly outlining some of the arguments in this methodological discussion.

Merleau-Ponty discusses Husserl's notion of the phenomenological reduction and the phenomenologist's ability to "loosen the intentional threads that connects us to the world in order to make them appear" (Merleau-Ponty, 1945/2012, p. Ixxvii). Normally, we are unaware of our engagement with the world, but in order to describe worldly phenomena, we need to distance ourselves from our being in the world. "Because we are through and through related to the world, the only way for us to catch sight of ourselves is by suspending this movement, by refusing to be complicit with it (...), or again, to put it put of play" (p. Ixxvii), Merleau-Ponty writes. Within anthropological terms, Jackson describes the phenomenological method as implying a practical relativism in which questions concerning the status of ideas and beliefs are set aside in order to fully do justice to the way people experience the world (Jackson, 1996, p. 10). This process of distancing does not entail a full transcendence, but rather a disengagement from one's own being in the world, and Jackson thereby transforms the philosophical question of the individual's ability to bracket his or her own perception of the world into applied anthropology and a method for understanding others' experiences. Especially scholars in anthropology advocating for an interpretive approach, however, question whether the phenomenological reduction is the key for anthropology when understanding experiences. Instead, it is stated, we should focus on different forms of expressions of experiences.

Anthropologist Victor Turner (1986) is often referenced in anthropological research on experience. Emphasizing the individual's searching for meaning and the symbolic meaning of expressions, Turner draws on a hermeneutical approach, and especially on philosopher Wilhelm Dilthey when understanding experiences. Dilthey is known for contributing to the hermeneutic tradition with an interest in the interpretive study of human behavior and of pointing to the social and historical contexts as essential factors when interpreting meaning (Pahuus, 1995, p. 112). While philosopher Friedrich Schleiermacher suggests that projection into the mind of the other is possible due to preexisting connections among all individuals, Dilthey on the other hand, argues that understanding is not merely based on contact between individual minds, but understanding is rather based on a reconstruction of the historical process that shapes expressions of experiences (Packer, 2011, p. 89). Following philosopher Wilhelm Dilthey, Turner makes a distinction between mere "experience" and "an experience," mere experience being "simply the passive endurance and acceptance of events", while an experience is the "structure of experience" (Turner 1986, p. 35). We constantly try to find meaning in experiences,

in what has disconcerted us, and by that we turn mere experience into an experience (p. 36). Hence, mere “experience” is the individual experience and “an experience” is the articulation of experience into an expression (Bruner, 1986, p. 6). “While all of us have experiences all the time,” Hastrup interprets Turner, “*an* experience is cut loose from the chronological stream in a non-arbitrary fashion” (Hastrup, 1995, p. 84, italics in original). Turner explains, again referencing Dilthey, how “experience urges toward expression, or communication with others” (p. 37). As social beings, we express our experiences through language and through different sources of aesthetic forms as for example social dramas and rituals, as Turner specifically focuses on.

Within anthropology, the question of how to study experiences is widely discussed. The difficulty with experience, anthropologist Edward Bruner (1986) writes, is “that we can only experience our own life, what is received by our own consciousness” (p. 5). Even if the anthropologist and the informant tasted the same bowl of rice, as anthropologist Tamara Kohn (1994) says, it would be impossible to know, if they had shared the same experience. “The ‘other’s’ sensory experience, whether or not there is a vocabulary to describe it, can never be completely shared, only imagined” (p. 20). Others may be willing to share their experiences, but “experience has to be turned into expression to become part of ethnography” Hastrup and Hervik argue (1994, p. 8). What Turner calls mere experience is impossible to grasp by the anthropologist, and we therefore need to “transcend the narrow sphere of experience by interpreting expressions” (Bruner, 1986, p. 5). The relation between experience and its expressions, however, is dialogic and dialectical since “experience structures expressions (ibid, p. 6), but “expressions also structure experience,” as Bruner states (p. 6). Hence, life as lived, life as experienced, and life as expressed are inevitably not the same, but are interrelated. We understand other people’s expressions based on our own experiences, just as cultural and historical narratives, rituals and different forms of art illuminate experiences, Bruner says. This relation between narrative expressions is examined by, among others, Good (1994a), who explores “how illness narratives are structured in cultural terms, and how these reflect or give form to distinctive modes of lived experience” (p. 136). Good asks if the stories he is told by his informants are “reports of experience” or if they are largely “governed by a typical cultural form or narrative structure” (p. 138) and concludes by stating that “narrative is a form in which experience is represented and recounted” (p. 139). Similarly, anthropologist Cheryl Mattingly (1998) points to the dialectics in how “narratives are not just about experiences. Experiences are, in a sense, about narratives. That is narratives are not primarily after-the-fact imitations of the experiences they recount” (p. 19). These perspectives seem to not only claim that experiences are possible to examine through expressions of different sorts, but expressions, in the form of narratives, even have the ability to structure experiences.

Often referenced are discussions of the anthropologist’s access to experience presented by anthropologist Clifford Geertz (1993) who represents an interpretative

approach to the study of experiences, and anthropologist Renato Rosaldo (1984/2004) who advocates for a descriptive and yet emotional approach. Geertz, like the anthropologists mentioned above, argues that the ethnographer cannot perceive what the informants perceive (Geertz, 1993, p. 58).

We cannot live other people's lives, and it is a piece of bad faith if we try. We can but listen to what, in words, in images, in actions, they say about their lives (...) Whatever sense we have of how things stand with someone else's inner life, we gain it through their expression, not through some magical intrusion into their consciousness (Geertz, 1986, p. 373).

Instead of trying to grasp the native's point of view, as he says, referencing Malinowski, the ethnographer must interpret the symbols by and through which the informant perceives in the form of rituals, texts, and narratives. Rosaldo, on the other hand, criticizes the interpretive ethnography for adding meaning to experiences that might not be recognizable to the informant. Rather, the ethnographer must try to capture the experience of his or her informants by taking their descriptions literally (Rosaldo, 1984/2004, p. 580). There is no meaning behind the descriptions, no hidden truth to be revealed. Rosaldo further argues that comprehending experiences depends on a common frame of understanding and that he did not understand the rage that follows bereavement and leads to headhunting – a phenomenon he had been studying for a long time – until he lost his wife and experienced the complexity of rage and sorrow (p. 580). His inability to conceive the force of anger in grief, at the beginning of his research, led him to seek another level of analysis in order to provide an explanation of the desire to headhunt. However, by being repositioned through the experience of loss, he understood the literal sense of anger and headhunting, which he never would have understood through a symbolic analysis of the phenomenon, he claims.

Rosaldo's argument makes the project of understanding experiences complicated if we as researchers need to personally share experiences with our informants in order to understand their experiences. And even if we share experiences, how can we know, as mentioned by Geertz and Bruner, if we actually understand the other's experience? I position myself between a phenomenological and a hermeneutical tradition. I follow the phenomenological ambition of studying lived experience "before it is subject to theoretical elaboration or conceptual systematizing", as Jackson (1996) states, as I wish to understand my informants' being in the world, their experiences of restlessness and of being different without having a prearranged analytical model to understand these experiences into. I enter the field with an ambition of bracketing my pre-understandings of ADHD and theories about medicalization of behavior, and I enter the field as a person, who draws upon my own experiences when trying to understand my informants' experiences. I sit with my informants, I listen to their stories, and I sense the restlessness they verbally and bodily express. However, I also agree with the hermeneutical approach that

recognizes experiences as already interpreted in the informants' expressions and that the analytical process in research implicitly entails an interpretive processing. I access experiences through different forms of expression; verbally in the form of narratives and metaphorical descriptions; bodily in ways of talking and being in the room; and figuratively from the use of pictures of ADHD often shared on the Internet and used by my informants. Social and cultural forms of expression shape my informants' expressions, as noted by Good, and I try to interpret these expressions based on my personal and anthropological capabilities. Both approaches consider the individual to be situated in the world and ascertain that human thoughts are always about something, experiences are always of something, and actions are always directed towards something. Experiences are socially embedded and the individual relates to the world and experiences in contexts. Similarly, I understand and examine experiences.

5.4. EXPERIENCES INFORMED BY DIAGNOSES

Based on studies of several disorders ranging from multiple personality disorder to obesity and the now commonly forgotten disorder fugue, philosopher Ian Hacking is one of the researchers who has contributed a conceptual framework for understanding the dynamics between diagnostic categories and individual experiences. Hacking does not account for his use of the concept experiences, but his descriptions of the effects of diagnoses on individual's experiences have been helpful in my examination of experiences of getting an ADHD diagnosis.

In his book "Mad Travelers" (1998) Hacking describes the man Albert, who was compulsively traveling around Europe in the late 1880's in a state of obscured consciousness, forgetting where he had been. Albert was committed to a psychiatric hospital and became the first patient ever diagnosed with fugue for what was considered mad traveling (p. 8). After the publication of a thesis describing fugue in 1987 and subsequently recognition of fugue as a medical disorder of its own, the diagnosis soon started to spread across Europe. Today, however, the diagnosis no longer appears in the diagnostic manuals and it seems to be forgotten. So how is that? Hacking argues that fugue is a "transient mental illness," which is "an illness that appears at a time, in a place, and later fades away. It may spread from place to place and reappear from time to time" (p. 1). A transient mental illness reflects what is considered pathological at a certain place and time. Illnesses come and go, diagnostic categories change and social and cultural circumstances foster new ways of being ill. As a contemporary example, Hacking points to ADHD as a diagnostic category just recently emerged. We have known about fidgety children for a long time, but since ADHD is a relatively new diagnosis, both researchers and lay people question if it is a real disorder or if it is a social construction. This question, however, leads to banal discussions, Hacking claims, and he suggests we rather try to understand the contexts in which certain mental illnesses thrive and examine the mechanisms of how diagnoses and individuals interact (p. 1). Hacking argues that

one fruitful idea for understanding transient mental illness is the ecological niche, not just social, not just medical, not just coming from the patient, not just from the doctors, but from the concatenation of an extraordinarily large number of diverse types of elements, which for a moment provide a stable home for certain types of manifestations of illness (p. 13).

Fugue emerged as a diagnosis in an age of tourism, when art and literature depicted adventurous journeys, but also in a time when the idea of the criminal vagrant scared people. Niches depend on a set of vectors or circumstances and the cultural polarity between tourism and vagrancy created a space for fugue as a phenomenon. Another vector is observability, and Hacking illustrates how demands of people carrying their papers of identification made it possible to trace people's wandering (p. 68). Only by taking these vectors into consideration and understanding the niches within diagnoses emerge is it possible to understand why diagnoses suddenly emerge and why some only shortly thereafter disappear again from the diagnostic manuals and as a category to identify with.

To examine how people diagnosed with fugue responded to the diagnosis is difficult since data mostly describe the process from the doctors' perspective. The voices of people diagnosed with multiple personality disorder (MPD), however, are present in various media, TV-shows and on the Internet. These expressions illustrate how diagnoses are "making up people," as Hacking calls it. People diagnosed with multiple personality disorder talk about being MPD and refer to the diagnosis when describing their experiences. From the moment the diagnosis was recognized, it offered a category to fit into, and MPD became a way of experiencing and of being human. Hacking lists two statements to illustrate his point:

- A) There were no multiple personalities in 1955; there were many in 1985
- B) In 1955 this was not a way to be a person, people did not experience themselves this way, they did not interact with their friends, their families, their employers, their counsellors, in this way; but in 1985 this was a way to be a person, to experience oneself, to live in society (Hacking, 2007, p. 299).

In the case of MPD, both statements are true, however, the first being too brief and contentious, Hacking says (Hacking, 2007, p. 299). While an enthusiast for MPD would say that option A is false because of its rejection of people experiencing alter personalities before the diagnoses was established, a skeptic would, likewise, claim that option A is false, but from the opposite reason, arguing that MPD has always been a specious diagnosis and that there were no MPDs after the diagnosis was established either. Rather than discussing the status of the diagnosis, Hacking is concerned with option B and the process of how new kinds of being emerge. In

Hacking's own words, he is interested in "the way that scientific knowledge about ourselves – the mere belief system – changes how we think of ourselves, the possibilities that are open to us, the kinds of people that we take ourselves and our fellows to be" (p. 10). Available descriptions in society offered by scientists, psychologists, therapists, media's narratives etc. make certain ways of being and experiencing possible, and the classifications into which we are put or put ourselves into, thus, have a formative effect on how we understand ourselves (Hacking, 1995). These kinds of beings are moving targets, constantly interacting with the classifications and the scientific knowledge attached to it in a dialectical relation or as a product or what Hacking calls "looping effect." When diagnosing, diagnosis and individual interact and inter-affect each other as the individual mirrors itself in the diagnosis and interprets him or herself accordingly and likewise the diagnosis reflects the individual's symptoms. In the case of MPD, Hacking illustrates how patients started to report more and more alter personalities and how the diagnostic descriptions were changed in order to meet the patients' symptoms (Hacking 2007). Hence, new ways of understanding and describing the illness alter as new ways of suffering change and vice versa.

5.5. EXPERIENCES OF ADHD

Hacking offers an interesting and compelling argument about the dialectic relation between diagnostic categories and individual experiences. While studies of medicalization processes primarily investigate the social, cultural, and political circumstances surrounding the individual that promote the emergence of diagnosis, Hacking contributes with a framework for understanding the dynamic relation between diagnosis and individual. However, something in the process of making up people is left in a black box, and we only briefly learn about the individual's experiences and the process of how the individual transforms into this new way of being human. Philosopher Serife Tekin (2014) critiques Hacking for claiming that diagnoses change individuals' sense of self without offering a clear account of what the self is and how exactly labelling processes change the subject's sense of self and she contributes to Hacking's framework with a psychological concept of the self. In my analyses of ADHD, I contribute with an anthropological and phenomenological examination of how the individual experiences symptoms related to ADHD and how they experience getting the diagnosis. I investigate the making up process, the everyday changes following a diagnosis, how explanations of the diagnosis are received and acted upon, and how the diagnosis offers a narrative to understand oneself by. Jutel describes how diagnoses rearrange identity as the diagnosis lets you become someone with that particular disorder; Rose argues that modern individuals have come to understand themselves in terms of their neurobiology; and Hacking claims that diagnoses are making new ways of being a person, of experiencing oneself, and of living in society available. Inspired by these perspectives, but focusing specifically on the individual's experiences, I examine the complexity of socially and culturally embedded experiences of ADHD.

CHAPTER 6. STUDY DESIGN, METHODS, AND HOW I GAINED KNOWLEDGE

For anthropology, ethnography remains vital, not because ethnographic methods guarantee certain knowledge of others but because ethnographic fieldwork brings us into direct dialogue *with* others, affording us opportunities to explore knowledge not as something that grasps inherent and hidden truths but as an intersubjective process of sharing experience, comparing notes, exchanging ideas, and finding common ground. In this process our social gumption and social skills, as much as our scientific methodology, becomes measures of the limits and value of our understanding (Jackson, 1996, p. 8, italics in original).

Jackson describes the anthropological project and the ambition of gaining knowledge as a process that not only requires specific techniques, but also entails an involvement as an individual with the field and people of the study. We enter the field as a person with feelings and ways of communicating and we bring our cultural and social background into the field. We must “give up the illusion that it is possible to absent ourselves from the constraints of history and the contingencies of our situation” Jackson (1996, p. 9) argues. We may try to see the world from the point of the other and try to disengage from our own perspective, but we can never achieve full transcendence and gain an overarching perspective. Exploring a field and gaining knowledge, therefore, must be an intersubjective process of exploration and interchanging views.

Similarly, Hastrup (2010) defines the anthropological project as a not only a matter of collecting data but also of producing knowledge. We go into a field, collect data, and produce a tacit knowledge about the field. We usually consider our knowledge as based on our data, but knowledge is much more than data, Hastrup argues. While data is the material you as a fieldworker collect from interviews and observations, knowledge is somewhat different. By situating yourself in a field and participating in activities along with you informants, you acquire a profound knowledge about the field and the interpersonal meanings produced in interactions between people and between people and society. This personal insight, when you as a researcher are embedded in the field, is the essence of knowledge production (p. 55). Knowledge is gained over time and through intersubjective processes and is not out in the field, awaiting discovery by application of a particular technique (Baarts, 2010; Gudemand & Rivera, 1995). To gain anthropological knowledge, however, is not the same as cultural knowledge, anthropologist Peter Hervik (1994) states, and he differentiates between knowing in the sense of knowing a particular social space as a

native and understanding it as analysts (p. 89). Through shared reasoning and shared social experiences, however, the basis for acquiring local knowledge expands, but “it still does not take the full step from ‘knowing’ the social space as participants to ‘understanding’ as detached analyst” (p. 90). As I pointed out in the previous chapter, I do not claim to be able to experience what my informants experience, and neither do I claim to hold the same knowledge about ADHD as my informants, but I definitely have gained knowledge about ADHD through my fieldwork that has led me to a different kind of understanding of ADHD than any books or statistics could ever provide.

In my analyses of adults’ experiences of ADHD I primarily use data from interviews with my informants. The interview data, however, is supplemented with and interpreted on the basis of knowledge I have gained through hanging out with informants, chatting with them on Facebook, following them to the doctor, talking to their relatives, and attending seminars and conferences about ADHD. Following the above anthropologists, I consider fieldwork as an intersubjective process of exchanging and challenging experiences and perceptions. In the following sections, I outline which methods I have used, the ways I have gained knowledge about adults’ experiences of ADHD, and what difficulties and ethical dilemmas I have encountered during the research process.

6.1. DEFINING MY FIELD

My fieldwork is not a classic ethnographic fieldwork in which I engage in a community and accommodate myself into the new surroundings, but it is more of a fragmented fieldwork, or what has been called a multi-sided fieldwork (Hannerz, 2006; Marcus, 1998), taking place in many different settings and among people with no obvious other resemblances or connections than the fact that they share the same diagnosis and nationality. When I started my project, my intention was to collect data from newspapers, attend support groups for adults diagnosed with ADHD and medical classes at the university about mental illnesses, and to interview adults diagnosed with ADHD. Inspired by Martin (2007) and her work on manic depression, I wanted to create a collage of how ADHD is represented and experienced in Denmark, including very different kinds of methods and data. But even if my project changed to focus more on experiences of ADHD and less on representations of ADHD, as I describe in the introduction, I still use the knowledge gained from reading newspapers and attending seminars on ADHD as a background for understanding the debates surrounding ADHD that my informants also relate and refer to. I examine experiences of ADHD in a time and place when ADHD is highly debated, and my informants often mentioned the general critique of ADHD as a trending diagnosis, making the debates and common explanations a natural subject for conversation. My extended field, then, is what I have previously referred to as a diagnostic culture, in which psychiatric diagnoses are used as tools

for understanding oneself, and more specifically, my field is a diagnostic category that people relate to in certain ways.

Hannerz (2006) outlines the general shift in anthropological fieldwork from being geographically bounded to being multi-sided (p. 23). Following this shift, the traditional “anthropology of immersion,” when the anthropologist is involved to the point of almost going native, is replaced by an “anthropology by appointment,” referring to the reality that access to informants is often limited, regulated and timed (p. 34). The notion of immersion implies that the field exists as a fixed entity, awaiting discovery and independent of the fieldworker’s engagement (Amit, 1999, p. 6), and the ambition of being immersed might therefore always have been an illusion. Similarly, Marcus (1998) suggests that the idea of rapport and that identification with informants is the only access to real knowledge, needs to be replaced by a relation based on complicity and collaboration with the informants. My fieldwork has been anthropology by appointment, in the form of participating in seminars, in doctor’s appointments, and in scheduled interviews. I have entered the field in limited periods of time and withdrawn from it afterwards. But still, my informants have offered me stories about their life with ADHD and I have been challenged on my knowledge of ADHD.

6.2. RECRUITING INFORMANTS

As I described in the introduction to this thesis, my knowledge about ADHD at the beginning of this project was limited to research about the emergence of diagnoses and I had no personal experiences with ADHD and knew no one (as far as I know) diagnosed with ADHD at that time. I was dealing with a diagnosis widely debated in the media, but the voice of the people diagnosed was rarely spoken, so I decided to begin with the people in concern. It was my intention to slowly start interviewing in order to get a hold on what ADHD was, what concerns the diagnosed had, and let these first insight direct my research.

I used two different channels for recruiting informants: Firstly, I was in contact with a clinic of general practitioners in a socially disadvantaged neighborhood through the Diagnostic Culture research group, and they offered to ask patients diagnosed with ADHD in their clinic if they wanted to participate in my research. Secondly, I posted a request for informants on a Facebook forum for adults diagnosed with ADHD. The clinic opened their doors for me, allowed me to participate in consultations when the patient accepted it, and helped establish contacts with some of their patients. At first hand, patients were interested in participating in the project and they were very open about my presence in the consultation room, but I came to learn that arranging time for an interview was more problematic. Some never responded to my phone calls or text messages, and some declared afterwards that they already had too many activities, but finally, three people from the clinic participated in the project. My post on Facebook was met with tremendous interest

and enthusiasm about participating in the project, and within a couple of days I had more than two handfuls of appointments in the pipeline. Some were curious about knowing more about ADHD and saw their participation as an exploring element in their own research about ADHD (and I had to remind them that they were the experts and I was the novice), while others were motivated by the possibility of telling their story to the public (and I had to inform them about the limitations of a Ph.D. project). Like my experience from the clinic, however, not all arrangements were possible to settle and I ended up with seven informants from the online forum who participated in my research. Additionally, one informant became part of the project after an ADHD seminar where my supervisor was doing a presentation, a friend of an informant joined, and yet another contacted me after reading about the project while researching information about ADHD.

My criteria for choosing informants were firstly that they needed to be diagnosed as adults (after turning 18 years); secondly, I wanted to have equally as many men and woman; and lastly, I wished to have informants within a broad age span (at least 20 years). These criteria were not based on an ambition of specifically investigating gender¹⁴, class, or social aspects¹⁵ of ADHD, but rather it was my intention to include a broad range of informants. Even if the common characteristic of my informants was the fact that they were diagnosed with ADHD and I was trying to identify patterns in experiences of ADHD, I was aware of not identifying my informants as a particular social group (Amit, 1999, p. 14; Gulløv & Højlund, 2003, p. 349), and I wanted to represent and leave room for each informant and their particular experiences in my analysis of ADHD.

After unfortunately losing contact with potential informants, I ended up with 13 informants participating in my project: five men and eight women, aged 26-45 years. They had all been diagnosed with ADHD within five years except for two informants who were diagnosed seven to eight years ago. The informants were occupied within a wide range of professions, from working in sales, being a social and health care assistant, working as a mechanic, working as an IT technician, being in a working ability testing program, and being a student.

¹⁴ Gender ratio estimates of prevalence of ADHD says 2:1 or 3:1 for males and females, and some studies even claim that the ratio is 1:1 among adults (Owens, Cardoos & Hinshaw, 2015, p. 242). I do not explicitly deal with the gender issue, partly because I do not have enough data to support gender differences and partly because the gender aspect did not figure as a distinctive theme in my informants' narratives.

¹⁵ Research shows a significant overrepresentation of people diagnosed with ADHD in prisons compared to the general population (Berger, 2015).

Name	Age	Occupation	Years since diagnosis	Family relations	Interviews
Peter	26	Mechanic	1	Lives with wife and two children	3
Karen	45	Health care assistant	4 ½	Lives with her three children	1
Ann	39	Working in health care	½	Lives with her three children	1
Susan	42	In work ability testing	2	Lives with her two children	1
Kenny	37	Pedagogue	7	Lives with girlfriend and child	2
Thomas	38	Warehouse operator	5	Lives with his two children	1
John	35	Working in sales	4	Lives with wife and two children	2
Susie	43	Health care assistant	½	Lives alone	3
Louise	26	Student	3	Lives with boyfriend	1
Christian	33	Working with IT	4	Lives alone	1
Jenny	28	Student	½	Lives with boyfriend	1
Kelly	26	Student	3 ½	Lives with boyfriend	3
Judith	45	Self-employed	7-8	Lives alone	1

All my informants had been on sick leave at least once due to stress or depression and the ADHD diagnosis was often received following this period. As an example, one of my informants, who I call Christian, told me the story of how he had experienced periods of unhappiness and of not functioning well, as he describes it, throughout his life. He remembers being bullied as a child, because he was different from the other children, and when he started studying, the pressure of administrating reading schedules and deadlines became too overwhelming. First, he was diagnosed with depression and was taking anti-depressants, but the bad periods kept returning and he had to quit his studies. Only then was he referred to a psychiatrist, who diagnosed him with ADHD. Another circumstance for getting the ADHD diagnosis was the diagnosing of a child, which was the case for five of my informants. As an example, a woman, who I call Judith, explained how the diagnosing of her son made her research ADHD and she was not only able to mirror her son but also herself in the diagnosis. Recognizing herself in the symptom descriptions made her see a psychiatrist, who diagnosed her with ADHD.

Anthropologist Ton Otto (1997) warns fellow anthropologists about basing research on informants whose views “may not be typical for his or her society, or may represent the perspective of a particular group” (p. 98). Considering the number of potential informants who showed enthusiasm for the project and contacted me based on the Facebook post, but whom I lost contact with despite numerous phone calls and text messages or who let me know that they were going through a difficult patch and therefore could not participate, my informants may represent some of the more

advantaged people diagnosed with ADHD (even if they also had difficult periods during the period I came to know them). Moreover, the informants I recruited from the online forum all chose to participate in a forum debating ADHD related issues and to actively contact me. Hence, using this channel for recruitment gave me access to people who actively relate to the diagnosis, search for information, and benefit from discussing the diagnosis with others, and precludes me from getting access to people diagnosed with ADHD who are less concerned with the diagnosis or maybe even oppose the diagnosis. This may also account for the lack of concerns about stigmatization among my informants and their general gratification with being diagnosed, as I briefly describe in chapter 4. The people I have interviewed, have all had the surplus of mental resources to respond to my request, arrange a meeting, and talk to me about their thoughts and everyday practices.

6.3. INTERVIEWING, BEING WITH, AND DOING OBSERVATIONS

Doing fieldwork is a “way of doing” and “a way of learning and conversing” (Gudeman & Rivera, 1995). It is an encounter between anthropologist and informant, and during my fieldwork, I have continuously had the ambition of doing research in collaboration with my informants. We have shared views, they have told me their stories, and I have presented my ideas, which they have challenged and help me modify.

6.3.1. INTERVIEWING

Following Kvale and Brinkmann (2009), I consider the interview to be a situation of an “Inter View” understood as “an inter-change of views” (p. 2). From this perspective, the interview represents the interaction between two people as well as the production of knowledge constructed between the two (p. 2). I did my first interview three months after I started my project and the last interview seven months before I handed in the thesis. The longitude fieldwork of almost two and a half years made it possible for me to reflect on the first interviews, make corrections to the interview guide based on my experience using it, develop new interests from the stories I was told, and share my initial analyses with my informants.

I conducted 21 interviews ranging from one to four hours. The level of structure varied in the interviews, some being closer to a conversation than an interview following a strict structure, but I chose to categorize conversations with my informants as interviews if they were recorded on my Dictaphone, were based on questions prepared in advance, and were transcribed afterwards. Eight of my informants were interviewed once, two were interviewed twice (two men) and three were interviewed three times (one man and two women). I wanted to keep contact and do follow-up interviews with a handful of my informants in order to elaborate or clarify subjects from the first interview and to get involved with and establish a closer relation with some of my informants, and it was my ambition was to re-

interview at least two men and two women. I managed to maintain a fair gender ratio for my revisits, but pragmatism also settled whom I kept contact with as I again experienced cancellations when some were going through a bad period.

The interviews were primarily conducted in the homes of the informants and I always initially suggested doing the interview in my informants' home, since this location offered a natural opportunity for not only asking and answering questions, but also for observing and talking about everyday practices and routines. However, three informants preferred doing the interview in another place and one preferred doing the interview by the phone. A messy house and the flexibility of meeting in another place or talking by phone were mentioned as explanations for not doing the interviews at home, and I acknowledged that inviting a stranger into one's home can be overwhelming or unwanted. Hence, one interview was conducted in my office at the university, one in my home, one at the local library, and one by phone.

The first interview with each informant focused on the person's life story, the diagnostic process, understandings of ADHD, what it meant to be diagnosed, everyday difficulties, and on the effects of medication; while the second and the third interview (with those who were interviewed more than once) opened up for discussing in further detail issues previously debated besides a general "since the last time." For the first interviews, I used a semi-structured interview guide that was structured thematically based on the following themes:

- Personal information: age, employment etc.
- Life story: upbringing and family relations
- Diagnostic process: the clinical encounter, life circumstances
- Everyday difficulties: how ADHD is experienced in everyday life
- Taking medication: experiences with and considerations about taking drugs
- Understandings of ADHD: how is ADHD explained
- Hopes and concerns for the future: job, family, treatment
- Using online groups related to ADHD: how are the forums used
- ADHD in the media: reflections on popular portrayals of ADHD

For each theme, I had between two and six questions. The questions were open, encouraging the informant to elaborate, for example: "Can you tell me about your first consultation at the doctor, when ADHD was mentioned?" Or: "What is ADHD in your own words – if you should explain ADHD to someone who knows nothing about ADHD?" And: "What happens when you take the medication – how does it feel?" For the follow-up interviews, I prepared a separate interview guide for each informant, addressing issues from the first interview and asking about specific events I knew had happened since the last interview, as for example: "Last time we spoke, you told me that getting the diagnosis was like entering a labyrinth – can you clarify what that means?" Or: "Last time you told me about the negative side effects of the drugs – did you talk to your doctor about changing label?" Sometimes, my

informants texted me in order to update me on their life or if they had come up with additional thoughts to our previous conversation, and I used these extra comments as a basis for developing the second interview guide. Just like I was examining life with ADHD, so were my informants exploring how to live with ADHD, and I was grateful for being included in their everyday reflections and observations.

Conventional interview techniques are challenged when doing interviews with people who have difficulties with attention and who get restless easily (Prosser, 2006, p. 9). Generally, my informants were answering my questions in great detail and coming up with examples to illustrate their story. Some had attended various kinds of therapy in their life and were used to telling their story while others were more unfamiliar with the situation of describing and remembering past events. My role as an interviewer, therefore, ranged from a guiding role, asking many questions, to an organizing role, making sure we more or less kept focus on ADHD related issues. I often experienced the interviews taking new directions as one story followed another in a stream of anecdotes and I frequently needed to remind my informant, on their request, of my question. These detours, however, offered me valuable knowledge as they led us to talk about issues beyond the questions of my interview guide and as they illustrated what my informants described as difficulty with concentration and resting on one thing at the time.

6.3.2. BEING WITH INFORMANTS

Interviewing not only provided me with my informants' verbal reflections on life with ADHD, the interviews also gave access to an embodied knowledge about ADHD. Anthropologist Anne Line Dalsgård (2003) argues that ethnographic knowledge stems from much more than interviews and observations. Emotions, sensory perceptions and bodily competences are mixed with intellectual knowledge and become experience (p. 330). During the interviews with my informants, I experienced the restlessness and the difficulty with concentration that my informants were verbally telling me about, manifested in their way of speaking and being in the room. From her fieldwork among blind people, anthropologist Pia Lundberg (2003) describes how doing fieldwork in a different sensory world is an act of gaining knowledge about a certain way of sensing, experiencing and being in the world (p. 139). Similarly, I began to recognize during my fieldwork, by being with my informants, that understanding ADHD entailed an exploration of ADHD as a certain way of experiencing and being in the world. I started taking notes of my informants' bodily movements, of their fidgeting with things, and of characteristics of their way of speaking during the interview as jottings (Bernard, 1994) as well as more extensively shortly after the interview as for example: "sits on his hands;" "stands up to open the door only to close it again a minute later;" "sometimes, I find it hard to follow her story as she jumps back and fourth in time;" or "I get the impression that he is having difficulty concentrating for long and that we need to take some breaks to make the situation [the interview] bearable." Although interviewing is

often accused for entailing a bias towards verbal and theoretical knowledge (Otto, 1997, p. 98), my experience with the practice of interviewing and of participating in the interview, was that not only the words but also the situation of being with my informants offered valuable knowledge.

Within anthropology, participant observation as a method is debated. The concept itself is said to be an oxymoron, as participation and observation are mutually exclusive. The positivistic, observational gaze and the phenomenological endeavor to participate in order to gain knowledge contradict each other, it is stated (Gammeltoft, 2003, p. 279). Moreover, the term participant observation suggests that the method implies a “straight forward and clear cut methodology about which there is consensus, whereas in practice it covers quite different ways of data collect and correspondingly different kinds of knowledge” (Otto, 1997, p. 96). Anthropologist Tine Gammeltoft (2003) challenges the traditional comprehension of participant observation by arguing that participating includes more than the anthropologist’s practical engagement in everyday life in a local community. Participation is involvement with another human being’s life and world, which the anthropologist attains through his or her imagination and ability to empathize, whether it is an involvement in practical activities or personal stories (p. 286). Anthropological knowledge, Gammeltoft states, is based on involvement and even if we cannot experience what the other person experiences, we can use our ability to emphasize to imagine what the other experiences (p. 284). The theoretical differentiation between interviewing and doing participant observation is often not clear-cut while doing fieldwork. In my fieldwork, interviews, conversations, participations, and observations were not always easy to separate as distinct methods, but rather while being with my informants, I made use of all these methods. Being in the car on our way to the psychiatrist with an informant, while talking about both expectations for the consultation and about everyday issues; drinking coffee in the kitchen while discussing the rise of people being diagnosed with ADHD; chatting on Facebook about the evening’s TV show from the Amazonas and discussing whether indigenous people living in the jungle have ADHD; or texting an informant in order to hear if he is doing better after a stressful week made him cancel our last appointment. These practices are just ordinary parts of doing fieldwork, but they all involve different aspects of involvement, participation, observation, and conversation and they all contribute to gaining knowledge.

6.3.3. DOING OBSERVATIONS

During my fieldwork, I did several observation studies. I followed two of my informants to the doctor: one visit to the general practitioner with each of the two informants and one consultation at a psychiatrist with one of the informants; I attended four public seminars and conferences for people diagnosed with ADHD and their relatives and for professionals working with ADHD; I followed different

online forums and blogs about ADHD; and finally, I kept updated on popular media coverage of the diagnosis. My role as observer varied from nonparticipation (Spradley, 1980, p. 58), when reading newspapers and following online debates and blogs, to passive participation (p. 59) at conferences and seminars, taking the role as a spectator, and to moderate participation (p. 60) when following my informants to the doctor and being identifiable as a researcher but not actively participating in the activity. When participating in consultations and at conferences, I took detailed notes, both descriptive and analytical notes (Bernard, 1994, p. 188), trying to write down as much as possible a direct conversation. From my observations online, I copied relevant discussions, perspectives and conversations into a word document.

The observations made it possible for me to observe how ADHD is discussed and expressed in different contexts and they contribute to my research as background for understanding the context in which my informants experience ADHD. Attending the seminars taught me about the official explanations of ADHD and ideas about coping with ADHD and following the online forums and blogs gave me insights into how ADHD to some is not only an individual diagnosis, but also a diagnosis to share with a community of others diagnosed with ADHD. Seminars as well as online discussions were well attended and the debates were vibrant and the participants exchanged ideas, experiences, and everyday tips. From my observations in the clinical rooms, my informants' stories about drugs as the central theme for conversations with their doctor were confirmed. The discussion of drugs was not only initiated by the doctor but also by the patient, and the observations gave me a small glimpse into the institutional and biomedical regime that the individual is included into when getting a diagnosis.

6.4. THEMATIZING, ANALYZING, AND WRITING

The process of analyzing my data has been winding, investigational, and a continuous activity throughout the PhD project. Early in my research, I was thrown into the analytic process, as two assignments (a ten-page paper for a PhD. course and a chapter for an anthology about diagnoses) demanded a written product from my hand based on my initial data. What I considered to be the exemplary model of firstly gathering and analyzing a full data set before starting the writing process was impossible to comply with. Hence, I have been working with tentative analyses almost from the beginning of my project. The constructive aspect of working tentatively and explorative with my material has been the recognition of writing as an analytic process. The writing process required engagement with my data and knowledge from the on-going fieldwork and I learned that the writing process itself generated analytical ideas and arguments. While working with the text, new perspectives unfolded and I started to actively use the writing process as an instrument for experimenting with and materializing ideas. The unconstructive aspect of this type of working procedure, however, was the lack of overview of my data. I started writing all three articles presented in this thesis before I had finished

my fieldwork, but had I followed a more linear procedure, I would probably have structured my three main arguments, each presented in one of the three articles, differently. For example, I might have dealt with the issue of taking drugs in a separate article rather than including it in the article: “Structuring the self: moral implications of getting a diagnosis.” Medication is a central theme in my data material, and a more thorough analysis of the motivations for and the consequences of taking drugs could have made an important contribution to the thesis.

My strategy for analyzing has primarily been a data-driven strategy (Gibbs, 2007). I have read my entire data material multiple times, and every time I am familiarizing more with the data, writing comments to myself in the margin, as illustrated with respectively a field note and an interview excerpt in the table below.

Field note, at the doctor	My comment
<p>Kelly says she would like to discuss her medication. She describes how she has stopped taking Zyprexa because it made her too tired and made her lose all initiative. She started taking 1 tablet, then she took only a half and now she has stopped taking them. “How is your sleep then?” the doctor asks. “It’s short but I sleep reasonably,” Kelly answers. The doctor nods and smiles. Kelly continues: “But Zyprexa, I would really like to not take it anymore.” “But your period of anxiety has also stopped, and that’s really wonderful. How about Ritalin, do you still need that for the restlessness?” the doctor asks. Kelly answers: “Yes, I need 40 mg in the morning until you say stop.” Kelly continues, describing how she has applied for a new job and would like her everyday life to work again: “I feel like I can manage again and that I can stay awake,” she says.</p>	<p>Experimenting with dosage and labels – how to negotiate between not being too tired during the day and still being able to sleep? How to manage a normal life?</p>
Interview excerpt	My comment
<p>There’s a before-Louise and an after-Louise. The life I lived before [the diagnosis] and the life I live now. It’s not at all the same. It’s not. It’s a readjustment process relating to it [the diagnosis]. For a period of time, I was looking at my life through ADHD glasses before I was able to separate things from each other. I mean: what was ADHD? All the things in my life. What if I didn’t have ADHD? All of a sudden you reconsider a lot of things</p>	<p>Benefiting from the diagnosis – but it’s a process of accommodation, acceptance and new self-perceptions.</p>

and think: what could have happened and how? It was a process I had to go through. But those first months - when you had to find out what exactly it meant - they were tough.	
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I did not practice a specific coding of my data, but I used my comments as a way of meaning condensation and meaning interpretation (Kvale & Brinkmann, 2009), and based on my comments, I clustered several general themes in my material. Psychologist Martin Packer (2011) points to the problems associated with coding, namely that it can lose the voice of each individual, it can destroy the interconnections in a transcript, and it assumes there is a single, fixed meaning (p. 79). Coding can mask the interpretive process of analyzing, by pretending to overcome subjectivity when following special rules or procedures, Packer argues. Hence, the messiness and fluctuation of the data disappears and the context is lost. I have tried to take advantage of the iterative aspect of my analytical process, re-reading my field notes and transcripts of interviews parallel with reading relevant theoretical texts, acknowledging the messiness of both my data and of the analytical process. I have moved forward and backward between sources of inspiration based on both a hermeneutic ambition of continuously reinterpreting my material and a pragmatic consequence of writing while doing longitude fieldwork.

6.5. ETHICAL (AND ANALYTICAL) CONSIDERATIONS

The American Anthropological Association's Code of Ethics (2007) lists fundamental ethical concerns regarding responsibility to the people with whom anthropological researchers work and study. Two concerns are especially relevant to my study, namely that the development of knowledge can lead to change, which may be positive or negative or for the people of study, and that researchers must carefully and respectfully negotiate the limits of relationship. During my research, I needed to be clear about the reach and the limits of this project. I was met with high expectations from my informants to improve conditions for and raise awareness about ADHD, and on the one hand I had to emphasize the limitations of my project as previously mentioned, and on the other hand I knew that I was entering a controversial debate in Denmark about psychiatric diagnoses and in particular ADHD and that the Diagnostic Culture project and publications from this group would attract some level of public attention. I was aware of not "faking friendship" (Kvale & Brinkman, 2009, p. 75) in order to get access to data, but I was involved with my informants and therefore felt both a professional and a personal responsibility for representing their experiences respectfully and in a way they would recognize and appreciate. Moreover, I had to position my research and my engagement in the Diagnostic Culture project, which critically investigated the rise of diagnoses, and find a balance between curiously questioning the development of diagnoses and pragmatically observe that people are increasingly getting psychiatric

diagnoses and examine the personal implications following a diagnosis. Concretely, I was contacted by a nurse working with psychiatric patients who was interested in my research and a man diagnosed with ADHD himself who challenged my arguments after reading a publication of mine (and accused me of not including neuroscientific research on ADHD). As with my informants, I entered into dialogue and had rewarding conversations with both about the ambitions of and the perspectives presented in my project, but the confrontations made me realize that I was not only representing my informants, my responsibility reached even further.

Another ethical dilemma I encountered was how to navigate between on the one hand writing articles based on what my informants were primarily concerned with and repeatedly returned to in our conversations (which often involved hassles with social service institutions and their lack of knowledge about ADHD and about the relief of getting the diagnosis), and on the other hand having an academic ambition of generating new knowledge and filling a gap in research. In many aspects, my research confirmed what was already stated by the (yet limited) literature on adults' experiences of getting an ADHD diagnosis, and I fervently wanted to contribute with new perspectives to the research field. But to what extent could my theoretical and academic interest guide my writing? The general themes identified from my material formed the basis for my arguments, but my eagerness for not reproducing already existent research on experiences of getting an ADHD diagnosis intrigued me into going in new analytical directions with my material. Some ideas crossed the line for what I later considered appropriate, but other ideas remained in different versions. In a way, my concerns reflected a general dilemma about how to represent others' experiences and lives and the extent to which the anthropologist's text portrays the writer's interpretations and preferences rather than his or her informants. But my concerns also reflected my attempt to position myself within the research field I entered and within the Diagnostic Culture group.

The first time I was confronted with the dilemma was while writing one of many drafts for what later became third article in this thesis about explanations of ADHD and ways of relating to the diagnosis. I had just started interviewing and I worried about not conducting authentic anthropological fieldwork. Moreover, being affiliated with the department of psychology and communication, I felt a need to adhere to my anthropological background. In one of his writings about headhunting, Rosaldo (1984/2004) reveals how he initially, in search for an explanation of the phenomenon, turned to traditional exchange theory, "because it had informed so many classic ethnographies" (p. 580). Being a central theme in anthropology, Rosaldo assumed the perspective would inform his research. He realized later, however, that there was no evidence supporting the perspective and that searching for a deeper explanation of headhunting detained him from understanding the phenomenon. Similarly, I might have been too enthusiastic about comparing ADHD to classic anthropological themes. From my interviews, I identified a certain way of speaking of ADHD as an entity, detached from the individual, and in order to

understand this way of relating to ADHD, I turned to ideas about spirit possession in anthropological literature. Descriptions of rituals, experiences of trance, and shamanism suddenly occupied my bookshelf as I explored anthropological accounts of these unfamiliar phenomena. I was not sure where this perspective would take me, but I had a troubling feeling that I had to abandon the approach. Like Rosaldo, I shared my thoughts with one of my informants as a way of testing the idea, and similarly to Rosaldo's informant, who unimpressively said he could imagine someone could think such thing about headhunting, so responded my informant. Still I worried that the analysis exoticised ADHD and I was afraid that the perspective could be offensive. I was interviewing people, who wanted to live an ordinary life and were struggling for acceptance, and here I was 'othering' them, paralleling their experiences to mysterious phenomena. Even if I found it analytically interesting to compare experiences of ADHD with experiences of spirit possession, and the idea would contribute to the existing literature with new perspectives on experiences of ADHD, I finally chose to only briefly refer to spirit possession as phenomenon rather than making it a key argument. As it appears in the article "My ADHD and me: identifying with and distancing from ADHD," the perspective was not completely shelved, and I returned to the idea in a moderate version and no longer as an attempt to explain experiences of ADHD, but rather to draw an analytical parallel.

The question of analytical choices and of being seduced by an idea reappeared when I was writing my second article "ADHD and temporality: A desynchronized way of being in the world" about ADHD as an arrhythmic being in the world. In this article, I particularly wanted to examine the phenomenology of ADHD and ask if ADHD covers a certain way of being in the world. Even if I had learned from reading Hacking (2007) that experiences of symptoms and knowledge about a diagnosis interact, and through my interviews with informants similarly learned that talking about ADHD without using the diagnostic language was sometimes a challenge (Nielsen, 2015), I had an ambition of examining the illness, the pathology, the way of being and experiencing, rather than examining the diagnosis. On the one hand, this article was my attempt to get close to the lived experience of ADHD, and on the other hand, the article applied a specific analytical framework, namely the rhythmanalysis offered by Henry Lefebvre (2004), and again I considered if the analytical perspective overshadowed rather than opened up what I wanted to illustrate. However, after presenting the idea to both fellow researchers and to a couple of my informants who enthusiastically encouraged me to unfold the idea, I convinced myself that the perspective could maybe represent my informants respectfully as well as contribute to the literature on experiences of ADHD. I genuinely hope that the analytical and theoretical choices I have made and the research presented in this PhD. thesis help nuance the debate on ADHD.

Lastly, I should mention that the project was approved by the Danish Protection Agency.¹⁶ The names of my informants have been changed and personal information, which may compromise anonymity, has been changed in order to protect my informants' anonymity. I informed all my informants about the project prior to the interviews and told them that they could withdraw from the project at any time.

¹⁶ In Danish: Datatilsynet

CHAPTER 7. STRUCTURING THE SELF: MORAL IMPLICATIONS OF GETTING AN ADHD DIAGNOSIS

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Structuring the Self: Moral Implications of Getting an ADHD Diagnosis

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ABSTRACT: In this article, I examine experiences of getting an ADHD diagnosis in adulthood. I illustrate how getting an ADHD diagnosis is a process in which existential questions are raised; judgements and choices are made; and everyday practices are scrutinized, evaluated and changed. Inspired by an analytical framework offered by anthropologist Cheryl Mattingly and based on interviews with adults diagnosed with ADHD, I analyse the implications of being diagnosed with ADHD. I argue that the implications entail different moral tasks that can be analysed from what Mattingly calls three moral scenes: 1) the trial where moral judgements are made; 2) the workshop where practices are cultivated; and 3) the moral laboratory where everyday experiments are carried out. In closing, I will briefly discuss the societal conditions for how diagnoses have become carriers of self-understandings.

KEYWORDS: ADHD, diagnosis, experience, morality, moral striving

When I got the ADHD diagnosis, I got calmness. The reason I got calmness was because I got medication. And then I was suddenly able to start understanding myself. I was able to use my strengths in a more focused way, to find a balance, and develop new strategies and the like. I've always had many strategies for how to live life. (Karen, 45 years, diagnosed at 41)

How can we understand experiences of getting an ADHD diagnosis and the practical, existential, and moral implications that follow? Karen's quotation above indicates how new ways of being, acting, and understanding oneself often accompany a diagnosis – some directly caused by the effect of medication, some by the explanatory force of the diagnosis, and others by the careful crafting of new practices.

In this paper, I examine experiences of getting an ADHD diagnosis in adulthood. According to the diagnostic criteria, anamneses must demonstrate symptoms of ADHD from the age of 12 or earlier in order to be diagnosed with ADHD (American Psychiatric Association 2013). Hence, the diagnosis offers a frame for interpretation that captures a whole life's sensations, feelings, and patterns of behaviour when the individual is diagnosed in adulthood. The diagnosis answers a number of questions and helps the diagnosed to identify, accept, and cope with problems by offering concrete explanations to and treatment of the experienced problems. However, even if the diagnosis is a great help for many, the diagnostic process is not only clarifying but it also brings new challenges and questions. Relating to the diagnosis and testing drugs is a process full of evaluations, experiments and readjustments, in which the individual must turn his or her attention inwards and evaluate everyday problems. Therefore, the actual diagnosing might happen at the psychiatrist's office, but acquiring and making use of the diagnosis happens in all sorts of settings and everyday practices.

Through excerpts from my fieldwork, I illustrate how getting an ADHD diagnosis is a process in which existential questions are raised; judgements and choices are made; and everyday practices are scrutinized, evaluated and often changed. Inspired by a framework offered by anthropologist Cheryl Mattingly (2012, 2014) that outlines how moral practices can be studied from three analytical perspectives, or as she calls it, three 'moral scenes', I analyse the implications of being diagnosed with ADHD. The moral scenes are: 1) the trial where moral judgements are made; 2) the workshop where practices are cultivated; and 3) the moral laboratory where everyday experiments are carried out. Mattingly argues that the three moral scenes, representing Nietzschean, Foucauldian and Aristotelian perspectives, respectively, can be used to analyse the same ethnographic material, but she advocates for the last. I, however, find each moral scene analytically helpful in illustrating how the process of receiving an ADHD diagnosis entails different moral tasks. Hence, my concept of morality has three dimensions, conceptualized by the three different moral scenes. From these analytical perspectives, I argue that the

diagnostic process entails a verdict and a process of recognizing oneself as someone with ADHD; a number of guidelines and a process of crafting new skills; and lastly demands of continuous self-evaluation and an experimental process of becoming the person you want to be. In closing, I will briefly discuss the societal conditions for how diagnoses have become carriers of self-understandings.

I will present excerpts from my interviews with adults diagnosed with ADHD and my observations while visiting and spending time with the interviewees. Throughout the last two years, I have interviewed 13 adults diagnosed with ADHD (five men and eight women, ages 26–45). Five of them have been interviewed two or three times while the others have been interviewed once. My informants describe their life as chaotic, their thoughts as messy, and they report of a life full of misunderstandings and of feeling different. In their struggle to find calmness in life, as Karen describes at the beginning of this article, the diagnosis has been helpful. The diagnosis helps order chaos in different ways by structuring self-understandings, giving guidelines for practices, and changing experiences and perceptions through medication. Each moral scene in this paper, therefore, represents a way of structuring the self. My take on the data is to see the process of getting an ADHD diagnosis as a process of moral striving, and my analytical framework takes as its point of departure an anthropology of morality that stresses the importance of investigating theoretically and empirically the individual's moral striving in life and in everyday practices. As anthropologist James Laidlaw (2013:3) states: 'The claim on which the anthropology of ethics rests is not an evaluative claim that people are good: it is a descriptive claim that they are evaluative'. I follow this claim about people as evaluative (and self-evaluative) in my study of individuals exploring the possibilities of an ADHD diagnosis.

ADHD and the effect of diagnosing

ADHD is characterized by symptoms of inattention, hyperactivity, and impulsivity, and studies estimate a 3.3–5.3% prevalence in adult population (Barkley, Murphy and Fischer 2008, p. 17). Research on ADHD is mainly done from a psychiatric or critical sociological perspective, describing ADHD as either a neurobiological disorder (Barkley, Murphy and Fischer 2008) or as a product of medicalization processes (Conrad 2007; Timimi and Leo 2009). Gordon Tait (2005) identifies three general theories about ADHD in popular and academic literature: 1) the true believers of ADHD who are often psychiatrists and neurologists; 2) the ones who believe ADHD might exist, but that it is too often diagnosed; and 3) those who do not accept ADHD to be true. My understanding of ADHD, however, is more pragmatic rather than either supportive or critical. In her study of bipolar disorder, anthropologist Emily Martin (2007:29) argues that the disorder *is* real because of the social and cultural meanings attached to the diagnosis. I consider ADHD to be real in the same way. Real people go to the doctor and are diagnosed, real people

understand themselves through the diagnosis, and medical treatment is based on the directions of the diagnosis.

Few studies have examined adults' experiences of getting an ADHD diagnosis. Convergent with my research, the results from the studies show that people welcome the ADHD diagnosis as an explanation for their problems, that the diagnosis brings new knowledge, that medication has a positive impact on their ability to function, and that the diagnosis brings acceptance of oneself (Andersen 2009; Halleröd, Anckarsäter, Råstam and Scherman 2015; Jones and Hesse 2014; Young, Bramham, Gray and Rose 2008). I contribute to this literature by illustrating how getting an ADHD diagnosis is also a moral and evaluative process. I want to focus on the formative aspect of the diagnosis and by that follow the 'moral turn' (Mattingly 2012) within anthropology that encourages anthropologists to raise questions concerning the individual's moral striving and 'how we should live and what kind of person we want to be' (Lambek 2008:134) by focusing on the individual's continuous striving for the good life.

The trial: A verdict called ADHD

Getting a diagnosis is like getting a verdict. The diagnostic process is the culmination of years of feeling different followed by months of assessing and weighing symptoms. The diagnosis is the demarcation of the normal from the abnormal and wellbeing from the pathological. I start by addressing the diagnostic process as an event of judgement by using Mattingly's notion of the trial to examine the moral implications of getting an ADHD diagnosis.

Mattingly (2012) introduces the trial as a moral scene where the moral 'I' is born. Inspired by Nietzsche, Mattingly describes this moral scene as a 'courtroom in which we stand accused' (p. 302), and as a place where 'we are brought to trial, so to speak, and asked to justify our actions' (p. 302). At the trial, the individual is blamed for his or her insufficiency, handed a verdict, and demanded moral responsibility of. In a context of diagnosing, the process of examining and completing anamnesis, scrutinizing childhood behaviour, school performance, and social skills parallels the justification and confession of the courtroom. The individual is the object of study and the one to change. He or she is held responsible and expected to take the necessary measures: to start treatment. Judith Butler (2005:10) argues that punishment posits the self as a causative force and thereby models a specific mode of responsibility: 'We start to give an account only because we are interpellated as beings who are rendered accountable by a system of justice and punishment'. Referencing Butler, Mattingly (2012:303) argues that we come to see ourselves as having an 'I' when we explain ourselves in the process of interrogation, writing that 'self-narratives are created as we – in terror – try to defend our own actions, casting a fearful look backwards at our past deeds, giving ourselves a history' (Mattingly 2012:303). Mattingly emphasizes the terrifying

element in the verdict – the moment when we realize that we are the ones pointed at. In my material the verdict is not received with terror. On the contrary, my informants welcome the diagnosis and they accept the diagnosis as a long-awaited explanation for their problems. However, the process of giving an account of oneself brings about a specific ‘I’ that is shaped by the interrogation process and the thoughts accompanying it.

An ADHD diagnosis often bumps into people’s lives during an evaluative moment of life, and the process of being diagnosed contributes to this evaluation with its questions and interrogation of childhood habits and everyday actions. Charts and questionnaires are filled out and for each box with symptoms ticked off in a test, a pattern of behaviour is transferred into a diagnosis. Ann, a 39-year-old woman who was diagnosed half a year before I talked to her, told me how the past year had brought various changes as she got divorced and was diagnosed with whiplash after a car accident. Ann has a history of different psychological problems and in this light; the ADHD diagnosis encapsulates a culmination of a life full of difficulties. The diagnosis enters into a process of evaluation and readjustment of life and contributes to clarifying thoughts and life choices. It directs Ann forward by offering explanations and treatment for her problems. In the following paragraph, Ann describes her reactions to the diagnosis:

Well, it [the diagnosis] made me realize why I struggle with some things. Before, I never got a hold on why I was struggling and why I was the way I was. [I] was so stressed out when too many things were happening. I kind of have a different understanding now, and I know how to act more appropriately. Things have got – well it hasn’t eliminated the problems – but it [the diagnosis] has given me an insight into why these problems occur. It made it possible for me to pin up my reactions and challenges to something. And in that way I’m actually happy and relieved to finally discover what was teasing me. I believe I’m nicer and kinder to myself [after the diagnosis]. I’m not so hard on myself anymore.

Ann’s story is not unique and I was continuously told that the diagnosis offers an explanation of a life full of difficulties. Another of my informants, Christian, who is 33 years old and was diagnosed four years ago, reports how the diagnosis made him change perspective about himself, his difficulties, and his entire way of looking at himself in relation to the surrounding world. Christian has suffered from depression and describes himself as a person who has always felt unfairly treated. The diagnosis, however, has changed his life philosophy. Christian explains:

Christian: I remember the thought it might not be the world that was wrong, but maybe it was the way I perceived it that was wrong, so to speak. I mean ... er ... in the sense that something was wrong with me.

And I remember that it was actually a pretty relieving thought in many ways.

Mikka: Okay?

Christian: About the same time, my sister was diagnosed with diabetes and I sometimes think that – it isn't the same of course – but I remember that to me it was nice ... because I wasn't feeling good at that time and being told that there was a concrete cause to it was actually really nice.

Right after the diagnosis, Christian changed his perspective on life, and the diagnosis infused him with hope that he could change. That things could be different. Today, he thinks more pragmatically about the consequences of the diagnosis, Christian tells me. He does not think of it as pivotal to the way he perceives himself, but he remembers that the diagnosis changed his perspective on why he is constantly confronted with hindrances in life. To Christian and Ann, the diagnosis systematizes and concretizes experiences of continuously bumping into problems and conflicts, and the list of symptoms and descriptions of typical problems related to ADHD gives clarity to what were previously diffuse challenges. Diagnosing is 'a ritual of disclosure,' when 'a curtain is pulled aside, and uncertainty is replaced – for better or for worse – by a structured narrative' (Rosenberg, 2002, p. 255), as historian Charles Rosenberg notes. The diagnosis collects scattered experiences and connects them into an entity and a treatable condition. Nurse and researcher Annemarie Jutel (2011:1) describes the effect of a diagnosis as follows:

Receiving a diagnosis is like being handed a road map in the middle of a forest. It shows the way – but not necessarily the way out. (...) With a diagnosis, things not necessarily get better, but they become clearer. The unexplained becomes explained, and management is defined.

From the point of view of a tangible, well-described disorder, indicating specific difficulties and offering certain guidelines, Ann's and Christian's problems are easier to address. The diagnosis might not eliminate their problems, but it makes them clearer, as Jutel says. After being diagnosed, Ann and Christian changed perception of themselves. Ann interprets her history in the light of the diagnosis and uses the diagnosis to explain her actions and her confused and troubled life. With the diagnosis in hand, Ann gives herself a history. A history that centres around ADHD and in which ADHD has been crucial for how things have developed. Similarly, Christian positions himself and his difficulties differently after being diagnosed and he connects the troubles he has met in life to ADHD rather than to a hostile world. Realizing the world is not against him, but that he himself carries not only the problems but also the key to handle them, gives Christian a new perspective and confidence that he can act and think differently in the future.

In the process of being diagnosed, the act of giving an account of ourselves implies the moral question: who are you as an individual and what are your responsibilities? A specific moral 'I' is produced along the diagnostic process, as responsibility is paradoxically both installed in and taken away from the individual. On the one hand, the problem is located within the individual and not in its surroundings, and the individual is thereby responsible for changing what is considered problematic. But on the other hand, the problem is translated into ADHD and thereby used as an explanation for the problems. In both cases, however, the individual is imposed with a moral task: he or she must relate to the verdict, make it at part of his or her history, and act upon it in order to address the identified problems. Knowing about the diagnosis renders new ways of being and acting possible. Thus, the diagnosis not only offers an explanation of past events and current problems but it also offers prospects of the future, new ways of thinking about responsibility, and a structured self-narrative. 'The past becomes different as the present and future change shape', as Mattingly writes (2014:18). My informants tell their life stories and the psychiatrist passes the verdict, but at the same time, the diagnosis offers a specific narrative and the two stories entangle into a structured diagnostic self-narrative in which the individuals interpret themselves and their life-trajectories.

The artisan's workshop: Structuring practices and crafting skills

While the diagnosis is determined in the psychiatrist's office, the practice of relating to it, discovering what it entails, and how to benefit from it happens in all sorts of places and is a long process that demands incorporation of new routines and continuous exercise. Treatment with central nervous system stimulants often follows the diagnosis and new practices and ways of administrating everyday tasks are refined in the effort towards 'living in chaos and striving for control' (Toner, O'Donoghue and Houghton 2006:247).

Inspired by Foucault's work on premodern virtue ethics and the notion of self-technologies, Mattingly introduces the second moral scene: the artisan's workshop. The workshop is where 'artisans carefully, painstakingly fashion their crafts, following exacting aesthetic standards' (Mattingly 2012:303). Contrary to the trial, where definitions are set and judgements are made, the artisan's workshop is a creative and productive moral scene, in which the individual works on him- or herself and crafts specific skills. As Foucault (1986:62) writes:

The subject's relation to himself in this examination is not established so much in the form of a judicial relationship in which the accused faces the judge; it is more like an act of inspection in which the inspector aims to evaluate a piece of work, an accomplished task.

The subject is the guardian of the task, and the moral self is created through ‘the voluntary disciplining and monitoring of thoughts, acts and especially bodies in line with the stylistic norms of the ‘guild’ to which one has pledged oneself’ (Mattingly 2013:303). As Mattingly informs us, the artisan’s workshop sheds light on the connection between crafting the self and learning, and how the individual refines body and mind according to certain aesthetic standards and guidelines. The perspective offers an analytical framework for examining practices as a means to cultivating a virtuous character and the individual’s everyday transformation of him- or herself (Mattingly 2012). From this perspective, the treatment and change of everyday practices is a moral, self-disciplining exercise, through which the individual crafts him- or herself by addressing certain difficulties and following certain guidelines offered by the diagnosis.

During my fieldwork, I have encountered several practices related to the cultivation of desirable behaviour. In ADHD-related forums on Facebook, people ask for advice concerning everyday difficulties; my informants use smartphone applications that help in administrating medicine; some structure daily activities on a big whiteboard; and finally, taking psychoactive drugs is a cultivation practice. Along with psych education courses (in both public and private settings), which a couple of my informants have attended, these different forums and activities promote certain ways of understanding, relating to, and acting upon ADHD. One of my informants, John, is curious to learn about ADHD. He reads literature about ADHD and has attended an ADHD coach course in order to learn about ADHD and maybe teach others about ADHD. Based on the course, John is practicing new techniques for coping with his temper and impulsivity. I ask him how these practices work. John answers:

John: Well, it’s all about training the brain, and about training myself to do things differently. To notice when the habitual behaviour comes. And then stop it and say: all right let’s go this way instead. I mean, when you react to something, you react based on feelings. And then you need to notice: when do these feelings come? When am I getting angry? What happened? Take a step back and notice: when am I getting angry? What’s the reason? What were my feelings before I got angry? And then next time you notice that feeling, instead of getting angry, I’ll try to take it easy. Like that ... it doesn’t just happen like that ... I think you need to practice for some years. Multiple times.

Mikka: So are you aware of this in the situation or is it something you evaluate afterwards?

John: In the situation, when it’s happening, you don’t think about it. It just happens. But then you get these tools for stepping back and thinking about it. And then you notice: what happened just before? And what’s

happening now? And then: how would I want it to be instead? And that last part is important in coaching.

Mikka: Can you better notice that now yourself? When it starts to blaze?

John: Yes, I believe so. Er... because now I'm more aware of it, it doesn't just happen. My reactions are more... if I see something on Facebook that pisses me off, I wouldn't just rush to the keyboard [on the computer], but I would think: what happens if I write this while I'm angry? Wait till tomorrow. And then I might forget about it.

According to John, the diagnosis has become a tool for changing his way of thinking and acting. He does not always succeed in incorporating the techniques from the coaching course, but he is continuously testing, examining, and crafting new skills and learning about how to control what he now identifies as ADHD behaviour. Foucault (1986:68) writes that:

The task of testing oneself, examining oneself, monitoring oneself in a series of clearly defined exercises, makes the question of truth – the truth concerning what one is, what one does, and what one is capable of doing – central to the formation of the ethical subject.

Crafting and learning, searching and realizing are interconnected and caring for the self is therefore also knowing the self. Foucault (1986:61) emphasizes the importance of self-examination and the practice of asking oneself the questions, 'What bad habit have you cured today? What fault have you resisted? In what respect are you better?' as part of the individual's care for the self. John relates and responds explicitly to similar questions as part of his examination of ADHD. Other informants more implicitly deal with such questions and challenges. My visit at Susie's place illustrates another way of cultivating practices.

Susie is in her mid-forties, living alone, and on a sick leave when I first meet her. She has been struggling with depression since her mother died two years ago, but she dreams about returning to her job and maybe upgrading her skills at work by taking some additional exams. Susie is going through an evaluative time in life, when some things have ended and new opportunities lie ahead. Her primary care person is dead; like herself, her adult son has just been diagnosed with ADHD; and she is determined to start a new chapter in life with more stability and care for herself. Susie tells me that her biggest problem related to ADHD is her inability to keep structure. Her handbag is a mess, her apartment is a mess, and her life has somehow always been messy. Cheerfully, and with a sense of disbelief, she shows me pictures of her messy apartment from just a few months ago. But the ADHD diagnosis and the treatment she receives have helped her find some kind of order in her chaotic life, she tells me. Besides her medical treatment, she has been offered body awareness therapy and a mentor who helps her clean up the apartment, which

she describes as essential for her current ability to take action in her life. She needs structure and stability and wishes she could continue with the pedagogical and body awareness treatment that has ended.

When I visit Susie a year later, she has started studying again. And even if she struggles (and ends her studies again a couple of months after my visit), she is trying every day to manage and keep herself on track. Some initiatives are huge (as her decision to not let her son's chaotic life influence her own) while others are smaller, but all of them mark a change in perspective, habits, and ways of managing life. With laughter in her voice, Susie shows me how she has made her own system of boxes, bags, and hooks for her to remember where she puts her stuff. She points at her wall and desk where all sorts of coloured boxes store make up, keys, pencils, notebooks etc. Like a large-scale pencil case or a printer's drawer, the end of Susie's apartment keeps most of the things she needs from the moment she wakes up until she leaves her place in the morning. The installations make me think of an external brain, in which different areas hold different functions: A tangible, practical memory system that visually communicates what needs to be done during the day. Some things are for morning rituals, others are for studying, and together the installation materializes the ordering of everyday practices. These small installations come forward – they somehow illustrate and orchestrate their own purpose – and they become part of Susie's way of acting and thinking.

A combination of medical treatment and practical help in housekeeping has enabled Susie to incorporate new practices and ways of handling her difficulty with structure. Still, she sometimes forgets things, but she is carefully using new techniques and crafting new skills in order to better function. Within the analytical framework of the artisan's workshop, we can understand Susie's organization of her apartment as a moral task, by which she disciplines practices according to certain guidelines and with a certain telos. Like John, Susie is exploring how she is affected by ADHD and is facing her difficulties. She is determined to overcome her problems and is exerting all her energy into the art of crafting herself as a person who is able to navigate in ordered chaos. This practice, this care of the self in Foucauldian terms, is a continuous challenge of self-evaluation that demands repetitious exercise before it is incorporated into the individual's life and self. Taking medication and practicing the ability to structure everyday activities are some of the moral implications of getting an ADHD diagnosis.

The moral laboratory: Experimenting with experiences

The practice of testing different drugs, judging their effect, and assessing levels and intervals of pill intakes is an experimental process that often follows an ADHD diagnosis. It is a process in which new experiences are made. Every day and in all sorts of activities, drugs influence concentration, bring calmness, and make everyday activities manageable, my informants report. But sometimes the drugs also

influence the individual's perception and ways of being in the world in staggering ways.

The third scene in Mattingly's analytical framework is the moral laboratory. Drawing on the neo-Aristotelian tradition of virtue ethics, Mattingly advocates for a focus on everyday ethics and describes what she calls the moral laboratory. As a heuristic term, the moral laboratory allows us to investigate moments and spaces where moral deliberations come to take centre stage and the metaphor emphasizes how everyday spaces can become 'spaces of possibility, ones that create experiences that are also experiments in how life might or should be lived' (Mattingly 2014:15). The moral laboratory captures the ethics of everyday life and the individual's many doubts, choices, hopes and practices, while trying to strive for the best good. Moral laboratories are 'experiments in hope and possibility' (p. 15). Mattingly (2014:63) insists on the ordinary and everyday activities as scenes for moral experience and experimentation, and argues that the everyday is 'characterized not merely by routine or the repressive but also by the new and the unexpected'. Contrary to the two previous scenes, in which certain texts, guidelines or laws structure the moral tasks, the moral laboratory is a scene in which the moral task is much more uncertain. Playing with the semantic relation between experience and experiment, Mattingly (2014:16) illustrates 'the experimental nature of experience itself'. In Mattingly's analyses, she describes the moral laboratory as a space, a location for moral experiences. In my material, the space is not necessarily a physical space but more of a metaphorical space: a space in an evaluative time in life. However, the concept of the moral laboratory is compelling because it emphasizes that moral deliberations exist not only as rational or aesthetic choices but also in everyday practices, and that considerations about how to live life and how to become a good person have an experimental character. My informants explore the possibilities of the diagnosis as researchers of ADHD in the laboratory of everyday life. Each day is an experiment in how life can be lived and while testing new treatment opportunities and challenges, each day holds new ways of perceiving and being in the world.

Most of my informants are treated with central nervous system stimulants. They describe symptoms of ADHD as restlessness that trembles through the body and as racing thoughts that complicate concentration and rest. Taking drugs often ease the bodily and mental chaos, I am told. However, having always experienced restlessness and considered it as a part of one's being, the sudden calmness brought by drugs can be overwhelming. Karen illustratively describes how she experienced taking her first Ritalin tablet:

Karen: I remember the first day, I was so excited and thought: it'll probably not work. I got Ritalin to start with. Then I got home, and it was quiet, and I took the pill, and when 20–25 minutes had passed, not a damn thing had happened. The shitty drugs don't work! Bloody hell that's not okay! I got disappointed of course. And then some time passed.

And all of a sudden my head was just totally quiet. I promise you, it was quiet. And I was like, everything stood on end. So I jumped over to the couch and sat down and waited till it was over, because that was just wrong! (Laughs)

Mikka: You've never tried that before?

Karen: Never! So I just sat there till it passed. 'Cause I couldn't manoeuvre in it, it was wrong, it was crazy.

Mikka: What did you expect?

Karen: Nothing, 'cause what was I to expect? Nobody told me how others experience it. Nobody had explained what I should expect. And I didn't know that many [with ADHD] at that time. (...) And it didn't take long before, with this Ritalin, I got the feeling that I was a total wacko. Completely. I promise you it was wrong. Then it was quiet, then it was chaos, then it was quiet, then it was chaos. I wish someone would have talked to me about what to expect, what I'm going through, what are the ... I mean it's the craziest thing I've ever gone through. Try to imagine that you've always been like that [restless and hyperactive] and then you get this drug and then someone pulls the rug out from under you, *swush*, and you lay down there. And it's slippery, as you can't even imagine. It's like being in an oil slick you can't come up from and there are no edges to hold on to. You just float around. And you see it coming - that is actually the worst of it - but what? Why? You have no idea.

Karen's description is extraordinary in its intense character and emotional richness and not all my informants give such a dramatic portrayal of their experiences with drugs. Some experience a sudden ability to do the dishes without being too distracted to finish the task and others sense a change in temperament and level of patience with their kids. Karen's description demonstrates the invasiveness of drugs on the individual's being in the world. This way of being – a calm, non-chaotic state – seems strange when it is first encountered and experienced. How to relate to this way of being and how to assess if this is how it is supposed to be? Karen is experiencing a profoundly different state of mind and being. All her life, her thoughts, bodily sensations, and actions have been chaotic and speeding, but Ritalin changes her condition dramatically, and consequently, it changes her relation with her children and her ability to be a mother. Karen tells me:

The medicine has made it possible for me to have my life back. It has made it possible for me to enjoy my kids and be with them. I can help them and be there for them and give them everything I have in me.

Living a life in chaos has interfered with Karen's ability to take care of herself and her children, but the ADHD diagnosis and the subsequent treatment has helped her

keep her thoughts straight – and, she tells me, it has been crucial in the path life has taken her.

Ann also describes how medical treatment has given her calmness and consequently made her enjoy moments with her children more. The drugs give ‘an inner calmness’, as she describes it and enables her to read bedtime stories to her children without having her ‘head speeding 180 [km/h]’. Being present in the moment and being patient with her children corresponds to the way Ann considers herself as a person and as a mother. However, the drugs also change her in some less desirable ways and Ann continuously experiments with labels and dosages of drugs in order to determine when side effects are acceptable, and when she is comfortable and able to recognize herself and her reactions. Ann continues:

I would prefer to find the right medical treatment because I feel it helps me. But I don’t want it to change my personality and make me different. I don’t want my way of being and the way I act towards others to change. I’ve always liked that about myself. But I feel, I’ve noticed a tendency for me to be more egocentric, if you can say that. It’s hard to put into words. But I’ve become a bit more introverted maybe. I feel I’m more me when the drugs are effective and there’re not too many side effects. When it comes to treating myself nicely and taking care of myself, it’s better with medication. But I sure need to get used to being on medication. A lot of things have been really good, ’cause I feel like I’m more patient with my kids and I don’t go off as easily. And that, I feel, is more me. Sometimes [before the diagnosis and the treatment] I felt like it wasn’t me going off, but it was something else doing it for me, and I was almost surprised by my reaction. And when it comes to that I think the medication has really helped me keeping calm and being the person I’d like to be.

Karen and Ann talk about experiences of being ‘more me’, being able to ‘give everything I have in me’, and being ‘the person I’d like to be’. A certain ‘I’ is examined, strived for, and experimented with and the drugs become the facilitators of the experimental process. Changing moods, abilities, and perceptions, drugs work as ‘capsules of potentialities’ (Trivelli 2014:159), creating prospects of another future and maybe even another ‘I’. Sometimes the drugs change the individual so profoundly that he or she loses oneself, as Ann demonstrates, while at other times the drugs help to reveal the ‘real self’ (Kramer 1993). Taking Ritalin is an experiment in hope and possibility as well as literally an experiment with experience in the assessment of how many, what kinds of, and in what interval the drugs must be taken in order to become that ‘I’. However, that ‘I’ is not a specific ‘I’. The process of experimenting and striving does not have an exact goal or telos. Rather, this ‘I’ is constantly experimented with in different contexts, with very different criteria, and more often than not, the experiments are conducted in messy situations, embedded in everyday practices and social life. These situations, in other words, are

not crossroads where the choice between left and right is clear-cut. Little changes in everyday life and changes in bodily sensations and reactions all become structuring for how Karen and Ann each assess themselves as a mother and as a good person.

Research examining the effect of Ritalin shows that the drug regulates self-perceptions and helps with self-management (Singh et al. 2010). Loe and Cuttino (2008), for example, speak of high school students' 'medicated self' and how the adolescents strategically perform 'identity management' in order to control their disordered body in an ambiguous experiment that strives to balance the experience of feeling true to the authentic self and managing the ideal self. Discussing the necessity of drugs in order to perform academically or more generally in order to live up to the complex demands of the contemporary job market is definitely relevant. However, my informants are not striving for an academic career. Their project is different and their experimentation with central nervous system stimulants is a part of a continuous striving for a manageable everyday life, for being able to do the dishes and to read bed time stories to their children without being distracted. 'The good' to my informants is what most people call everyday life. From the perspective of the moral laboratory, Karen and Ann are experimenting with possibilities, new ways of experiencing and being in the world, and new ways of being a parent. The means in the form of taking Ritalin might be radical, but the assessment of the effects happens in mundane, everyday contexts and the evaluation of the drugs becomes part of a much bigger evaluation of the self and a general process of becoming, in which new practices and reactions reveal the new 'I'. Mattingly (2014:16) refers to Hannah Arendt and her description of the 'I', the moral self, that emerges through practices. Individuals create 'the new' through practices, and through this new, they create themselves (p. 16). Karen, Ann, and my other informants are similarly creating themselves through new practices, rendered possible and experienced anew by the effect of drugs.

Moral striving in a diagnostic culture

When my informants describe a chaotic mind and a chaotic life as some of their primary challenges and the diagnosis as the key to help them order life, it illustrates aspects of what they hope and strive for and how they understand their difficulties. It also, however, tell us something about the status of diagnoses and what normative demands the individual meets (and fails to live up to). It prompts us to ask the questions: How and why have psychiatric diagnoses become tools for self-understandings? And what does the need for a diagnosis tell us about our conceptions of how to manage adult life? Diagnoses have become 'indisputable social actors' (Rosenberg, 2002:240), diagnoses are increasingly used as instruments for self-interpretations (Jutel 2011; Rose 2013), and psycho-pharmacology has opened up a new world for people to participate in (Martin 2007:xix). Particular social conditions are breeding grounds for certain diagnoses and ways of understanding human suffering, and each diagnosis reflects normative codes for

behaviour in that specific social and cultural context (Ehrenberg 2010; Hacking 1998; Petersen 2007). Researchers even claim that we live in a ‘diagnostic culture’ (Brinkmann, Petersen, Kofod and Birk 2014), in which individuals increasingly interpret themselves and their sufferings through a diagnostic language. While the diagnostic language and the diagnostic comprehension of human suffering spreads, other ways of understanding the human being (social, existential, moral, religious etc.) becomes less influential and the overall palette of understanding but also addressing human suffering narrows (p. 393). Referencing Baumann (2007), Brinkmann (2016) argues that in a ‘liquid society’ (p. 83), diagnoses can be seen metaphorically ‘as anchors that somehow promise to solidify people’s experiences of suffering’ (p. 83). Rather than struggling to break free from norms, people struggle to catch up with development and thereby orient themselves according to ‘the antinomy of the possible and the impossible rather than the antinomy of the allowed and the forbidden’ (p. 83).

As individuals, we are intertwined with the diagnostic culture, and Susie, Christian, Karen, Ann, John, and my other informants make use of the available technologies in their different projects of understanding themselves and of navigating in a world full of challenges. Karen describes her search for a diagnosis as a consequence of being in a turbulent time in life, when she needed help to develop new strategies and re-establish her life: ‘I was tearing down and building up my life and I was reaching the point of being stuck, something needed to be done, but what the heck was I supposed to do?’ As an anchor in a liquid society, my informants use the ADHD diagnosis as a solidifying, structuring element in a chaotic world. They struggle to catch up with expectations for leading an ordered life, examine what possibilities to strive for, and search for ways of anchoring their experiences of suffering. The diagnostic language helps formulate and ask moral, existential questions such as: who am I? What am I capable of? And what are my responsibilities? In that perspective, diagnoses become central actors in individuals’ evaluative projects of examining and experimenting with the possible and – as I have illustrated in the three moral scenes – considerations about the good life and initiatives for managing life are unfolded, practiced and experimented with within a diagnostic framework.

Conclusion

What can an analytical focus on morality tell us about experiences of getting an ADHD diagnosis? While the limited literature on the topic illustrates how the diagnosis offers an explanation of problems experienced and how medical treatment helps the diagnosed to function better, the moral aspect of the implications of getting an ADHD diagnosis reveals new mechanisms in the implications of being diagnosed with ADHD. Each moral scene unfolds certain aspects of how diagnoses and medication produce narratives, practices, and changes in perception that become part of a process of understanding oneself, caring for oneself, and striving to be a good

person. In this article, I have illustrated how individuals use the ADHD diagnosis as a part of a self-evaluative and self-constitutive project of becoming and how the diagnosis becomes the available tool in the endeavour to structure, evaluate, and experiment with possibilities in a life of chaos, differentness, and difficulties. The diagnosis offers a narrative for the individual to use in the process of accounting for one's actions and understanding one's life-trajectory, it gives guidelines and encourages the individual to craft new skills, and it organizes the individual's experiences and perception. All these practices and experiences are moral. They are structuring for the 'I' for each individual – the way they perceive themselves, how they act, and what they hope and strive for.

While my empirical point of departure is ADHD, I believe the analytical framework offered by Mattingly and presented in this article can be applied to research on the experience of getting other psychiatric diagnoses as well. The dramatic rise of not only ADHD diagnoses but of psychiatric diagnoses in general through the past couple of decades calls for research in the practical and existential implications of getting a psychiatric diagnosis. Investigating further the interplay between the individual's moral practices, social conditions and norms, and diagnoses as mediators and interpretive frameworks might contribute to nuanced understandings of the moral implications of diagnosing.

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CHAPTER 8. ADHD AND TEMPORALITY: A DESYNCHRONIZED WAY OF BEING IN THE WORLD

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ADHD AND TEMPORALITY: A DESYNCHRONIZED WAY OF BEING IN THE WORLD

Mikka Nielsen

ADHD is, I argue, an impairment in sense of time and a matter of difference in rhythm. In this article I explore how ADHD can be understood as a certain being in the world, or more specifically, as a disruption in the experience of time and a state of desynchronization and arrhythmia. Through excerpts of interviews with adults diagnosed with ADHD and observations from the interviews I illustrate how impairment in time is manifested in an embodied experience of being out of sync. I suggest that the experience of ADHD is characterized as 1) an inner restlessness and bodily arrhythmia; 2) an intersubjective desynchronization between the individual and its surroundings; and 3) a feeling of lagging behind socially due to difficulties in social skills. In closing, I argue that an increasingly accelerating society is augmenting the experience of being out of sync rather than eliminating it.

Keywords: ADHD, desynchronization, phenomenology, rhythm, temporality

Running title: ADHD and temporality

Media teaser: ADHD disrupts the experience of time and is experienced as a state of desynchronization and arrhythmia.

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ADHD (attention deficit hyperactivity disorder) is a psychiatric disorder described in the DSM-5 as involving symptoms of inattention, hyperactivity, and impulsivity. Patterns of behavior are characterized by a failure to pay attention to details, difficulty organizing tasks and activities, excessive talking, fidgeting, and an inability to remain seated in appropriate situations. ADHD was previously held to be confined to childhood, but in the last couple of decades, adults have increasingly been diagnosed with the disorder¹ (Barkley, Murphy and Fischer 2008:9). According to the diagnostic criteria, symptoms need to be traceable from the age of 12 years and must be apparent in different contexts, with the implication that the disorder is solely located in the individual, independent of time and place. In this article, however, I suggest that ADHD is not only an individual phenomenon, symptoms of ADHD appear in relations, clashes, interactions, and different contexts. I examine what we categorize as ADHD² as impairment in sense of time and difference in rhythm. Using Lefebvre's (2004) phenomenology-inspired rhythmanalysis and Fuchs's (2014, 2013, 2005) theories about mental disorders and temporal disorientation, I explore how to understand ADHD as a certain being in the world and specifically, as a disruption in the experience of time and a state of desynchronization and arrhythmia. This perspective emphasizes the corporeal, embodied and intersubjective elements of ADHD and calls for an acknowledgment of intercorporeality and how bodies resonate with each other (Fuchs 2014:405). Hence, "tasks that require mental effort over a long period of time," tendencies to "interrupt or intrude on others," and being "on the go acting as if 'driven by a motor'," for example, symptom descriptions that correspond to what my informants describe and are included in the diagnostic criteria, I suggest can be understood within a context of different rhythms clashing and of desynchronization.

Through data excerpts from my field research on ADHD and interviews with adults diagnosed with ADHD, I illustrate how impairment in time is manifested in an embodied experience of being 'out of sync'. I argue that ADHD is characterized as 1) an inner restlessness and bodily arrhythmia; 2) an intersubjective desynchronization between the individual and his or her surroundings; and 3) a feeling of lagging behind socially due to difficulties in social skills. In closing, I argue that the increasingly accelerated pace of contemporary society might augment the experience of being out of sync, rather than eliminating it. I do not propose to explain whether the arrhythmia that I identify as part of the experience of ADHD is either cause or effect related to certain neurological processes; my aim is rather to offer a framework for understanding ADHD as an embodied and relational phenomenon. I believe this perspective can contribute to our understanding of ADHD as not only a neurobiological disorder or a diagnostic category that is "making up people," as Hacking (2007:288) puts it, but also as a certain way of perceiving, acting and being in the world.

PERSPECTIVES ON ADHD

ADHD tends to be presented in one of two ways. The first is from a neurobiological perspective describing the disorder as an impairment in executive functions (Barkley 2008). The alternative is from a critical, sociological perspective, whereby ADHD is explained as a consequence of the medicalization of deviant behavior and social control (Conrad 2007; Timimi and Leo 2009). Neither of these perspectives tell us about the experience of living with symptoms of ADHD, or of how ADHD unfolds within specific contexts and relations. Research conducted with people with schizophrenia, mania and depression have explored these disorders as disruptions in temporal perception (Fuchs 2013; Ratcliffe 2012), and I use this research as a basis for understanding ADHD as a specific way of temporally being in the world. In this article, I add to the literature on the relational elements of time and ADHD, by comprehending ADHD as a rhythmic phenomenon.

The relation between time and ADHD is identified in the psychiatric literature. Clinical experiments demonstrate that people with ADHD allegedly have an impaired sense of time. Barkley and colleagues (2001, 1997), for example, tested children's ability to evaluate temporal durations, and concluded that children with ADHD tend to under-reproduce time intervals when asked to reproduce certain time intervals (Barkley et al. 1997). From experiments measuring children's perception of time intervals, Walg and colleagues (2012) suggest that children with ADHD perceive time intervals as longer than others due to "an internal clock that runs with a higher rate" (2012:2) due to a different brain structure in temporal processing. The authors proposed that if the internal clock in children with ADHD runs faster than others, "their impulsivity could arise from the fact that, from their subjective point of view, a rather long time interval has already passed" (Walg et al. 2012:2). Similarly, in a study examining ADHD as a product of a diminished sense of rhythm, Gildea and Marusich suggest that people with ADHD "have a rhythm cut-off that is faster in tempo than those without ADHD" (2009:265). By testing the ability of adults diagnosed with ADHD to synchronize and reproduce a metronome's rhythm, these researchers found that people with ADHD start meandering or losing the rhythm when the tempo is slowed down, and therefore have greater difficulties than others reproducing the rhythm within a certain tempo.

Within the anthropological literature, Goodwin (2010) also links ADHD to theories about time and becoming. ADHD is not a single thing, Goodwin argues, but rather it "refers to a multiplicity of symptoms, bodies, [and] practices" (2010:2). Hyperactivity and impulsivity, on which Goodwin focuses, are not simply symptoms of a person trapped in a body or in a brain, but rather processes operating through the body and bodily practices. Within a frame of time and consumption, Goodwin argues that rituals of self-stimulation like body rocking are used as a strategy for "becoming the moment" (2010:15); the phrase, borrowed from Deleuze, means to "inhabit time without concern for the future (the main criterion of

impulsivity), and thus to live differently in the present” (Goodwin 2010:50). It is a practice of “losing track of oneself and connecting with the outside world through the intensive process of sensation” (Goodwin 2010:50). Following Barkley, Goodwin describes time as a burden to people with ADHD. He further body rocking is a way of escaping time and “inhabiting a body, and more broadly the world, in, or out of, time” (2010:15). Body-rocking, in this sense, holds a special relation to time in the way it consumes time. By immersing oneself into a world one controls (e.g., by performing body-rocking), time is made entirely one’s own, at least momentarily, Goodwin argues. In the same way that new technologies (e.g. iPods and videogames) shelter us from the surrounding world and allow us to rest in bubbles of entertainment, body-rocking provides instant gratification and an affective regime of becoming the moment (Goodwin 2010:50).

THEORETICAL AND METHODOLOGICAL RATIONALE: STUDYING METAPHORS AND RHYTHMS

This article is part of my PhD thesis, in which I examine adults’ experiences of getting an ADHD diagnosis and of living with symptoms of ADHD. Throughout the three-year period of research conducted in Denmark, I interviewed, spent time with, and had informal conversations with people diagnosed in adulthood with ADHD; I followed some of my informants to the doctor; and I participated in several public seminars and conferences about ADHD for patients and professionals in order to investigate various aspects of how ADHD unfolds. This article is based on the analysis of 21 interviews (ranging from one to four hours) with 13 adults (five men and eight women, aged 26-45 years) diagnosed with ADHD, using a semi-structured interview guide, and on observations made during the interviews. The interview guide was structured thematically, treating the experience of getting the diagnosis, the bodily aspects of the disorder, and practices related to handling the illness. The interviews were primarily conducted in the homes of the interviewee, which offered a natural opportunity not only to ask and answer questions, but also to observe and talk about everyday practices and routines.

Taking my point of departure in rhythmanalysis, I examine ADHD as a rhythmic phenomenon using two different approaches: I understand metaphors in my interview data as mediating experiences of ADHD and I use my own bodily experiences of being with my informants as data. Examining embodied experiences of ADHD through verbal communication naturally has its limitations, but as I will demonstrate, verbal as well as bodily interactions may give access to embodied experiences and the rhythmicanalytical approach can help us glimpse into ADHD as a certain way of being in the world. Lefebvre states that “everywhere where there is interaction between a place, a time and an expenditure of energy, there is rhythm” (2004:25), and I take this assertion as a fundamental point of departure. I study the

rhythms of bodies, of thoughts, and of interactions. Bodies are located in specific places, times and interactions. Time, space, and everyday life are interrelated and need to be thought of together; the method for doing this, Lefebvre suggests, is rhythmanalysis (2004:25). Pointing to time as relative, Lefebvre (2004) describes rhythms as a measure: “A rhythm is slow or lively only in relation to other rhythms (often our own)” (2004:25) and “we each have our preferences and frequencies” (20). Whether they are thought of in relation to societal rhythms of working hours, biological rhythms of sleep, or social rhythms of interactions, rhythms always exist in reference to something or someone. To study symptoms of inattention, hyperactivity and impulsivity from a rhythmanalytic perspective therefore entails an investigation of ADHD as a relational phenomenon in reference to time. Here I draw on Fuchs (2014; 2013; 2005) and his theory of temporal experiences and states of desynchronization. When rhythms are not in accord, Lefebvre speaks of arrhythmia, and when differences in temporal experiences occur, Fuchs speaks of desynchronization. Both phenomena address the pathological, examine the moments of clashes, and of the body imposing itself. These perspectives serve as my point of departure for understanding ADHD as a rhythmic phenomenon and a desynchronized being in the world.

In analyzing the interviews, I was stunned by how metaphorically rich a language my informants used, and especially how similar their descriptions of the bodily experience of ADHD were. I started searching for metaphors describing the bodily experiences of ADHD, and found picturesque material of speed and energy accumulating. Metaphors of driving and racing were continually used when describing ADHD, and I began to collect these passages in order to make an assemblage of accounts. Literature about metaphors points to their fundamental role in enabling us to conceptualize experiences. Metaphors both express experiences and structure our perception of the world and way of navigating it (Lakoff and Johnson 1994). Our metaphorical descriptions and experiences are entangled; experience and concept are one. “Metaphor is not merely a figure of speech, drawing an analogy or playing on a resemblance for the sake of verbal effect,” Jackson (1983:131) argues – pointing to the idea that metaphors not only refer to something else nor are they used solely as comparisons or associations – that they describe actual experience. Referring to Binswanger (1963), Jackson (1996) states that when we use physical metaphors for emotional experiences – when for example “disoriented individuals speak of the ground giving way beneath them, of being thrown, losing their footing, and of falling, these are not...physical metaphors of mental states. Body and mind are effectively one, and what these images give evidence of is the actual experience of disoriented Being” (Jackson 1996:9). Jackson argues that a “metaphor reveals not the ‘thisness of a that’ but rather that ‘this *is* that’” (1983:132). Thus, descriptions of a head speeding at 180 km/h and thoughts about being a hodgepodge do not reveal the “thisness” of how ADHD is experienced. This *is* the actual experience of ADHD. The descriptions do not just serve as figures of speech, but are actual expressions of a speedy and chaotic being.

Based on this argument, I use the metaphorical descriptions of ADHD as accounts of my informants' actual experiences and being in the world.

While the interviewees described feelings of being misunderstood, speeding thoughts, inner restlessness, and struggles with timing, I also often felt confronted with feelings of restlessness, misconnection and misinterpretation during the interviews. The intuitive sense of living at a different pace than the person I was sitting in front of supported the metaphorical descriptions of ADHD I got from the interviews. I felt my own rhythm challenged, and I used this information to support and elucidate what my informants were telling me about ADHD as a chaotic and restless state of being. According to Lefebvre, to gain an understanding of rhythms, the rhythm analyst needs to experience the rhythms through his or her own body. "The rhythm analyst ... draws on his breathing, the circulation of his blood, the beatings of his heart and the delivery of his speech as landmarks" (Lefebvre 2004:31). Lefebvre encourages researchers to call in their senses when studying rhythms, to "arrive at the concrete through experience" (2004:31) and to pay attention to rhythms through concentration and by spending time in the field. Inspired by Lefebvre, I used my own experience of being out of sync and sensing my own rhythm being challenged. "To grasp a rhythm, it is necessary to have been *grasped* by it; one must *let oneself go*, give oneself over, abandon oneself in to its duration," Lefebvre (2004:37, italics in original) says. Taking my own rhythm as a reference point in my research, using my body as a metronome, and trying to be grasped by or adapt to the rhythm of my informant, I include my own experiences and notes from the interview settings to illustrate the feeling of desynchronization and of rhythms clashing.

THE RHYTHM OF THE BODY

My informants describe themselves as restless, unable to find inner calmness, and they explain how the feeling of restlessness manifests itself as racing thoughts and a craving for movement. Focusing on the rhythms of the body, I start by exploring ADHD as characterized by an inner restlessness and a bodily arrhythmia.

Experiences of incongruence between mind and speech or body and mind are often portrayed in interviews as causing misunderstandings in interactions with other people. Kelly describes herself as "too busy to sit down and understand what's going on," and reveals how she is sometimes ahead of herself, thinking faster than she speaks:

I've been very flighty in my thoughts and in my construction of sentences [especially before she started taking Ritalin], and earlier, it brought a lot of misunderstandings. I believe I've said a

whole word or a full sentence, but I haven't. A word such as 'not' is quite crucial in a sentence! If I have a sentence in my head, and I'm about to say it, but I skip the essence while I keep on talking, it's not hard to see why people don't get it. So in that perspective, there's been many misunderstandings and much frustration and I've been thinking: why can't people understand what I just said. But I haven't necessarily.

Another of my informants, Kenny, describes his mouth as occasionally getting the best of him, especially if someone interrupts him or changes the subject of the conversation: "It's getting out of control and my mouth and brain are not connected any longer. It's running way way too fast. It starts like if I'm having carbonic acid in my arms and it has to get out," Kenny says, also describing his speech "like a fire from another world." Throughout the years, many relationships have ended due to Kenny's outbursts; even more doors have taken a punch when he loses control.

Kelly and Kenny both have difficulties controlling their speech as they experience their mouths taking over, leaving rationality or specific words behind. There is a discrepancy between mind and mouth and when distractions occur, these verbal stumbles happen. Kelly explains the phenomenon as if her head speeds too fast and her mind perceives too much: "You haven't got time to take everything in. You try to engage in 20 things, but you can only participate in one or two at a time. So you have to cool down, pull over, and ask: how far did we get? What is our goal? And what can be saved for later?" Similarly, Kenny describes the phenomenon as thoughts racing too fast but adds the element of bodily expressions to the feeling of losing control. In the following, he elaborates on the bodily feeling of ADHD and how he copes when ADHD strikes:

Kenny: Mostly, I can feel the tensions here [he points at his head] and it's like... it's like trembling electricity through the brain 'bizzzz'. Those are the physical symptoms. And then I realize that I start shaking my legs [he is moving one of his legs restlessly].

Mikka: What's with that leg?

Kenny: Well, it's nothing now. But it's because the energy accumulates. And it has to come out somehow. When I go to a meeting for example where we have to sit on our butts and are being taught from the black board – then my legs start moving. I fiddle with something. It's like carbonic acid all over and that energy needs to be released. So I'll sit and jump a bit.

Mikka: So that's the valve?

Kenny: Yes, it is. It brings calmness.

During the interview with me, Kenny moves restlessly on the chair, waving his arms to underline his arguments, he has tics in his left eye. He speaks almost non-stop with great enthusiasm, gesticulating to emphasize his points. The experience of restlessness and the need for ‘calibrating’ the body or letting the energy out is consistent in my data. The body is speeding and the thoughts are racing. Only movement – or drugs – can ease the restlessness. A woman, Susan, explains how the medication has changed her body – or the ‘tempo’ of her body:

I get an inner calmness. I guess that’s the best way to describe it. For example, when reading bedtime stories to my kids, they are too big for that now, but when I did, it almost like... I did it, but it was not the nice experience that I wanted it to be – before I got the medication. Because my head was speeding 180 [km/h] while I was reading. I didn’t have the calmness to do what I was doing. I also tended to be really short-tempered and everything just shot out of my mouth and maybe sometimes inappropriately. The medication helps with that as well. It’s a kind of general calmness in the body. I have so much more calmness in my body. But I have to get used to it; driving in a lower gear, if you can say it like that, and accept it. I find it quite hard realizing that my body feels drowsy in my world. But I guess that’s just because I’m in a normal tempo now. But compared with previous-me, this is drowsy to me and I have to accept that it’s okay and don’t feel guilty about not running around all the time.

The drugs help Susan to find ‘a normal tempo’, and even if the current tempo seems drowsy to her, she appreciates the benefits of the slower tempo.

According to Lefebvre, “the body consists of a bundle of rhythms, different but in tune. It is not only in music that one produces perfect harmonies. The body produces a garland of rhythms, one could say a bouquet” (2004:30). The rhythm of the body here refers to the beat of the heart, the repetition of breathing, and to the circular element of rest, sleep and work. “Each segment of the body has a rhythm ... (and) “these rhythms are in accord or discord with one another,” Lefebvre (2004:47) states. The body is a polyrhythmic subject producing and containing different rhythms that need to correspond or resonate in order to maintain health and rest in a state of what Lefebvre calls eurhythmia (2004:78). Lefebvre continues: “Rhythms unite with one another in the state of health, in normal (which is to say normed!) everydayness; when they are discordant, there is suffering, a pathological state of which arrhythmia is generally, at the same time, symptom, cause and effect” (Lefebvre 2004:25).

My informants experience restlessness and a feeling of mind and speech that do not always follow each other. Like other phenomenological philosophers arguing that the body becomes the center of attention in times of disturbance or illness (Leder 1990), Lefebvre claims that “normally we only grasp the relations between rhythms, which interfere with them. However, they all have a distinct *existence*. Normally, none of them *classifies* itself; on the contrary in suffering, in confusion, a particular rhythm surges up and imposes itself: palpitation, breathlessness, pains in the place of satiety” (2004:31). From a rhythmanalytic perspective, we can understand the restlessness connected to ADHD and the feeling of speediness as a kind of rhythmic disharmony. The thoughts race too fast, the blood runs too fast, the limbs move too much. And they do not always follow each other. The different rhythms of the different segments of the body are not in accord or do not resonate with each other, so creating a state of arrhythmia. Falling asleep becomes difficult, concentrating on reading bedtime stories is almost impossible, and sitting still at meetings demands fidgeting with pencils and movements of the legs in order to let some of the accumulated energy loose. Feeling the inner restlessness draws attention to the physical body that is normally not present, and the bodily arrhythmia is experienced as disturbing and pathological. What Leder calls a “dys-appearance” (1990:84) of the body or an “absence of an absence” (1990:91) of the body, which we normally ignore, Lefebvre describes as a rhythm surging up and imposing itself. When it feels to Kenny like carbonic acid or electricity is running through his body, his limbs call attention to them, revealing a disharmony. And when Susan realizes that her head is speeding at 180 km/h, her thoughts impose themselves, disturbing her ability to concentrate on reading and being in the moment with her children.

WHEN THE WORLD IS IN A DIFFERENT PACE

Understanding ADHD as a phenomenon of bodily arrhythmia was my first analytical point. By focusing on the intersubjective aspects of rhythms, my second argument points to ADHD as the desynchronization of the individual and his or her surroundings. My informants continuously told me how they are always late and how they find it difficult to manage time when working on a task, as illustrated by Judith:

It just not there. The sense of time. It’s now, now, now. It’s about being in the present. That’s how we are. I only just learned about time. Well, not watching the clock and seeing what time it is, but I mean sense of time and having an idea about how long things take. How long it takes to do grocery shopping and knowing when I’ll be back home again. Like getting a sense of it.

Judith's description illustrates some of the troubles with assessing time and why managing time can be difficult. From the psychiatric perspective presented by Barkley and his colleagues (2001, 1997), Judith's sense of time might be impaired. Judging time poorly creates misunderstandings and incongruences when making agreements and coordinating things with other people, but my argument about ADHD as a certain temporal way of being in the world involves even more complex experiences of rhythmic confrontations. An excerpt from my field notes exemplifies how difference in rhythm often characterized my interviews and interactions with my informants.

I'm visiting one of my informants, Peter. We sit on his couch, it is morning, and we have couple of hours to catch up from our last talk before I follow Peter to his psychiatrist. Peter describes how he still feels restless even though he has started taking drugs. Too many thoughts fill his head and he wants to discuss with the psychiatrist whether he should increase the dosage of medication. He slept badly last night. His girlfriend woke him up because he was kicking and moving toward her side of the bed. According to Peter, it is because he did not take his medication yesterday and never reached the deep sleep because of his restlessness.

Peter describes his restlessness and how it affects his everyday life. My digital recorder lies on the table and records Peter's every word. But something – not caught by the digital recorder – illustrates Peter's restlessness just as well as his words. While we talk about his restlessness and his many thoughts, Peter is everywhere. He looks into his phone to check the alarm he sets in order to remember his medicine; he lights a cigarette with the lighter he has been fiddling with since we sat down; and one of his leg is moving up and down during our conversation. Every time I ask a question, we somehow end up in a totally different place. I sense that I am getting confused from our staccato conversation, as we jump from subject to subject, and from all the activities happening during our conversation. Peter's restlessness fills the room. I get the feeling that we are speaking and thinking in different tempi and directions. Peter interrupts before I am done talking, not because he is impolite – his is one of the most polite people I've interviewed – but because new thoughts keep striking him, independent of my questions and our conversation. I sense Peter's restlessness. It sneaks into my body. I observe and sense the restlessness he describes with his words with much more than my hearing. It crawls into my way of talking, as I have to stop my sentences half way through in order to adapt to our abrupt conversation. My concentration weakens as I follow Peter's eyes

to his phone and lights another cigarette. My breath almost shortens. I need to improvise to find common ground with Peter.

While Peter has difficulties finding inner calmness, the interview probably adds to his feeling of restlessness. I demand concentration on specific details and I guide our conversation following a certain structure, which I know is difficult for Peter. "I'm way ahead. I'm not even listening," Peter tells me when he describes how receiving details of an order from his boss or teacher is difficult, because he is already thinking about performing the task. When the conversation gets too slow, he starts meandering, like the test persons from the rhythmic experiments, and I get the feeling that Peter is already ahead of me too, losing focus on the present question.

Fuchs (2014) makes an interesting analytic comparison between different temporal orientations in states of mania and of depression. What characterizes mania, according to Fuchs, is "an *acceleration* and finally uncoupling of the individual from the world time" (2014:411; italics in original). "The manic person is constantly ahead of himself, addicted to the seemingly unlimited scope of possibilities. Interest in the present is always distracted in favour of the next-to-come. The future cannot be awaited and expected, but must be assailed and seized immediately" (Fuchs 2014:411). Fuchs emphasizes that our experience of time is not a solipsistic phenomenon but happens in reference to others. There is an intersubjective element as we engage with and are ordinarily temporally synchronized with others (Fuchs 2014:81). The body is a "resonance body" in which "interpersonal and other 'vibrations' constantly reverberate" (Fuchs 2014:405). The body interacts with other bodies in a continuous interplay of reciprocal understanding or intercorporeality, Fuchs argues, referencing Merleau-Ponty (2014:405). Everyday contact with others implies a "fine-tuning of emotional and bodily communication and intercorporeal resonance" (Fuchs 2014:409) in order to establish a feeling of being in accord with others. This fine-tuning or social synchronization, however, can be challenged in various ways by either "a retardation or acceleration of inner time in relation to external or social processes" (Fuchs 2013:75), causing a state of desynchronization. We are not always synchronizing with our environment, and we can be either "too late" or "too early." Waiting, for example, imposes on us a slower time structure to which we can respond with patience or impatience (Fuchs 2013:81). Peter and I are not following the same rhythm, and a kind of uncoupling takes place. Peter accelerates. He is way ahead, and becomes restless when I keep returning to his previous answer and ask him to elaborate. Our intercorporeal resonance and fine-tuning is challenged by what I experience as Peter's acceleration and what he probably experiences as me stretching out time. We find ourselves in a state of desynchronization.

If we return to Kenny and Susan, they too offer examples not only of inner arrhythmia but also of desynchronization. For Kenny, attending a meeting is a

confrontation with a specific time set. There is probably an agenda for the meeting and a specific rhythm to the interaction. Following the argument that people with ADHD have “an internal clock that runs with a higher rate,” as illustrated by the experimental studies, we can understand Kenny’s impatience. Kenny is confronted with another rhythm, another time than his own. The feeling of the energy accumulating in his body, as Kenny describes it, reflects the continuous accumulating time difference between his internal time and worldly time. Seeing Kenny’s impatience at the meeting, Peter’s restlessness in the interview setting, or Susan’s inability to concentrate on reading bedtime stories to her children while her thoughts are speeding, as matters of desynchronization, opens up a new way of understanding ADHD as a phenomenon that is not just located in the individual but is also intersubjective or relative. The feeling of energy accumulating at Kenny’s meeting, and Susan’s conscious attention to her thoughts while reading bedtime stories illustrate how confrontation with others creates a desynchronization that results in discomfort. Sometimes the different rhythms of the body are not in accord with each other; at other times, the desynchronization happens between the individual and its surroundings. Analytically, I differentiate between these two kinds of temporal differences, although they might happen concurrently. The mouth outpaces the brain when Kenny is interrupted; Susan’s thoughts are racing, making the quiet situation with her children challenging; Peter becomes restless and jumps from subject to subject when he is interviewed by me. All are examples of an inner state of arrhythmia happening in interactions with others or in specific contexts that demand a certain time structure, therefore resulting in desynchronization.

SOCIAL SYNCHRONIZATION: TRYING TO KEEP UP BUT LAGGING BEHIND

In their analysis of the importance of rhythm in social performance, King and de Rond write (citing Collins) that “rhythmic synchronization is correlated with solidarity” (2011:76). Examining a boat race between legendary Oxford and Cambridge oarsmen, the two authors describe how one team demonstrates a unity and creates a feeling of togetherness by moving together (and finally winning the race). Only when a common rhythm is found, is a social performance and an experience of solidarity successful, they conclude. Although this makes sense in the case of rowing, it also makes sense in the broader context of being social, being in accord, and finding common ground.

My third analytical point relates to a different aspect of timeliness connected to ADHD. It is not about how ADHD is a different way of being but about the social consequences of this being. The consequence of being different are dispiriting, my informants remark, and they often tell me about feeling different, having difficulties with being social, and continuously experiencing

misunderstandings. Lilly describes how she kept to herself before she started taking Ritalin:

I have always been kind of... back then... I distanced myself... and I've just been thinking: my brain is speeding so fast, and it actually... it has always been like that with me. Because it was always racing. 20,000 thoughts. No one had any idea that it was racing like crazy in here. And I remember that, because it was also like that, when I was a kid. I could stay in my own world and those thoughts were just going around and round. I kept to myself. I wasn't open. But I was very observing, I remember that. And was thinking a lot of thoughts. I remember how I felt. And when I was looking at myself in the mirror I remember that inner.... I felt like... I was restless inside and I felt like... I don't know...

The feeling of being different can cause withdrawal from social settings, as can the feeling of having too many thoughts and too much restlessness, causing the need for a social “timeout”. In that way, the phenomenological being out of sync results (among other things) in a very concrete social desynchronization. What is normally felt as an indefinable difference sometimes leads to severe exclusion, as Karen, a woman in her mid-forties, explains:

Karen: I once read this piece that made me so extremely sad, and it still does. Someone was doing a presentation about ADHD, and when I saw the slides afterwards on the Internet, it said: It's not a question of whether you're excluded from sociality; it's a question of when you are. And I was so happy reading it first, but then I was so so sad.

Mikka: Why?

Karen: Because it's true. I was being excluded, even though I still tried to be inside and tried to keep at it, and tried to be like the others think you're supposed to be. And then it said it right there: it's not a question of whether but a question of when. And it's true, 'cause you get no social training. You get a whole lot less because you have to withdraw. You can't hold all that shit that's happening around you. So if you only get like a fourth of the social training compared to others, well then I'm constantly 75% behind. The result is, now that I'm 45, I am supposed to manage that level of sociality, but I'm not. There're a lot of basic things I'm not able to.

Jensen (2017) uses the concept of chrononormativity from queer theory to analyze the general comprehension of autism as a development disorder,

and autistic individuals as being behind in terms of language and social development. In a queer context, chrononormativity is a description of heteronormativity applied to perceptions of time, and refers to the idea that queer persons are out of sync with society's expectations for people to follow a specific chronology in life (Freeman 2010). In the context of expectations of social skills, people with autism often lag behind of what is expected. Similarly, the social skills for adults experiencing symptoms of ADHD are weaker than chrononormatively expected from adults. From a rhythmalytic point of view, bodies are trained to follow the rhythms of calendars, institutional work hours, and interactions as part of a "dressage" of the body (Lefebvre 2004:48), and there is a normative expectation of the individual, particularly from a certain stage in life, to rhythmically integrate into interactions without effort. Intercorporal resonance happens in daily contact with others, as Fuchs writes (2013:81); withdrawal from sociality impedes the opportunity to establish and fine-tune synchronization with others. After years of socializing less than her peers, Karen cannot live up to the level of social skills expected from her as an adult in chrononormative terms and her desynchronization with others intensifies. The rhythmic synchronization has tough conditions, and it seems to be a vicious circle where the feeling of being different causes withdrawal from social settings, leading to a lack of social training. Karen tells me how she is constantly restraining her body from moving restlessly to avoid "getting 'punches' from others" annoyed by her constant movement. She shows me how she is twisting her feet around the legs of the chair and crossing her arms to keep control of her body. But despite her good intentions and efforts to fit in, Karen still needs to withdraw sometimes and cannot catch up with others when it comes to fitting in.

I am not stating, by pointing at some of the social consequences of being out of sync, that arrhythmia is a result of lack of social training. Rhythmic attunement and synchronization processes are, as I propose throughout this article, complex phenomena that manifest themselves in both interactions and within the body. However, social interaction, as a form of art, requires rhythmic synchronization: "At the centre of an interaction ritual is the process in which participants develop a mutual focus of attention and become entrained in each others' present bodily micro-rhythms and emotions" (Collins 2004:47). Social activities are shaped by interaction rituals, and whether we participate in a boat race or in ordinary social interactions, a sense of connectedness and "successful collective performance" (King and de Rond 2011:583) depends on the entrainment of bodily rhythms. Karen, Lilly and my other informants struggle with rhythmic synchronization and with keeping up to the chrononormative expectations of their ability to socialize. The consequence of arrhythmia is sometimes a feeling of difference and social exclusion.

IS SOCIETY CATCHING UP ON ADHD?

So far I have proposed that ADHD can be understood as a desynchronized and speedy way of being in the world. People experiencing symptoms of ADHD may perceive the surroundings as too slow because of racing thoughts and a restless body, but also sometimes they find the outer world chaotic because the inner world is occupied with too many things.

One might think that a speedy being would be an advantage in a world where everything goes faster and faster. Rosa (2015) argues that modern society is continuously accelerating in all kinds of spheres: technological, social and in the pace of life. New computer models increase their processing speed every couple of months; the average time people spend sleeping and eating decreases; changes of intimate partners and places of residence are also faster and faster (Rosa 2015:63). The heightening of the tempo of life, “understood as an increase in episodes of action or experience per unit of time” (Rosa 2015:78), results in an acceleration of actions and/or a stacking of actions (multitasking), leading the individual to feel a continuous lack of time (2015:78). At first, this perspective seemingly proposes that synchronization between the person experiencing symptoms of ADHD and the surroundings would happen over time. If the time of a speedy individual is met by accelerating world time, then we might expect synchronization and the impatience and restlessness of the person might be neutralized as the world catches up. However, researchers contradict the perspective, claiming that the complexity of modern society and changes of school and work conditions account for the increasing number of individuals who experience symptoms related to ADHD (Timimi 2009; Nielsen and Jørgensen 2010). Høgh-Olesen (2005) takes Rosa’s argument further and asks: what are the personal consequences of the acceleration of western society? According to Høgh-Olesen, each individual has an optimal level of stimulation, whereby the individual is neither bored from being under-stimulated or stressed out from being over-stimulated (2005:61). To answer his own question, Høgh-Olesen argues that the restless pulse of western society causes an increased level of stimulation and so creates different kinds of mental deprivation, from anxiety to anorexia, for those who cannot cope with the bombardment of stimulation. People with ADHD are said to have an impairment in the brain’s reward system, causing both boredom and a strong reaction to environmental stimuli (Gordon, Lewandowski and Lovett 2015). From that perspective, getting the right level of stimulation, in Høgh-Olesen’s terms, is a balancing act between under- and over-stimulation. The question of synchronization, of being in accord with surroundings, also becomes a matter of accommodating to a society that keeps bombarding the individual with stimuli.

Being a middle-aged adult in modern society demands rhythmic synchronization in both social interactions and engagements with institutional, occupational and domestic life. Lefebvre and Régulier speak of work as “the

reference to which we try to refer everything else back” (2004:83). We organize the day according to our work. Our bodies are expected to adapt to the temporal regime of society and follow the rhythm of a seven-day week and eight-hour job. These disciplining practices, this dressage of the body in both social and institutional perspectives, require that individuals are capable of multitasking, managing time, and rhythmically adapting. In military and sporting training, intervention through rhythm has a goal, Lefebvre writes, “to strengthen or re-establish eurhythmia” (2004:78), and Fuchs points to the benefits of resynchronizing therapy for people with depression in order “to give rhythm to everyday life” (2014:408). My informants use various strategies for resynchronizing with the surrounding world, aligning with the temporal regimes of modern society, and overcoming feelings of restlessness. Using calendars and apps on the phone in order to remember appointments and take medication on time is a common practice; constraining and locking the body can be a strategy for acting in ways that correspond to the norms of social behavior; moving the limbs can momentarily ease the experience of time being too slow, and as argued by Goodwin, consume unbearable time. Taking medication is also a strategy for creating calmness and strengthening the ability to concentrate and rest in the present moment.

To assume that an accelerating society and a speedy being fit perfectly together would be a consequence of taking both claims too literally. Symptoms of ADHD (and other disorders) do not ease when the pulse of society accelerates. On the contrary, demands of multitasking might trigger and aggravate feelings of restlessness and chaos. A bodily experience of racing thoughts or of restless limbs does not necessarily lead to a more productive everyday life (often the opposite) since the speediness, my informants describe, manifests itself as, for example, chaotic thinking, and jumping from task to task without finishing them, preventing productivity. An accelerating society only intensifies the experience of inner chaos and acceleration. What my informants need are strategies to find a valve, as Kenny describes it, or to put their thoughts in a slower tempo, as Susan explains, and alternative strategies for resynchronizing not accelerating surroundings.

CONCLUSION

In this article, I have examined ADHD as a matter of difference in temporal experience and rhythm, and I have argued that ADHD is manifested in an embodied experience of being out of sync. By using the metaphorical descriptions from my interviews with adults diagnosed with ADHD as portrayals of actual being in the world, I have illustrated how differences in perception of time, bodily restlessness and the experience of speedy thoughts are connected, and how these can be understood within a frame of rhythm and desynchronization. Phenomenological research on rhythm and experience of time has guided my analysis and led me to

conclude that ADHD can be understood as a rhythmic and desynchronized way of being in the world.

Purposely, I have eschewed discussion of the legitimacy of ADHD as a psychiatric diagnosis, and instead I have taken it as an underlying basis of my analysis that some people experience specific symptoms related to what we categorize as ADHD. As demonstrated by Hacking (2007) and Singh (2011), among others, the demarcation of diagnosis and illness experience is complex; the two are inevitably entangled. As noted by Good, “illness narratives are structured in cultural terms” (1994: 136). My claim, however, is that even when acknowledging the entanglement of diagnosis and experience, and recognizing that experiences are informed by cultural narratives of suffering, we may also as researchers try to address aspects of the different ways of experiencing that form our diagnostic categories. I believe that a rhythmic perspective, as I have presented here, can offer an important contribution to the existing literature on and understanding of ADHD by examining it as a certain way of perceiving, acting and being in the world. My contribution is an attempt to investigate the phenomenology of the disorder to gain insight into the embodied experience of ADHD. This does not mean that we should ignore the societal structures and the problems imposed by an accelerating society on people with symptoms related to ADHD. Rather, we should keep investigating how suffering can be understood and how different ways of being in the world unfold from multiple perspectives.

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NOTES

1. Research points to a 3.3-5.3 % prevalence in the American, adult population (Barkley, Murphy and Fischer 2008).
2. Prospectively, I use the term “ADHD” when I refer to the symptoms and bodily experiences connected to the diagnostic category ADHD.

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CHAPTER 9. MY ADHD AND ME: IDENTIFYING WITH AND DISTANCING FROM ADHD

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My ADHD and me: Identifying with and distancing from ADHD

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Abstract

In this article, I illustrate how individuals diagnosed with ADHD relate to, engage with, and interpret ADHD and explanations of the diagnosis. Based on my research on adults' experiences of ADHD, I describe how my informants 1) identify with ADHD as a specific way of being human as well as 2) distance themselves from ADHD by separating themselves from and disclaiming behavior connected to ADHD. Notions of ADHD as a brain disorder, I argue, form the basis of both ways of relating to ADHD. Lastly, I discuss how neurobiological explanations of ADHD produce specific choices about and hopes for treatment. The analysis is based on interviews with 13 adults diagnosed with ADHD in adulthood; on observations made at conferences and seminars about ADHD for professionals, patients and relatives; and lastly on observations from online blogs and forums about ADHD as part of a two-year anthropological fieldwork conducted in Denmark.

Key words: ADHD, diagnosis, entification, identification, neurobiology

The number of people diagnosed with ADHD has risen immensely within the last couple of decades, and researchers argue that individuals increasingly search for diagnoses in order to understand their experienced problems (Brinkmann, 2016; Conrad, 2007; Jutel, 2011). ADHD is listed in the diagnostic manual DSM-5, but the diagnosis is not only used by doctors in order to categorize suffering and direct treatment. People diagnosed with ADHD also use the diagnosis as a resource for understanding themselves. In this article, I illustrate how individuals diagnosed with ADHD relate to, engage with, and interpret ADHD and explanations of the diagnosis. Based on my research on adults' experiences of ADHD, I describe how my informants, who have all been diagnosed with ADHD in adulthood 1) identify with ADHD as a specific way of being human and 2) distance themselves from ADHD by separating themselves from and disclaiming behavior connected to ADHD. Notions of ADHD as a brain disorder, I argue, form the basis of both ways of relating to ADHD.

Early in my research, I interviewed Susan, who was diagnosed at 40 years old. As her Facebook profile picture, she has a cartoonish drawing of a man with an orchestra in the top of his head and a caption saying "ADHD is like a symphony orchestra without a conductor". Susan's use of the picture and her description of ADHD illustrates some of the aspects I will examine in this article about how people diagnosed with ADHD understand and relate to ADHD. Referring to her profile picture, Susan explains what ADHD is:

Well, if you see it as a workplace, there's the doorkeeper in the back of the head who doesn't know how to close the doors so everything comes in...And then there are some confused employees in lack of a leader to tell them what to do so they're scuttling around like confused chickens. And then sometimes the frontal lobes are acting like the boss. So all the knowledge is in the brain, but it's a long way sometimes because those neuro-things don't know their way so they're jumping around before they find their way, right. Well, I don't know. I don't know how to describe it. All I know is that I find it harder to keep a sense of perspective and I get easily confused and stressed – easier than most people.

The Danish ADHD association made the picture, Susan tells me, and I can see why she, a humorous woman with a merry personality – whether it is caused by ADHD or not (as she phrases it) – has chosen the comical drawing as her profile picture. The picture illustrates Susan's identification with ADHD and her wish for being open about the fact that she is diagnosed with ADHD. But the picture also demonstrates how ADHD is commonly described and perceived: as a brain disorder. Susan's picture of ADHD as located in the brain points to a central theme in this paper, namely the widespread neurobiological explanation for ADHD.

In the sociological and anthropological literature on the consequences of neurotechnology and neuroscience, it is argued that not only scientists' but also laypeople's perception of the human being is being altered, and several studies declare the neurosciences to be the order of our time and contemporary society (Farah, 2012; Illes & Racine, 2005; Lynch, 2009; O'Connor & Joffe, 2013). Researchers have examined the biological turn in psychiatry and argued that the human being (and human suffering) is being understood through a neurobiological lens, and that this way of thinking establishes certain criteria for how to think about and explain human behavior and self-understandings. Some researchers argue, for instance, that we take for granted that "our brain is necessary for our self" (Dumit, 2003, p. 39); that we perceive ourselves as "neurochemical selves" (Rose & Abi-Rached, 2013); that neuroscience legitimizes mental illnesses as "real" (Cohn, 2012); and that we understand personhood as "brainhood" (Vidal, 2009). In a biomedical time, investigating how people absorb neurobiological knowledge is highly relevant. Neurobiology, however, does not exclusively determine how we think of ourselves as moral beings, even when diagnosed with what is conceived as a neurobiological disorder. Psychologist Ilina Singh (2013) has analyzed children diagnosed with ADHD and their discourses about self, brain, and behavior. Singh challenges what she calls the neurocentric literature that describes "a collapse of the self into the brain" (2013, p. 817). Rather, Singh suggests, "individuals resist significant external pressures to subjugate the self to the brain" (2013, p. 814), and children's discourses exhibit evidence of notions of agency and responsibility despite having an ADHD diagnosis. In this article, I do not claim that people diagnosed with ADHD unambiguously subjugate the self to the brain, but I try to outline different positions and ways of relating to ADHD as a brain disorder. I will examine how my informants make use of existing explanations of ADHD and illustrate how they creatively position themselves in relation to ADHD.

The analysis is based on 21 interviews and several conversations with 13 adults (five men and eight women, ages 26–45) diagnosed with ADHD in adulthood as part of a two-year anthropological fieldwork conducted in Denmark.¹ All my informants, except two who experienced severe unwanted side effects, receive pharmaceutical treatment for ADHD. During the research, I have attended conferences and seminars about ADHD for professionals, patients, and relatives as well as followed several online blogs and forums about ADHD. My interviews dealt with questions regarding experiences of receiving the diagnosis, understandings of ADHD, and practices related to handling the illness. None of my interview questions explicitly mentioned the brain or addressed neurobiological aspects of ADHD, but as I will show in the article, my informants often referred to brain processes when explaining what ADHD is and how it is part of who they are, or when blaming the brain for making them act in certain ways.

I will start by briefly introducing ADHD as a diagnostic category and pointing to some of the explanations of ADHD I have encountered during my fieldwork. Then I

will describe the two positions of how my informants identify with and distance ADHD, and finally, I will discuss the implications of neurobiological explanations of ADHD in relation to considerations and expectations about treatment.

Explaining and relating to ADHD

According to the American Psychiatric Association's diagnostic manual (APA 2013) ADHD is categorized as a neurodevelopmental disorder, and symptoms are defined as inattention, hyperactivity, and impulsivity. The Danish Health Authority's clinical guidelines for diagnosing and treating ADHD in adults recommend treatment with central nervous system stimulants, and if the patient is assessed to benefit from it, medical treatment can be combined with cognitive behavioral therapy. Despite decades of research, neuroscience has not yet granted specific biological markers that can determine mental illnesses, but the neurological explanation of ADHD seems to be dominant in public information about ADHD.

If you visit www.sundhed.dk ("sundhed" means "health" in Danish, and the website is hosted by Danish Regions and the Ministry of Health), and search for "ADHD" you will find a short video explaining what causes the disorder. On a black background, the contour of a head with a fluorescent blue brain appears. We recognize the colors from pictures of brain scans and the video has a very "scientific" look to it. A voiceover explains that "attention deficit hyperactivity disorder, called ADHD, is a frequent behavioral disorder caused by problems in the brain". The video zooms into the brain and we see from the graphics how neurotransmitters communicate information before the voiceover continues: "Some researchers state that ADHD is caused by a genetic error in particular neurotransmitters" and "other theories point to the fact that poorly working nerve receptors that recognize dopamine causes ADHD". We are told about neurons, neurotransmitters, synapses, and receptors, and finally how symptoms of the condition are impulsivity, hyperactivity, and lack of ability to concentrate. The graphics guide us through the brain and the voiceover explains the mechanisms of all the different physiological processes in ADHD.

Philosopher Ian Hacking claims that diagnoses are "making up people" (2007, p. 288) and that diagnoses are creating new ways of being human that was not available before the particular diagnosis was recognized. Similarly, anthropologist Emily Martin (2007) argues that a diagnosis brings new subject positions. Once diagnosed, the individual is no longer a person with life problems but a person living under the description of the particular diagnosis. According to Hacking, diagnoses offer new ways of being a person as well as new ways of relating to one's body, oneself, and one's environment. Experiences can be interpreted in a diagnostic context and pathological picture, and previous experiences are reinterpreted and verbalized within this framework. Certain social and cultural contexts, or what Hacking (1998) calls "ecological niches" (p. 13), produce certain conceptions of the

human and of the normal and abnormal. Rose (2007) argues that in a time when we have become “neurochemical selves” who have come to “understand ourselves, speak about ourselves, and act upon ourselves – and others – as beings shaped by our biology” (p.118), neuroscience “not only establishes what counts as an explanation, it establishes what there is to explain” (p.192). Within Hacking’s theoretical framework, the proliferation of neuroscience into multiple disciplines finds a niche into which human behavior, preferences, and mental illnesses are explained in biological terms. Our contemporary times and Western societies hold specific perceptions of suffering, explanations for illnesses, and expectations of human capabilities, and within this niche, an ADHD diagnosis and its explanation offer a specific frame for understanding notions of being human. Hacking’s analysis describes the mechanisms of how diagnoses emerge, the dynamics between diagnoses and the diagnosed, and why some diagnoses suddenly appear and others are removed from the diagnostic categories. The emergence of ADHD as a diagnostic category and explanations of ADHD as caused by errors in neurotransmitters or poorly working nerve receptors establish ADHD as something that can be pictured in a video, that can be addressed with psychoactive drugs, and that can explain unwanted behavior and sensations.

During my fieldwork, whether I attended conferences, followed debates about ADHD, or interviewed people diagnosed with ADHD, the brain was continuously mentioned as the locus of the disorder. The message was that ADHD brain works in certain ways, it prompts certain behaviors, and medical treatment can alleviate the unwanted symptoms. “You *are* not ADHD – you *have* ADHD” was repeatedly mentioned at every conference I attended, and ADHD was often described as a disorder that needs treatment and ought to be recognized in the same way as diabetes or a broken leg. This biologization of mental illnesses (Rose & Abi-Rached, 2013) ranks ADHD alongside any somatic disease and explains ADHD as a matter of brain processes just as diabetes is a matter of insulin production and a broken leg a bone fracture. What I came to learn by interviewing people diagnosed with ADHD, however, was how the neurobiological explanation of ADHD was used in complex processes of understanding actions, sensations, and ways of being human. The broken leg metaphor is not only simplistic for understanding how people diagnosed with ADHD relate to ADHD; it might actually have the opposite effect than the intended legitimizing effect. On the one hand, my informants consider ADHD to be something separate from the person, causing problems and suffering, but on the other hand, ADHD is also described as another way of being human that needs to be recognized. The condition needs treatment since it causes various difficulties, but at the same time it needs to be acknowledged as a way of being a person. “You cannot cure ADHD, there’s not something wrong with me. I’m just different. I’m not broken”, as Kelly, one of my informants, describes it. ADHD is not just a disorder; it is also a way of being human and the diagnosis is used as a mirror for interpreting humanness. Even if ADHD is considered a physical brain disorder and if the inattentive, impulsive, and hyperactive behavior is a consequence of brain

mechanisms, ADHD differs as a diagnosis from a broken leg because of the ways people diagnosed with ADHD relate to ADHD, act upon it, and use it as a mediator for understanding themselves.

Identifying with ADHD

Susan has downloaded a cartoon picture of an ‘ADHD brain’ to use on her Facebook profile and a great deal of ADHD merchandise is available online ranging from cups and stickers to t-shirts with *AD/HD* printed on the chest, referencing the logo of the rock band *AC/DC*. The Danish ADHD association sells jewelry such as a heart-shaped locket called “The wild ADHD heart” with “ADHD” engraved on the back of it. A text describes the symbolic meaning of the locket: “Open it and show the world the true you. Close it again and be who you are. Carry the jewelry with pride.” The industry of ADHD merchandise reflects an interesting phenomenon of people diagnosed with a psychiatric diagnosis, who take on the diagnosis, infuse it with pride, and use it as a resource. Goffman (1963) once described how people experiencing stigma make use of different strategies of stigma management by either trying to cover up for the stigma or revealing it and performing a voluntary disclosure (p. 125). Generally, people try to pass as normal, not revealing their differentness, Goffman says, but the use of ADHD merchandise illustrates another strategy of establishing ADHD as a legitimate identity by voluntarily disclosing it. ADHD is something to carry and hold with pride, as the locket’s description says. The diagnosis is not only accepted as a clinical explanation, it is also acted upon and used as a way of expressing oneself. In that perspective, the clinical diagnosis is transferred into an identity marker to play with, relate to, and mirror oneself with.

One of my informants, Karen was diagnosed four years ago at age 41. She does not wear ADHD clothing or jewelry, but she identifies with ADHD as a way of being different, and the diagnosis has helped her understand how and why she is different. The consequences of not being diagnosed earlier have been severe, Karen’s tells me, and she wishes she had been diagnosed when she was younger:

I’ve always had it [ADHD], but I’ve never learned... no one ever showed consideration for me, I was never recognized as the person I am, which had the effect that I wasn’t thriving. And it had the effect that I didn’t get to know myself and I didn’t use my resources appropriately.

Karen considers ADHD to be a fundamental part of her and she believes that the diagnosis has brought recognition and understanding of who she is, which earlier was never revealed or acknowledged. She has always been hyperactive “‘cause hyperactivity keeps the brain awake”, as she says, but she never learned how to use the hyperactivity constructively and was continuously reprimanded for her behavior. Today, she is determined not to be ashamed of the person she is and to discover how to navigate in life, knowing that she is different from other people. Because people

with ADHD are different from normal people, she tells me, they are made for another purpose:

It's like we're all cars, but we're not made for the same purpose. A Ferrari drives extremely fast and someone's arriving as an old Skoda. I mean hello, they're not made for the same thing. But they're vehicles. And then you have buses, but it's just a shame that I'm not made for transporting passengers and that makes it difficult for others to understand.

Karen's explanation resembles many other descriptions of ADHD I met during my research. Metaphorically, Kelly describes herself as being like a plug with a grounding connection as opposed to a normal plug without a grounding connection: "In a normal power socket with only two holes, the plug with the grounding connection doesn't fit. I'm just made differently. You can say that I have more, I just don't have time to process it all." And Thomas describes himself as running another operating system than other people. In the following, I ask him to elaborate on what he means by that, and he says,

Well, let's say a computer uses Windows as its operating system. And then you run Windows, but it's not like... I just use another operating system! I control things differently. I mean ... it's not a disadvantage, if you learn how to live with that. And you can. If you have the ability to take advantage of the impulsivity and the creativity you have because you're extra impulsive, you can create miracles, I think. But you have to live in this ... well, I think if I had lived many, many years ago, I would probably have been a good hunter and have been very well-liked, but because I have to conform to this society, it doesn't comply with ADHD, so ...

The description of ADHD as another operating system was not new to me. On the many Facebook forums I follow, a frequently shared picture depicts red flourishing, free floating, entangled organic lines on a black background with text written across the picture saying: "ADHD isn't a system error, it's just another operating system". The picture gives associations to electric voltage or human tissue studied through a microscope and the text teaches us that ADHD is not a human fault but just a different way of functioning.

The idea that different ways of being, acting, and perceiving are caused by different "operating systems" or that the ADHD brain is "like an orchestra without a conductor" reflects a way of thinking about mental illness as caused by different biological designs of the human being. A massive medical literature deals with ADHD as a neurobiological disorder and explains human differences as biological variants. As an example, a genetic study of a particular Kenyan ethnic group has been used to explain ADHD as a product of evolutionary adaptation (or the lack

thereof) and why some particular receptor variants in the brain related to ADHD are an advantage for tribesmen living as nomads and a disadvantage for settlers (Eisenberg, Campbell, Gray, & Sorensen, 2008). The study was referenced in newspapers worldwide and used as an explanation of why some people do better under certain societal circumstances and how natural selection has not adapted to the increasing urbanization of modern society. A similar perspective is presented by author and radio host Thom Hartman (1994), who associates ADHD with an evolutionary adaptation to the environment and links ADHD to the quality of prehistorical hunting skills. Within discussions and research about autism, the question of neurodiversity and of autism as representing a different neurotype than the so-called neurotypical human is put forward (Silberman, 2015). Parallel to the position stating that ADHD is just another operating system or neurological variant, Silverman argues that autism is simply a naturally occurring cognitive variation that differs from the most common brain. Rather than looking at autism, ADHD, and dyslexia as checklists of deficits and dysfunctions, these cognitive variants should be regarded as strengths that contribute with particular skills to the cultural and technological evolution (p. 16). Noticing, for example, that surprisingly many IT engineers in Silicon Valley have children diagnosed with autism, Silberman asks whether they represent a certain “tribe”. Silberman’s investigation of autism leads him to different activists, one of them explaining why they refer to themselves as “autistic” instead of “people with autism”: “We talk about left-handed people, not “people with lefthandedness” (...) It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person” (p. 441). Similarly, the people I have interviewed emphasize that people with ADHD are not “broken”, as Kelly says and Karen even describes how people with ADHD speak “ADHD’ish”, following a different logic than other people.

In their research on adolescents’ experience of having an ADHD diagnosis, psychologists Sheila Jones and Morten Hesse (2014) argue that

by being conceived as a brain dysfunction, ADHD becomes an understanding that is applied not only to the difficulties of inattention, hyperactivity, and impulsivity, but also in some sense to the person as a whole, to their self-image, and to their identity (p.1).

According to the two authors, ADHD can be regarded as a “technoscientific identity” – an identity produced through the application of technologies as for example diagnoses. On the one hand, a technoscientific identity is inscribed upon individuals, who thereby are required to define themselves as lacking certain abilities and “flawed in their very constitution” (p. 2). But on the other hand, a technoscientific identity can “work to increase a sense of control over experienced illness by applying bio-medical information and characteristics directly to the person’s sense of self and thereby encourage the person to *become* the classification”(p. 1). Within the framework offered by Hacking, diagnoses make

certain ways of being and experiencing possible, and the classifications into which the individual is put or put him or herself into, thus, have a formative effect on the individual's self-understanding. The person becomes the classification, as Jones and Hesse writes.

My informants creatively engage with the diagnosis. They apply information about the diagnosis to their self-image and use the diagnosis as a mediator for understanding themselves as a technoscientific identity. However, my informants do not define themselves as “lacking certain abilities”. Rather, they redefine ADHD as a particular construction of the human species, who is “made differently” or for another “purpose.” Using the diagnosis and the explanations attached to it as something to carry with pride and acknowledging different neuro-versions of the human species as performing diverse functions in society opens up new ways of relating to the diagnosis. ADHD is much more than an illness. It is a specific way of managing (and failing to manage) based on certain neurological structures in the brain, my informants note. Living in a society that favors certain behavior over others might lead to unfulfilled expectations and experiences of failure and my informants all emphasize that living with ADHD is challenging. Other ways of being are the norm. But my informants oppose stigmatization and prepare for the challenges they meet. They identify with ADHD as a certain way of being human and insist on being accepted, understood, and helped with their difficulties.

Distancing from ADHD

While my informants relate to ADHD as a category to identify with, they also sometimes distance themselves from ADHD. By distancing I do not refer to the act of rejecting the diagnosis, but I use the term distancing to describe what my informants report of as experiences of ADHD as something “other” that acts through them, something that takes control, and determines actions.

At the beginning of the article, we met Susan with the cartoon picture of the ADHD brain. Susan has difficulties controlling her temper, and, especially before she started taking Ritalin, she sometimes would burst out with accusations. In the following, Susan explains how ADHD makes her react in ways she cannot recognize as hers:

My sense of pedagogy tells me that you don't yell into the head of a child or push it. That was definitely my ADHD. It was also my ADHD that made me react totally exaggerated if someone accidentally touched me when I was on the bus. That's not me as a person because I'm always happy and positive. I also wonder, how I could sometimes sit and talk to somebody 'la la la' and be happy, and then somebody just incidentally touched me, and then I was like 'What the hell are you doing?' And then

I suddenly became like, ‘I’m really sorry.’ It just came out of nowhere. I mean, that is definitely my ADHD.

Susan’s description of ADHD as acting through her and seizing her in ways she cannot avoid demonstrates a distancing between herself as a person and ADHD as an entity. ADHD is part of her, yet it is separate from her as a person. Susan identifies with ADHD and uses the diagnosis to understand her actions, but she also distances herself from it. Externalization is a common therapeutic technique for separating the problematic behavior from the person in order to address this behavior without accusing the person for it (White, 2007). Psychologist Svend Brinkmann (2014) describes the process of transferring responsibility from the person to the entity of ADHD as an action of “disclaiming mediation” (p. 130). By converting a temperament into an object, or what Brinkmann refers to as “entification” (p. 128), the trait is separated from the person.

Kenny, another of my informants, makes a similar distinction between himself as a person and ADHD – or more specifically, between himself as a person and his brain. In this interview excerpt, he answers my question of what the diagnosis means to him:

It makes me accept that this is how things are. It’s not my fault. It gave me calmness to get the diagnosis because: ah, that’s the explanation to why I’ve done as I’ve done and behaving bad. That’s still comforting. Because if nothing was wrong with my brain or what to call it, then I’d be the one having the problem, I mean Kenny the person and not my head. It can’t be an excuse, but it’s an explanation. It is. To me.

Kenny has read a lot of literature about ADHD and knows about common explanations of ADHD, but the description of ADHD as something “other” than him as a person is not only a theoretical explanation of brain mechanisms and neurobiology, but also a very concrete, bodily experience of ADHD as acting through him. He describes ADHD as tensions in his head, as electricity running through his brain, and explains how the accumulation of energy in his body sometimes results in dramatic outbursts. He experiences a restlessness and bodily unease and he labels these experiences ADHD. Knowledge about synapses and neurotransmitters offers a language and an explanation that help interpret experiences in specific ways. In her auto-ethnographic study of depression, Elena Trivelli (2014) writes, “when ‘illness’ takes over as the explanation of one’s behaviour, unconscious processes, life circumstances and decision-making faculties turn into neurons, synapses or failed electric impulses. In this paradigm, one does not act. Illness does” (p. 157). Kenny’s description of ADHD is similar: ADHD acts. It infiltrates his body and makes him react in inappropriate ways. However, distancing from the behavior and bodily experience is not the same as rejecting responsibility or autonomy. Even if Kenny is distancing “Kenny the person” from “the head”, he is emphasizing that he, Kenny, is the one who is responsible. Since he

has identified his problems as ADHD, he is more aware of his reactions and how to cope with them, and he feels even more obliged to regaining and not disclaiming responsibility.

Rose and Abi-Rached (2013) argue that the influence of neuroscience does not imply a perception of personhood as brainhood: “it’s not that we are brains but that we have brains” (p. 22), as the authors put it. The brain and its functions are brought into focus, but we do not incorporate the instrumentalist view that our brain solely dictates who we are as a person. The same is true for my informants. Naturally, ADHD describes only certain aspects of the individual and is not sufficient for understanding the whole person. However, O’Connor and Joffe (2013) suggest that people tend to adapt neuroscientific knowledge into their self-perception if they have been provoked to consider their “brainhood” during a diagnostic process (p. 263). “The brain may not intrude spontaneously in day-to-day consciousness, but rather becomes salient when something goes wrong”, O’Connor and Joffe (2013 p. 263) assert. In the event of a diagnosis, the functions of the brain, which are rarely the object of attention, make a kind of “dys-appearance” (Leder, 1990, p. 84) and become inescapably present. The so-called normal brain is considered passive and “lets the real self talk *through* it” (Dumit, 2003, p. 45), while the mentally ill brain “substitutes itself for the real self and speaks instead” (p. 45), as Dumit states. When Kenny experiences his thoughts as racing, and when he behaves contrary to his intentions, he understands this as a consequence of his brain. In this way, he draws on a neurobiological explanation of ADHD in his interpretation of his bodily experiences and his behavior. However, Kenny’s descriptions also demonstrate how brain mechanisms do not dictate who he is as a person, precisely because he is able to transform ADHD into an entity and knows what to distance himself from.

In his study of experiences of chronic pain, anthropologist Byron Good (1994) describes how pain can provoke experiences of the body as an object, distinct from the acting self: “The pain has agency. It is a demon, a monster lurking around, banging the insides of his body. (...) At the same time, pain is a part of the subject, a dimension of the body, a part of the self” (p. 39). While we normally consider the self as the author of our actions, that “we act in the world *through* our bodies” (p. 39), the body becomes an object when it is in pain, Good argues, just as Leder and Dumit do. Experiencing a force or an agent acting through you, it appears, is not exclusively connected to ADHD, but is a common human experience. Good refers to a study by Godfrey Lienhardt who conducted fieldwork among the Dinkas, a people living in the southern part of Sudan. The Dinkas are exposed to possession, to being taken over by a power. In order to act on the power of possession, a name needs to be called out and the power identified. In Lienhardt’s words:

With the imagining of the grounds of suffering in a particular Power, the Dinka can grasp its nature intellectually in a way which satisfies them, and thus to some extent transcend and dominate it in this act of

knowledge. With this knowledge, this separation of a subject and an object of experience, there arises for them also the possibility of creating a form of experience they desire, and of freeing themselves symbolically from what they must otherwise passively endure (Lienhardt as cited in Good 1994, p. 43).

In Good's analysis, medical treatment for chronic pain is like Dinka divination. By grasping the suffering as an agent and by calling out a name in the form of a diagnosis, an image of the pain is constructed in the body of the suffering person: "To name the origin of the pain is to seize power to alleviate it " (p. 45). For the Dinkas, as for Good's and my informants, the naming and the concept of suffering as an entity or an object is about grasping the experience in a way that satisfies us and corresponds to our cultural conception of the origin of suffering. While powers of possession legitimately explain suffering among the Dinkas, neurobiological explanations help Kenny, Susan, and other with similar experiences understand their actions and bodily sensations. Experiences of tensions in the head, of losing control, and of bursting out are explainable and can even be pictured in an animated video as mechanisms functioning in specific autonomic ways. Only by making an entity of the suffering is it possible to distance oneself from it. And by distancing oneself from ADHD it is possible to handle the difficulties related to ADHD.

Explanations of ADHD and expectations to treatment

"If you suffer from something that can be treated with drugs, then obviously you can't say that it's part of your personality, because you don't treat personalities," my informant Jenny explains when we discuss whether ADHD is a disorder or not. According to Jenny, the answer is complicated. If ADHD is not a genuine disorder, psychiatry would not treat it. But as she elaborates later in the interview, ADHD and personality are intertwined: "Well, your personality is made in the brain, and if ADHD is implemented in the brain functions, then it's hard to separate." Jenny's answer exemplifies the complexity of how people diagnosed with ADHD relate to ADHD and, similarly, it illustrates the connection between comprehensions of ADHD and decisions about treatment thereof.

During my research, I realized that a certain narrative about taking drugs for ADHD is widespread: It was repeatedly described by my informants and by participants at online forums that drugs prescribed for ADHD only work if you have ADHD. The effect of the drug is the litmus test that will determine whether you have ADHD or not since the drug will have a relaxing effect if you have ADHD and a stimulating effect like amphetamine (which the drug is closely related to) if you have a normal functioning brain. Explanation and treatment mutually confirm one another: If ADHD is caused by a (dys)function of the brain, drugs addressing that function are the solution; likewise, if the drugs work as expected, the brain must be (dys)functioning in a specific way. Figuratively speaking, swallowing the pills means swallowing the meanings attached to them and vice versa. As another

informant, John, answers when I ask him why he started taking Ritalin, "I guess you follow the assumption that the drugs can do something to the brain, and well, then you have to try it out." The neurobiological explanation is not only descriptive and neutral, but it produces choices and hopes for treatment.

If we look back on medical descriptions of behavior connected to what we call ADHD today, the disorder has a long history of being considered a brain disorder that needs pharmaceutical treatment (Comstock, 2011; Mayes & Rafalovich, 2007). As noted by Fernando Vidal (2009), the neurobiological explanation fits our Western conception of the human being as an autonomous self, and patients have endorsed the chemical imbalance theory as a morally neutral way of explaining people's difficulties. Cultural narratives and explanations of illness and treatment are connected, and patients' decisions about accepting the offered treatment often rely on whether explanation and treatment correspond. The neurobiological explanation and the pharmaceutical treatment that follows it, however, sometimes fall short. One of my informants, Peter, had high hopes when he started treatment for ADHD, but he is not only surprised by the experimental process of finding the right label and dosage of the drugs, he is also disappointed with the uncertainty of psychiatry and biomedicine:

I can't understand why science isn't better than that. They have discovered how depression is caused by lack of serotonin in the brain, and how some substance in the brain, which I can't remember, causes ADHD. So why haven't they discovered what [drugs] to give you?

Peter is frustrated with science's inability to produce the exact substance his brain is missing. And John, who decided to accept taking drugs because "it could do something to the brain", feels left alone with his problems after his visit to the psychiatrists, which only left him with a prescription for Ritalin. John explains:

It was just: 'What kind of drugs should we prescribe? Do you think you need more or less? Should we increase or decrease the dosage?' I think they were really preoccupied with the drug thing. And: 'we'll try out some new drug if you experience problems with the current drug.' But actually I also needed to talk about some of the things I was fighting with at home.

That neurobiological explanations to illnesses reduce human experiences to brain mechanisms are widely criticized. Martin (2010) argues that neuroscience "claims to explain phenomena on one scale (those embodied for example in social relationships, places, practices and institutions that have a material existence outside the brain) by means of phenomena on another scale (those embodied in the brain)" (p. 369). Psychiatrist Thomas Fuchs (2012) has a similar concern and claims that neuroscientific explanations overshadow other explanations or simplify the dynamics of mental processes and therefore leave out other possibilities of

treatment. As an organ of mediation of biology and social processes, the brain is embedded in interrelations between the social environment and the individual, and isolating mental disorders to brain structures only reveals one side of the coin, Fuchs argues. Nevertheless, as anthropologist Janis Jenkins (2010b) writes, “the pharmaceutical imaginary has come to pervade subjectivity as the cultural and existential ground in everyday life” (p. 17). As “pharmaceutical selves” we not only “orient ourselves towards drugs, but are produced and regulated by them” (Jenkins, 2010a, p. 4). To my informants, pharmaceutical treatment is the primary treatment and only a few have been offered alternative help in the form of housing assistance, body therapy, psych education, and conversation therapy, and while such activities have been temporary, pharmaceutical treatment is considered lifelong. The conception that drugs can compensate for the impairment in the brain and that a certain response to drugs verifies the diagnosis leaves the individual in a position, in which drug treatment seems to be the obvious choice. And on the one hand, my informants welcome the pharmaceutical treatment, since it corresponds to the comprehension of ADHD as a brain disorder and not the least help them managing everyday life. But on the other hand, my informants experience various kind of life problems, as also John expresses, and while drugs help alleviate some unwanted effects of ADHD, complex problems sometimes require multifaceted solutions outside the realm of drug treatment.

Conclusion

Researchers have pointed out that diagnoses are not only a tool for doctors to direct specific treatment, but the individual who receives the diagnosis engages with it and uses it as a mediator for understanding him- or herself (Brinkmann, 2014; Jutel, 2011). Neurobiological explanations of mental illness and a general biologization of human behavior and emotions shape how individuals think of their illness and difficulties in life (Rose & Abi-Rached, 2013). In this article, I have examined how ADHD is interpreted and related to by adults diagnosed with ADHD. My research supports other studies pointing to the fact that an ADHD diagnosis not only stigmatizes or turns individuals into passive patients but also brings relief and leads to actions and an increased sense of responsibility (Halleröd, Anckarsäter, Råstam, & Scherman, 2015; Young, Bramham, Gray, & Rose, 2008). The way my informants relate to ADHD does not entail a “total collapse into the brain”, as Singh puts it, even if they understand themselves and their difficulties in neurobiological terms, but they creatively interpret what it means to be a human being with a specific neurologically structured brain.

I argue that distancing from ADHD implies a separation of the self from the brain and an opportunity to act on ADHD, and not a sense of being determined by the brain. Moreover, my research illustrates how people can identify with ADHD as an alternative way of being human. I found elements of both positions of identifying with and distancing from ADHD in most of my interviews and my informants do not

hold either one of the positions, but rather they switch between them when explaining different aspects of ADHD. Both positions involve the underlying premise that ADHD is located in the brain, but they entail opposite perspectives on the relation between the person and the brain. Examining how people diagnosed with ADHD relate to ADHD and how explanations of ADHD inflict decisions of treatment opens up a nuanced understanding of the dynamics between diagnostic explanations, self-understandings, and treatment. My research illustrates that relating to ADHD involves complex and nuanced self-interpretations and actions, rather than a singular mode of interpreting oneself. However, my research also shows that identifying problems in neurobiological terms implies the acceptance of dealing with the problems in a certain way, and additional or alternative strategies to drug treatment are often disregarded or less prioritized.

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CHAPTER 10. CONCLUSION

In this thesis, I have examined adults' experiences of ADHD. I have studied aspects of life with ADHD, embodied experiences of ADHD, the implications of being diagnosed with ADHD, and ways of relating to the diagnosis. It has been my ambition to analyze the phenomenology of ADHD, unfold experiences of ADHD, and comprehend these experiences within the context of our time, culture and ways of understanding the human being. Two research questions have guided my study, namely 1) how can we understand experiences of living with symptoms of what we categorize as ADHD? And 2) how do individuals experience getting an ADHD diagnosis as an adult, and how is the diagnosis understood, used and acted upon? In order to answer these questions, I have drawn upon the data I have collected and the knowledge I have gained throughout my fieldwork the past three years, which consists of interviews and conversations with adults diagnosed with ADHD as adults and of observations at doctors' consultations, conferences and online forums about ADHD.

As I have described previously in this thesis, the majority of research on ADHD presents either neurobiological perspectives on ADHD or explains ADHD as a social construct and the emergence of the ADHD-diagnosis as a consequence of medicalization processes. I have not positioned myself within any of these explanations of ADHD, but rather I have examined how the explanations have an impact on individuals' experiences of ADHD. My research has delved into the intersection between experiences and diagnostic categories, as I understand experiences as socially and culturally embedded. I have examined experiences of ADHD in relation to social relationships, family struggles, cultural explanations of suffering, and expectations of being human without understanding these experiences as simply products of social and cultural dynamics but rather in constant relation to these. In the following, I will outline the arguments, contributions and conclusions of the three articles in this thesis, I will summarize some of the general findings in my research, and lastly, I will point to avenues for future research on experiences of ADHD.

10.1. THREE CONTRIBUTIONS: MORALITY, TEMPORALITY AND NEUROBIOLOGY

Each of the three articles in this thesis has offered a perspective on the exploration of experiences of ADHD and helped answer my research questions. The first article "Structuring the self: moral implications of getting an ADHD diagnosis" has investigated experiences of being diagnosed and the practical and existential consequences thereof, the second article "ADHD and temporality: a desynchronized way of being in the world" has examined the phenomenology of ADHD and

experiences of living with symptoms of ADHD, and the third article “My ADHD and me: identifying with and distancing from ADHD” has analyzed how my informants use a neurobiological explanation of ADHD when relating to ADHD in different ways. While the second article has mainly answered my first research question about how we can understand experiences of living with symptoms of what we categorize as ADHD, the first and the third article have primarily answered my second research question about how individuals experience getting an ADHD diagnosis as an adult, and how the diagnosis is understood, used and acted upon.

10.1.1. ADHD AND MORALITY

Moral aspects of psychiatric diagnoses are often treated in examinations of diagnoses as distinguishing the normal from the abnormal, of stigmatizing effects of diagnoses, or of diagnoses as tools for social control (Conrad, 2007; Goffman, 1963; Jutel 2011), all perspectives dealing with social and cultural expectations of the individual. As I outlined in chapter 2 of this thesis, some researchers claim that behavior connected to what we call ADHD today has been identified in children throughout the last couple of centuries, dating back to pediatrics diagnosing children as suffering from immorality and defects of moral control. These insights illustrate how psychiatric diagnoses mark the transgression of moral boundaries and chart normative standards for behavior and emotions. My analysis of the moral implications of getting an ADHD diagnosis, however, has examined different moral aspects of psychiatric diagnoses, as I have focused on the individual’s experiences of being diagnosed rather than assessed the societal status of psychiatric diagnoses. The analysis is therefore also a contribution to the existent literature on adults’ experiences of getting an ADHD diagnosis. In the article “Structuring the self: moral implications of getting an ADHD diagnosis” I have examined the formative process of getting an ADHD diagnosis and how individuals diagnosed with ADHD use the diagnosis as a part of a self-evaluative and self-constitutive project of becoming in the effort of structuring, evaluating, and experimenting with possibilities in a chaotic life. Inspired by Mattingly’s (2012; 2014) notion of three moral scenes from which practices can be analyzed, I have argued that the implications of being diagnosed with ADHD entail different moral tasks when existential questions are raised, judgments and choices are made, and everyday practices are scrutinized, evaluated and often changed following the diagnosis.

From my fieldwork I noticed three main implications of the diagnosis: Firstly, my informants find the diagnosis relieving. They understand the diagnosis as an explanation for their problems and use the diagnosis as a frame for interpreting their life-trajectory as well as a prognosis for their future. The diagnosis has “made it possible for me to pin up my reactions and challenges to something,” as one of my informants said, noticing that she is treating herself better after her difficulties have been accepted as a medical condition. I have analyzed this first process of being diagnosed as a trial in which the individual is interrogated and handed a verdict in

the form of a diagnosis. In this process, a certain self-narrative – structured around the diagnosis – is produced along with a moral ‘I.’ This moral ‘I’ is shaped by the diagnostic narrative and it is held responsible for taking the necessary measures of handling the identified problems. Secondly, my research showed that resources following the diagnosis in terms of medication, guidelines, access to ADHD communities, and occasionally therapy or housekeeping assistance, help my informants incorporate new routines. By analyzing the process of changing ways of thinking and acting as a workshop in which the individual cultivates practices, I have illustrated how the diagnosis initiates moral deliberations about how to manage everyday difficulties. Thirdly, my informants describe the effects of the medical treatment as a never-experienced calmness and an increased ability to overcome practical as well as personal challenges, but also as a (sometimes unwanted) profound change in ways of being and perceiving. My informants experiment with experiences while assessing when the drugs facilitate the experience of being “more me” or “being the person I’d like to be,” and I have analyzed this process as a moral laboratory, where the ‘I’ is examined and experimented with in order to be a good parent and a good person. I have called the different implications of the diagnosis moral tasks. I find that each moral scene unfolds aspects of how a diagnosis and medication produce narratives, practices and changes in perception that becomes part of a process of understanding oneself and caring for oneself. My informants’ search for a structuring element in their chaotic life is met by the diagnosis, which in turn carries a moral commitment of structuring the self according to the normative ideals of becoming “the person I’d like to be.”

10.1.2. ADHD AND TEMPORALITY

The relation between time and ADHD is identified in the psychiatric literature and clinical experiments demonstrate that people diagnosed with ADHD have an impaired sense of time and assess time differently than others (Barkley, Koplowitz, Anderson & McMurray 1997). My contribution to this literature on ADHD and time is a phenomenology-inspired analysis of the rhythmic, intersubjective, and intercorporeal aspects of ADHD, and hence the analysis also contributes to the quite limited literature on embodied perspectives of ADHD. In the article “ADHD and temporality: a desynchronized way of being in the world,” I have suggested that ADHD is not only an individual phenomenon, but symptoms of ADHD appear in relations, clashes, interactions, and in different contexts.

My informants describe themselves as restless, unable to find inner calmness, and they explain how the feeling of restlessness manifests itself as racing thoughts and a craving for movement. From a rhythmanalytic perspective, I have analyzed these embodied experiences of ADHD as expressions of rhythmic disharmony or what Lefebvre (2004) calls a pathological state of arrhythmia. The body is a polyrhythmic subject producing and containing different rhythms that need to correspond or resonate in order to maintain health, but when thoughts race too fast and the limbs

move too much, as my informants express, the rhythms of the body are not in accord, which creates a state of arrhythmia and discontent. To further examine the intersubjective and intercorporeal aspects of ADHD, I have drawn on Fuchs' (2014) idea that we experience time in reference to others. The body is a resonance body, as Fuchs states, and we constantly fine-tune bodily communication and intercorporeal resonance. However, when inner time accelerates in relation to outer time and external social processes, as I have argued is the case in ADHD, a desynchronization occurs. In everyday activities, such as when attending meetings or reading bedtime stories to their children, my informants are confronted with another expenditure of time than their own and the body imposes itself as restless or speedy. The rhythmalytic perspective has also opened up an examination of the social implications of desynchronization and for a general discussion of the pace of modern society and I have proposed that people with symptoms of ADHD struggle to follow normative expectations of integrating into the rhythms of working hours and social interactions, to dressage the body, as Lefebvre calls it. In an accelerating society (Rosa 2015), when demands of multitasking and adaption to shifting milieus intensify, the risk of rhythmically losing track similarly increases.

10.1.3. ADHD AND NEUROBIOLOGY

The effect of neuroscience on contemporary understandings of the human being is intensely discussed within the social science literature and researchers argue that neuroscience establishes certain criteria for how to think about and explain human behavior and self-understandings (Farah, 2012; Illes & Racine, 2005; Lynch, 2009; O'Connor & Joffe, 2013). In the article "My ADHD and me: identifying with and distancing from ADHD" I have contributed to this literature by illustrating different positions of how individuals diagnosed with ADHD relate to ADHD when drawing upon neurobiological explanations of ADHD.

From my fieldwork, whether I attended conferences, followed debates about ADHD, or interviewed people diagnosed with ADHD, I noticed that brain processes and ADHD were continuously linked together, stating that the 'ADHD brain' works in certain ways, prompting certain behavior, and that medical treatment can alleviate unwanted symptoms. But even if neurotransmitters and synapses are central in explanations of ADHD, my informants use the neurobiological explanation of ADHD in complex ways in order to understand themselves. I have argued that my informants relate to ADHD by both identifying with ADHD as a way of being human and by distancing from ADHD when separating the self from ADHD and disclaiming behavior connected to ADHD. To understand ADHD as a way of being human, using the diagnosis and the explanations attached to it as something to carry with pride, and acknowledging that alternative neurological wired brains perform different functions in society are examples of how to identify with ADHD, I argued. In this perspective, ADHD is much more than an illness. It is a specific way of managing (and failing to manage) based on certain neurological structures in the

brain. Distancing from ADHD similarly involves a reference to ADHD as a brain condition, but in this process my informants separate ADHD from the self. I have examined my informants' descriptions of unwanted outbursts and unintended actions as examples of how ADHD is transformed into an entity that is acting through and seizing the individual in unavoidable ways. Naming the experiences ADHD and explaining them as caused by brain mechanisms corresponds to our cultural conception of mental illness and enables a distancing from ADHD. The neurobiological explanation, however, is not neutral and besides producing certain ways of relating to ADHD, it also produces choices and hopes for treatment. "Brain-centered understandings can lead to brain-centered interventions" Martin (2010: 279) argues, and likewise my research has shown that my informants all receive or have received psychopharmaceutical treatment for ADHD. Even if the neurobiological explanation of ADHD renders various ways of relating to ADHD possible, the explanation might reduce comprehensions of how to live with ADHD and options for coping with the difficulties ADHD bring.

10.2. EXPERIENCES OF ADHD: A RELATIONAL PERSPECTIVE

In the three articles, I have presented different perspectives on experiences of ADHD that each have demonstrated aspects of the implications of being diagnosed, difficulties with restlessness and chaotic thinking, and ways of understanding and relating to the diagnosis. Common to the perspectives, however, has been the exploration of ADHD as a relational phenomenon. Throughout the thesis, I have examined the dynamic relation between experiences and diagnostic category and I have illustrated how experiences of mental illnesses are socially embedded. I have argued that cultural narratives of illness inform experiences of ADHD and that experiences of ADHD are situated within relations, interactions, and in social contexts.

Firstly, I have found it important to emphasize that experiences of ADHD are intertwined with the desire of being a good parent, of wanting to navigate in society, of keeping a job, maintaining friendships, and of being accepted. Similarly, experiences of restlessness and feeling socially out of sync with people around you provoke the feeling of being different and misunderstood. In chapter 1, I introduced Karen, who told me how she had reached a point in life when her own strategies for managing no longer sufficed and that the diagnosis brought new resources for her to implement in her effort to navigate life. Karen and the other people diagnosed with ADHD I have interviewed evaluate themselves in relation to their role as a parent, as a friend, and as an employee. They orient themselves in the world based on expectations from themselves and others and their experiences of ADHD are shaped by and situated within relations to others. When life is chaotic, a diagnosis and treatment following the diagnosis may help structure everyday practices and thoughts and facilitate experiences of striving to meet one's own and other's expectations. Secondly, I have wanted to emphasize that within our specific culture

and place in time, certain ways of being in the world and certain ways of understanding oneself are available, and experiences of ADHD exist within these particular circumstances. In a time and place when the diagnostic language dominates our way of understanding and making sense of suffering (Brinkmann 2014a) and when diagnoses offer legitimacy to people's experienced problems, people reach for diagnoses in order to cope with their difficulties. My research has shown, along with previous studies, that an ADHD diagnosis offers a vocabulary and a narrative for the individual to interpret his or her experiences through and that explanations of the diagnosis are used as models for understanding oneself. Experiences of ADHD are entangled with the diagnostic language and previous life events as well as future opportunities are assessed through the diagnostic descriptions.

10.3. AVENUES FOR FUTURE RESEARCH

During my research I have followed five of my 13 informants for one or two years. Some of my informants were recently diagnosed with ADHD the first time I met them and were still exploring the implications of being diagnosed, while others had been diagnosed for several years. In the article "Structuring the self: moral implications of getting an ADHD diagnosis" Christian described how he thinks more pragmatically about the consequences of the diagnosis now than he did in the years after receiving the diagnosis. Unfortunately, due to limited time and number of informants, I have not been able to further examine the aspect of how my informants relate to and potentially relate differently to the diagnosis over time.

My informants report that the ADHD diagnosis has helped them develop new perspectives and new strategies even if they still struggle with everyday practices and in social relations. In evaluative processes of experimenting with different strategies for how to live life, diagnoses serve as instruments for interpreting challenges and opportunities, I have argued. But as Christian says, the importance of the diagnosis might change over the years. Similarly, concerns in life might change, abilities to manage life might change, and life situations might change. Asking questions regarding the temporal aspect of being diagnosed could contribute with valuable perspectives on individuals' experiences of living with a psychiatric diagnosis. Will the diagnosis become insufficient for understanding and managing new difficulties in life if the individual's life circumstances change? Will a diagnosis be inadequate and maybe even withdrawn if the individual develops strategies for coping with his or her difficulties in such a degree that symptoms of ADHD disappear? You might "grow into your ADHD rather than grow out of it" a participant in an online debate answers a question about whether another participant still has ADHD if he no longer experiences the same difficulties that previously led to a diagnosis. Children sometimes outgrow symptoms of ADHD, research says (Barkley, Murphy & Fischer 2008, p. 69; Jørgensen, 2014, p. 75). But can adults also develop in ways that render a diagnosis superfluous? And in that case, what are

the implications on the individual's self-perception? Or what if the characteristics of the diagnosis change? For each new edition of the diagnostic manuals, diagnostic criteria are changed, which renders new possible ways of understanding suffering. What are the implications on individuals' identification with a diagnosis when diagnostic criteria change – if any? This PhD. thesis has pointed to ADHD as socially and culturally embedded, it has emphasized that experiences unfold in various contexts of interactions, and that the individual is constantly changing and formed by his or her relation with the world and others. An interesting avenue for future research could be to further study ADHD from a relational perspective and additionally examine how individuals diagnosed with ADHD relate to the diagnosis in a life perspective and through changing circumstances.

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SUMMARY

This thesis is an examination of adults' experiences of ADHD. It is a study of life with ADHD, embodied experiences of ADHD, the implications of being diagnosed with ADHD, and ways of relating to the diagnosis. The number of people diagnosed with ADHD has increased within the last couple of decades and so has the number of prescriptions for drugs treating ADHD. We know, however, only little about the effects of diagnosing and about phenomenological aspects of ADHD. By analyzing how individuals experience symptoms of ADHD, interpret themselves through the diagnosis, and make use of the resources following the diagnosis, this thesis is a contribution to a limited literature on adults' experiences of ADHD.

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