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Surrounded by controversy:

Perspectives of adults with ADHD and
health professionals on mental
healthcare

Samuel Johannes Cornelis Schrevel

Members of the thesis committee:

- Prof. dr. Ilina Singh
- Prof. dr. Jan Derksen
- Dr. Annemiek van Rensen
- Prof. dr. Joske Bunders

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VRIJE UNIVERSITEIT

Surrounded by controversy:

Perspectives of adults with ADHD and health professionals on mental healthcare

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
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in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Aard- en Levenswetenschappen
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De Boelelaan 1105

door

Samuel Johannes Cornelis Schrevel

geboren te Rheden

promotor: prof.dr. J.E.W. Broerse
copromotor: dr. C.M.W. Dedding

Voor Sebastiaan, Johannes en Cornelis

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Account

Chapters 4 to 8 are based on articles that have been published in, accepted by, or submitted to international peer reviewed journals. I have maintained the we form in co-authored articles.

Chapter 4

Schrevel, S. J. C., Dedding, C. Aken, J. A. van, Broerse, J. E. W. (2015) 'Do I need to become someone else?' A qualitative exploratory study into the experiences and needs of adults with ADHD. *Health Expectations* DOI: 10.1111/hex.12328

Chapter 5

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Chapter 6

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Chapter 7

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Chapter 8

Maassen, E. F., Schrevel, S. J. C., Dedding, C., Regeer, B. J. (submitted) Comparing patients' perspectives of 'good care' in Dutch outpatient psychiatric services with academic perspectives of patient-centred care. *Journal of mental health*

Chapter 1: Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a common psychiatric disorder which is characterized by inappropriate levels of attention, hyperactivity and impulsivity. Prior to the year 2000, ADHD was defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a childhood disorder that fully remitted after adolescence. The diagnosis and treatment of ADHD in children has received substantial attention in the medical literature over the past 50 years. Health professionals, however, still struggle with the diagnosis and the treatment with stimulants which, especially in the USA, has grown tremendously over last years (Mayes 2008). The ever-increasing incidence of stimulant treatment raises the moral question of whether every child with hyperactivity and inattentiveness should receive pharmacotherapy. Another question is how psychosocial therapies can contribute to the management of ADHD. To date, there have been a limited number of studies of psychosocial therapies and solid evidence for their effectiveness is not yet available (Diller and Goldstein 2006, Singh 2008). Moreover, the childhood ADHD construct and the widespread administration of stimulant medication has been the target of scientific criticism and opposition (Thomas, Mitchell et al. 2013).

From the year 2000 onwards, it was increasingly acknowledged that the symptoms of ADHD may persist into adulthood (Wender, Wolf et al. 2001, Kooij, Bejerot et al. 2010). As a much more recent disorder, adult ADHD not only inherited the same uncertainties and controversies of its childhood counterpart but also has some specific problems of its own. The diagnostic criteria were originally developed for children and it was not until the publication of DSM-IV-TR in 2000 that some amendments were made to make the criteria applicable to adults. Although adult ADHD is increasingly acknowledged, there remains uncertainty regarding the applicability and suitability of its diagnostic criteria. There is no empirical evidence that either supports or refutes the criteria for adults (Kooij, Bejerot et al. 2010) while the diagnostic validity of adult ADHD, vis-à-vis childhood ADHD, is questioned (Moffitt, Houts et al. , Moncrieff and Timimi 2010). Even though the positive effect of stimulant treatment in reducing ADHD symptoms in adult patients is generally accepted, there are doubts about the efficacy and safety of the medications (Koesters, Becker et al. 2009, Moncrieff and Timimi 2013). Moreover, in the Netherlands, as in most of Europe, medications are only licensed for children which means that stimulant prescription for adults happens off-label (Rösler, Fischer et al. 2009). Off-label prescription involves a clinician prescribing a medicine in a way which is not formally approved by the national drug evaluation agency, namely the Dutch Medicines Evaluation Board (College ter Beoordeling van Geneesmiddelen, CBG),

which is a common and legal practice. Consistent with treatment of childhood ADHD, psychosocial therapies are typically offered for adults with ADHD to address comorbid disorders, dysfunctional thought patterns and problems with self-image (NICE 2008, Kooij, Bejerot et al. 2010).

Hand-in-hand with these uncertainties and growing criticism, biomedical scientists have increased their efforts to find the biological causes of ADHD and possible biomarkers to support clinical practice. Despite progress, no solid biological models of ADHD have yet been empirically validated (Coghill, Nigg et al. 2005, Thapar, Cooper et al. 2013, Efron 2015). At the same time, social scientists have become increasingly interested in social and cultural explanations for the emergence of ADHD and the dramatic increase in stimulant prescriptions (Conrad and Potter 2000, Mayes and Rafalovich 2007, Mayes 2008). These scholars have especially focussed on the medicalization of 'normal' childhood behaviour, the expansion of medical categories, definitions of what counts as a disorder and whether the individual or society should be 'blamed' (Conrad and Potter 2000, Timimi and Taylor 2004, Bowden 2013). They point at the strong contextual and cultural aspects which complicate the diagnostic validity and the diagnostic process (Timimi and Taylor 2004, McClure 2013). Biomedical and social scientists have differing perspectives on how to define and deal with 'abnormality' in society but these perspectives seldom encounter each other at scientific conferences or in journals because these groups have their own scientific worlds (Singh 2008, Albert, Laberge et al. 2009). As a result, the field of ADHD research is polarized with respect to the facts and values underlying ADHD and its treatment.

Childhood and adult ADHD are also surrounded by substantial public concerns. In particular, the dramatic increase in stimulant prescriptions has fuelled public scepticism. ADHD is said to be a diagnosis that since its conception has been strategically used by the pharmaceutical industry to generate revenue (Conrad 1975). In addition, illicit use of stimulants by students to increase their performance touches on the sensitive subject of human enhancement (Teter, McCabe et al. 2005, Franke, Bonertz et al. 2011). This, combined with the complications involved in diagnosing ADHD raises doubts whether the many ADHD diagnosis are 'real ADHD'. There is increased political interest and pressure to decrease the number of ADHD diagnoses and stimulant prescriptions (Schippers 2012, Gezondheidsraad 2014). Nevertheless, health professionals and ADHD advocates argue that a substantial proportion of the population experiences problems that can be helped by an ADHD diagnosis and treatment (Rodrigues Pereira, Kooij et al. 2011). In short, ADHD is a complex medical and societal problem that is surrounded by uncertainty and debate and, as such, it demands exploration from a variety of perspectives.

To date, the field of ADHD research has been dominated by biomedical and clinical scientists. The perspectives of health professionals who work with ADHD on a daily basis and, in particular, the perspectives of people diagnosed with and treated for adult ADHD are rarely explored. Adults with an ADHD diagnosis have a number of outstanding questions relating to the border between normal or problematic behaviour, the possible causes of the disease, the need for medical or alternative treatment, how the use of medication fits within their lives, and how the disease affects their participation in society (Helman 2007). In most Western health systems, increased efforts are made to involve patients in health research and health care in order to contribute to a health system that is responsive to the needs of patients and which offers affordable and good quality care (Caron-Flinterman, Broerse et al. 2005, Abma and Broerse 2010, Tambuyzer and Van Audenhove 2013). As a consequence, patient perspectives and patients' right to be heard are increasingly acknowledged (Entwistle, Renfrew et al. 1998, Tritter and McCallum 2006).

Exploring the experiential knowledge of patients and health professionals is important for three reasons: (1) it fills a long-standing knowledge gap; (2) it aligns with current health system reforms which involve patients in research and treatment decisions; and, most importantly, (3) this knowledge, in tandem with existing research evidence, can be used to improve quality of care and to question and to fine-tune clinical recommendations, guidelines and practices. In this context, this thesis aims to provide insights into the perspectives of patients and health professionals on adult ADHD and ADHD care in order to contribute to continuing efforts to increase the quality of care and the wellbeing of people with ADHD.

Use of language

In this thesis I use both the words 'patient' and 'adult with ADHD'. I am aware of the normative connotation of the word 'patient' and the subordinate role it suggests. Nevertheless, in the clinical encounter, especially with psychiatrists, adults with ADHD often perceived themselves as patients. Therefore, in general, I use the term 'patient' to describe adults with ADHD in the clinical context, whether they are under treatment or whether they are part of clinical research. When I address study participants as persons and knowledgeable social actors I prefer the term 'adults with ADHD'. In chapter 6, I interviewed adults with ADHD who received coaching at a private coaching centre in the Netherlands where the term 'client' was commonly used. Therefore, in chapter 6 or when referring to chapter 6 I use the term client. I use these terms as I do in order to reflect the language actually used in my data but also to acknowledge the differing roles that adults with ADHD have and take in mental healthcare.

When addressing people who are involved in the diagnosis and treatment of adults with ADHD in the clinical setting, I use the term 'health professionals'. Where appropriate, I will specify the specific discipline of the health professional, such as General Practitioner (GP), psychiatrist, psychologist, mental health nurse, and ADHD coach.

Chapter 2: Theoretical background

In this section, I first describe ADHD from a biomedical perspective, namely its aetiology and prevalence, diagnostic process and treatment. I then turn to a short philosophical discussion of the nature and definition of disease and disorder that underlies the sociological accounts of ADHD. Closely intertwined with the sociological perspective, is the socio-economic and political landscape that enabled disorders of attention and hyperactivity to emerge and become increasingly diagnosed and treated. Subsequently, the growing interest in patient-centred care is discussed. Finally I bring these insights together in a transdisciplinary model of evidence-based practice that includes the experiences, perspectives and needs of patients and health professionals on adult ADHD.

2.1 ADHD from a biomedical perspective

Attention Deficit Hyperactivity Disorder (ADHD) is classified by the American Psychiatric Association (APA) in the Diagnostic and Statistical Manual of Mental Disorders (DSM). It is characterized by inappropriate levels of inattention, hyperactivity and impulsivity. Historically, ADHD has been perceived as a childhood disorder that fully remitted after adolescence (Wender, Wolf et al. 2001). The diagnostic criteria and the symptoms, therefore, were initially defined for children only. However, in the early 1990s the first indications emerged that ADHD symptoms may persist into adulthood and be the cause of serious impairment and dysfunction (Wender, Wolf et al. 2001, Kooij, Bejerot et al. 2010).

At the time of gathering data for this thesis research, the fourth edition (DSM-IV-TR) was being used by health professionals and researchers.¹ In the DSM-IV-TR, ADHD is categorized under clinical disorders (axis I) that are usually first diagnosed in infancy, childhood or adolescence. The manual does not suggest that there is a clear separation between child and adult disorders, but the symptoms of these disorders usually become evident in children. Sometimes, the symptoms can go unrecognized until adulthood, in which case health professionals have to retrospectively establish whether symptoms were already present in childhood. For ADHD specifically, it needs to be clear that the symptoms present more severely in comparison with peers of the same developmental level. Moreover, the symptoms of

¹ In 2013 the DSM-V was published presenting changes in the diagnostic criteria for both childhood and adult ADHD; this version of the manual received substantial criticism which I will shortly address in section 2.5.

ADHD should not be a reaction to one specific stressor, but should emerge in multiple aspects of life over longer periods of time. In other words, for a diagnosis it is important to establish that the symptoms emerged spontaneously and are the prime cause for impairment. The full diagnostic criteria for ADHD in the DSM-IV-TR are specified in *box 1*.

2.2 Aetiology and prevalence of adult ADHD

According to most biomedical scientists ADHD is considered a neurodevelopmental disorder. This means that symptoms of ADHD emerge during childhood and are the result of subtle abnormalities in brain development when compared to non-affected peers (Friedman and Rapoport 2015). Neurological research correlated the presence of ADHD symptoms to a number of volume reductions of specific brain areas and abnormal functionality of other areas when compared to 'healthy' peers. The main contemporary hypothesis is that ADHD is correlated to abnormalities in the dopaminergic systems in the brain. Underlying these abnormalities, molecular genetic studies identified a number of target genes that are related to the dopaminergic system which is estimated to explain 3.2% of the variance in ADHD symptoms in children (Kuntsi, Neale et al. 2006, Li, Sham et al. 2006). Even though the majority of neuroimaging studies are in children, there are indications that the same brain regions and functionalities may be correlated with adults with ADHD (Kooij, Bejerot et al. 2010). Additionally, familial genetic studies using twin and adoption studies found a strong heritability for the development of ADHD. All in all these factors provide an estimated heritability of 76% (Faraone, Perlis et al. 2005). The development of ADHD may be mediated by environmental factors, such as prenatal nicotine and alcohol exposure; maternal stress during pregnancy; and exposure to compounds in the environment such as lead (Swanson, Kinsbourne et al. 2007, Kooij, Bejerot et al. 2010).

Box 1. Diagnostic criteria for ADHD in the DSM-IV-TR, (APA 2000) pp 92-93

A. Either (1) or (2):

(1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

- (a) *Inattention*
- (b) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- (c) often has difficulty sustaining attention in tasks or play activities
- (d) often does not seem to listen when spoken to directly
- (e) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)
- (f) often has difficulty organizing tasks and activities
- (g) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- (h) often loses things necessary for tasks or activities (e.g. toys, school assignments, pencils, books, or tools)
- (i) is often easily distracted by extraneous stimuli
- (j) is often forgetful in daily activities

(2) six (or more) of the following symptoms of **hyperactivity-impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

- (a) *Hyperactivity*
- (b) often fidgets with hands or feet or squirms in seat
- (c) often leaves seat in classroom or in other situations in which remaining seated is expected
- (d) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (e) often has difficulty playing or engaging in leisure activities quietly
- (f) is often "on the go" or often acts as if "driven by a motor"
- (g) often talks excessively

- (h) *Impulsivity*
- (i) often blurts out answers before questions have been completed
- (j) often has difficulty awaiting turn
- (k) often interrupts or intrudes on others (e.g. butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age of 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g. at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Code based on type:

314.01 Attention-Deficit/Hyperactivity Disorder, Combined Type: if both Criteria A1 and A2 are met for the past 6 months

314.00 Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type: if Criterion A1 is met but Criterion A2 is not met for the past 6 months

314.01 Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type: if Criterion A2 is met but Criterion A1 is not met for the past 6 months

Coding note: For individuals (especially adolescents and adults) who currently have symptoms that no longer meet full criteria, "In Partial Remission" should be specified.

In the Netherlands, no hard statistics are available on the number of people diagnosed each year compared to the general population. Some prevalence studies have been conducted that included the Netherlands in their estimation. These studies, however, are problematic since they employ prospective methodologies whereby trained interviewers have ‘diagnostic interviews’ with randomly selected citizens using a validated ADHD scale to measure the incidence of *symptoms*. As these interviewers are not health professionals and performing psychiatric anamneses is complicated, this can result in over- and misdiagnosis and, thereby, inaccurate estimations of ADHD prevalence (Thomas, Mitchell et al. 2013, Dehue 2014). Given the limitations of prevalence studies, some statistics can be provided on basis of sample surveys and meta-analyses. Kooij, Buitelaar et al. (2005), using a sample survey based on 1813 respondents derived from a General Practitioner client system, estimated the prevalence of adult ADHD to be 2.5%. Fayyad (2007) performed a multi-country prevalence study, based on a sample survey of 516 Dutch respondents selected by postal code, and estimated the prevalence of ADHD in the Netherlands at 5.0%. The Dutch Trimbos institute, which focuses on research and knowledge production on mental health, in a large national sample survey with 6.646 respondents between 18 and 64 years estimated the total lifetime prevalence of ADHD at 3.0%, with more men than women reported having ADHD, being 4.4% and 1.5% respectively (de Graaf, ten Have et al. 2012).

The only hard statistics that are available in the Netherlands are the number of stimulant prescriptions stratified per age group, which are monitored by an independent foundation “Stichting Farmaceutische Kerngetallen” (SFK). These statistics show that the consumption of stimulants increased substantially between 2006 and 2011 (see fig 1). Even though these statistics give a reflection of the growth in diagnoses, it is impossible to translate this to the exact number of people using stimulants. Nevertheless, these statistics show a trend of increasing stimulant consumption for all age groups over the past decade (Stichting Farmaceutische Kerngetallen 2014).

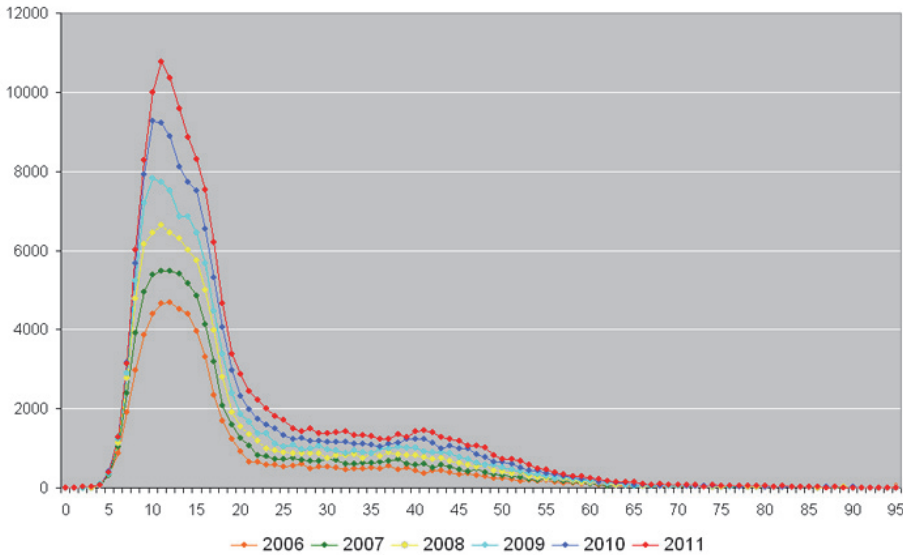


Figure 1. increase in number of stimulant prescriptions (x-axis) per age group (y-axis) between 2006 and 2011 (Stichting Farmaceutische Kerngetallen 2011).

2.3 Clinical presentation and diagnosis of adult ADHD

The diagnostic process for adults with ADHD may be more complex than in children because the expression of symptoms seems to be more subtle and, therefore, the criteria may be less applicable to adults (McGough and Barkley 2004, Kooij et al. 2010). For example, hyperactivity in children, such as running around excessively or climbing in trees, is inapplicable to adult life and can better be described as an inner sense of restlessness or the inability to relax. In addition, comorbidity is very frequent with about 75% of all adults with ADHD having another comorbid disorder, such as bipolar disorder and depression (Biederman et al. 1993).

Adults with ADHD can develop various real-life problems over the course of their lives. They are typical underachievers with histories of finding and losing jobs and high educational drop-out rates (Biederman et al. 2008). Additionally, due to impulsive behaviour they are more prone to develop substance use disorders, being unable to maintain intimate relationships or a family and becoming involved in criminal behaviours (Harpin 2005, Eakin et al. 2004). Due to these problems adults with ADHD can develop a low self-esteem and self-image and may have lower mental and physical wellbeing (Murphy and Barkley 1996).

In the European consensus statement, Kooij et al. (2010) outline the preferred diagnostic process for adults which I will briefly address here. Assessment typically starts with the self-report of ADHD symptoms, followed by a Diagnostic Interview based on a validated screening tool, the Diagnostic Interview for Adults with ADHD (DIVA; “Diagnostisch Interview voor Volwassenen met ADHD”). This is a semi-structured interview guide based on the DSM-IV-TR criteria in which the clinician explores the presence and frequency of symptoms. Crucial for the diagnosis is that the symptoms are present throughout the lifespan with an onset early in childhood. Therefore, Kooij et al. (2010) suggest the value of corroborating the findings of the diagnostic interview with a heteroanamnesis with, for example a living parent or other family member involved in the childhood of the patient. The symptoms should cause clinically significant impairment in at least two aspects of life such as the home situation and occupational functioning. This is important since the symptoms of ADHD are distributed broadly within the population making a distinction between affected and healthy persons problematic. In addition, Kooij et al. (2010) stress that it is important to establish that the symptoms are not better explained by other DSM classified disorders (since there is considerable symptom overlap with borderline personality disorder and bipolar disorder) or a reaction to a difficult situation or environment. Also, they warn that some effects of a life with untreated ADHD may mimic other DSM disorders; for example, repeated failures, common to adults with ADHD, may result in depressive symptoms. It is important to establish whether these problems are caused by the symptoms of ADHD or whether they represent a disorder that stands alone as it has implications for the preferred treatment. Last but not least, given the beneficial effects that pharmacotherapy, notably psychostimulants, have on the attention of ‘normal’ people, it should be established whether the diagnosis is being used primarily to enhance individual performance.

2.4 Treatment of adult ADHD

Treatment typically comprises a combination of pharmacotherapy, and psychosocial therapies. By far the most studied form of therapy is stimulant medications, particularly with Methylphenidate (Ritalin). The safety and effectiveness of pharmacological treatment in reducing core ADHD symptoms has been shown in several Randomized Controlled Trials (RCTs) (Mészáros et al. 2009, Surman et al. 2013, Adler et al. 2009, Biederman et al. 2006, Fredriksen et al. 2013). In addition, RCTs have shown a positive effect of stimulants on aspects of ADHD such as emotional functioning (Marchant et al. 2010), social functioning (Wender et al. 2011), executive functioning (Bron et al. 2014), and an overall improvement on

experienced quality of life (Mattos et al. 2013). ADHD medications are not registered for adults in the Netherlands and, therefore, the use of these medicines is done through off-label prescription. In spite of their effect, pharmacological treatment alone may not sufficiently improve negative impacts of ADHD, therefore many scholars and health professionals recommend a combination of pharmacotherapy, mainly in the form of psychostimulants, and psychosocial therapies such as psycho-education and Cognitive Behavioural Therapy (CBT) (Emilsson et al. 2011, Kooij et al. 2010, Murphy 2005, Weiss et al. 2012). Psycho-education includes skills training and ADHD coaching, and aims to increase the life management skills through training in, for example, bookkeeping and financial management (Kubik 2010, Murphy 2005, Wender, Wolf, and Wasserstein 2001). Cognitive Behavioural Therapy can prove effective in addressing problems with self-image and self-esteem and negative thought processes acquired over life with untreated ADHD (Bramham et al. 2009, Safren 2006, Weiss et al. 2008). Current evidence in these studies does not support the use of psychosocial therapies in the treatment of ADHD as stand-alone treatment (Kooij et al. 2010). However, research on the psychosocial treatment of ADHD alone is sparse and, therefore, no definitive conclusions regarding non-pharmacological treatment of ADHD can be drawn (Weiss et al. 2008). Reasons to employ only non-pharmacological approaches are contra-indications for the use of medications, such a heart disease or patient preference to not take medicines (Kooij et al. 2010, NICE 2008).

2.5 ADHD in a broader perspective

Health and illness are human experiences and comprise, therefore, more than just biomedical research and medical practice. Health and illness are shaped by historical, social, political and economic factors and are influenced by cultural beliefs and values. In order to explore the broader perspective on ADHD, I first turn to a discussion of different definitions of disorder; thereafter I briefly elaborate on the history of disorders of hyperactivity and inattention and place this in the current social, political and economic landscape.

Naturalism and normativism in disorder

Two philosophical underpinnings of defining disorder are important in understanding the broader perspective of ADHD: the 'naturalistic' definition and the 'normative' definitions. Naturalists perceive disorder mainly as an *objective state* that can be discovered by and observed through the scientific method and then objectively, without the interference of value judgments, be distinguished from

normal or healthy states (Ereshefsky 2009, Kingma 2014). Normal or healthy states refer to individuals of the same class who, on a group level, do not show the observed disorder (Ereshefsky 2009). For example, a broken leg can easily be observed, either from the outside or through an x-ray image, and it is also easy to see that it differs from healthy individuals where the same bone is not broken. Normativists, contrastingly, contend that 'disorder' always is the result of value judgments: certain phenomena or traits are perceived as undesirable which then may become objects of medicine (Ereshefsky 2009, Kingma 2014). As Bowden (2013, p9) exemplifies:

How do we know from the brain alone whether one neurological state is a disorder and another not? Something about the state must conflict with our desires or expectations about how our brains are to work.

The hard dichotomy of Naturalism versus Normativism is, according to many, an artificial one, as in most situations there are both naturalistic and normative aspects. That is, the same disease can have very different implications from one context to another. As Mead and Bower (2000, p1089) exemplify:

A compound leg fracture will not be experienced in the same way by two different patients; it may cause far less distress to the office worker than the professional athlete, for whom the injury potentially signifies the end of a career. Similarly, the medical treatment (even cure) of disease does not necessarily alleviate suffering for all patients.

For both people, the naturalistic part, the fracture, is a fact whereas the social implications, judgements and experiences are completely different. Ereshefsky (2009) suggests that debates about disease revolve around both 'state descriptions' which are properties of the body or its physiology and 'normative claims' which are judgments whether those properties or physiology are healthy or sick. He asserts that state descriptions or normative claims alone are not enough to define disease or disorder. That is, there are state descriptions that are given by nature and deviate from the average, such as having blue eyes or being inattentive. The state description alone, however, is not enough; we need a normative claim to define when a state description is a disorder: blue eyes are not considered a disorder whereas being inattentive is. The reverse is true too, being homeless or rude are not desired but are not necessarily linked to having a disorder (example from Bowden (2013)). Moreover, both are dependent on context: blue eyes are much rarer in Morocco than in Scotland and being inattentive may be much less problematic without a school to drop out from.

Various social scientists reject the purely naturalistic definitions of ADHD that are stressed by most biomedical scientists. According to these scientists ADHD refers to behaviours that are deemed undesirable or pervasive by society and, thereby, they take a more normative stance towards the disorder. They do not reject the idea that there may be biological mechanisms underlying ADHD behaviour, nor the 'existence' of ADHD as a disorder. Their priority, however, is to understand how ADHD behaviours manifest themselves in the social world and why they become seen as undesirable. The main field of sociological inquiry about ADHD has, therefore, focused on the medicalization of ADHD behaviours. That is, how, when and why did hyperactivity and inattentiveness become labelled as problematic and how, when and why did these behaviours become objects of medicine (Conrad 1975, Conrad and Potter 2000, Mayes and Rafalovich 2007, Bowden 2013, Conrad and Bergey 2014).

Short history of ADHD

The English paediatrician George Still, was the first to describe children with ADHD. The children he described mainly portrayed a defect in moral control while being of normal intellect. They had violent outbursts, were mischievous and destructive and were not responsive to punishment. Additionally, these children were restless and fidgety and showed problems maintaining attention, making school problematic (Still in Mayes). George Still perceived this poor moral control as a medical problem with a biological basis. These paediatric problems became more visible after the passing of the Education Act in 1886 which made school attendance compulsory (Tredgold in Mayes). Even then, Tredgold, who was studying these children, assumed that mild brain damage was at the basis of these moral defects. In other words, the association between disruptive behaviours and physiological abnormality traces back to the first descriptions of disruptive behaviours, despite the lack of substantial scientific evidence (Conrad and Potter 2000).

The connection between the brain and deviant paediatric behaviour was solidified after the influenza pandemic in 1918. Researchers observed that survivors of *encephalitis lethargica*, an acute infection of the brain resulting in brain damage, portrayed severe disruptive behaviours. Some of these behaviours – severe over-activity and the inability to hold concentration – resemble those that are associated with ADHD nowadays. Mayes and Rafalovich (2007, p441) stress, even though modern ADHD would hardly describe the encephalitis survivors, the discussion of encephalitis lethargica was significant, not simply because it drew suspicion to the causal effect between behaviour and neurological impulse, but because it medicalized unconventional behaviour specific to children.

Since then, the direct link between child disruptive behaviour and brain damage dominated the discourse resulting in the conceptualization of the ADHD precursor known as 'minimal brain damage'. Additionally, the positive effects of stimulant treatment on these behaviours was already known and increasingly studied (see box 2): Originally stimulants were studied to alleviate headaches, but, later on it was accidentally observed that they have positive effects on children's school work. In the 1960s an increasing number of scholar criticized 'minimal brain damage' for being too restrictive: they encountered children that could classify for the disorder but showed no evidence of brain damage. These children also positively reacted to stimulant treatment. Therefore, the original Minimal Brain Damage was transformed into Minimal Brain Dysfunction, still emphasizing neurological factors as causes of the disorder, rather than social or environmental factors (Lange, Reichl et al. 2010).

The change from the DSM-II, where hyperactive behaviour was still central, to the DSM-III, where inattentiveness (with or without hyperactivity) became the central characteristic of the disorder, caused a vast increase in the number of individuals eligible for the diagnosis (Mayes 2008). This process of expanding did not stop there. Weiss, Hechtman et al. (1979) observed that young adults who were diagnosed with ADHD in childhood continued to show impairment in adolescence and adulthood. Under the pressure of ADHD advocacy groups and public claims by adults who identified themselves as having ADHD, a campaign started for the official acknowledgement of ADHD in adults (Conrad and Potter 2000). This was taken up by leading scholars in the field of ADHD, notably Barkley and Biederman, who started investigating adult ADHD and its treatment, making adult ADHD a medical category without yet an official classification in the DSM. Only when the DSM-V was published in 2013, was the diagnosis in adults officially acknowledged. However, the DSM-V has been criticized for creating yet another expansion of the category by lowering the symptom threshold for adults and elevating the age of onset. These changes may increase the number of diagnoses adults by another 27% (Matte, Anselmi et al. 2015). Specifically, a member of the DSM-IV taskforce, Allen Frances, became a frontrunner in the critique towards the new version of the DSM warning for out of control psychiatric diagnosis and diagnostic inflation (Batstra and Frances 2012a, Batstra and Frances 2012b).

Box 2. A short history of the discovery of stimulant treatment for deviant behaviour

The discovery of stimulants as possible treatment for ADHD happened accidentally. In 1937, Bradley published a paper wherein he explained how Benzedrine had a positive effect on children's school performances and compliance to house rules, such as making the bed (cited in Mayes and Rafalovich (2007)). He did not, however, use Benzedrine to actualize that effect but was hoping to find a medicine that could help in relieving the severe headaches children experienced after lumbar puncture for pneumoencephalography. Instead of relieving the headaches, Bradley noted, children's behaviour was dramatically changed, characterized by an increased interest in school work, better working habits and reductions in disruptive behaviour. For two decades, researchers who studied child hyperactivity reported on the positive effects of stimulants but no significant increases in stimulant consumption was observed until Ritalin was approved by the FDA in 1961. From thereon, the evolution of ADHD and research in and consumption of stimulants as treatment for hyperactivity and inattentiveness went hand in hand. However, stimulant treatment for the disorder increased further after the definition of Attention Deficit Disorder (ADD) in the DSM-III in 1980. The major change here was that inattentiveness gained dominance in the definition of the disorder, with the possibility of additional hyperactive behaviour (Lange et al. 2010). This is in contrast with earlier conceptions of the disorder in which the hyperactive and disruptive behaviours were seen as the most important. The fact that children with attention problems reacted better to stimulant treatment was central to this shift in prescription habits (Douglas in (Lange et al. 2010)).

Social, political and economic landscape

Many scholars point at the increasing role of patients themselves in the expansion of medical categories (Conrad 2005, Mayes 2008). Having an official 'existing' diagnosis can give those, who experience substantial life problems, an explanation for what is happening and a justification that they are not merely lazy or bad people (Conrad and Potter 2000, Dehue 2014). Moreover, when problems become medicalized, they open the doors not only to medical attention but also to secondary gains that increase the chances of success in life. In the case of ADHD, for example, adult students can get an extra year of government study funds or get extra time at exams. This, in turn, solidifies the sense that something is wrong with oneself and that medical attention is needed: of being a patient rather than a failure. But why do people themselves want to be seen as patients and what is the role of the social, political and economic landscape? In this section I address three important factors that might influence the lives of individuals with ADHD, namely: (1) the increased responsibility for personal failure and success; (2) government healthcare reforms intended to address the increasing costs of healthcare; and (3) the public debate that surrounds ADHD.

Conrad and Porter (2000) argue that adult ADHD is the medicalization of underachievement. They illustrate this by stories of adults who always had a sense of underachievement but with the help of a

diagnosis and stimulant treatment can live life to its full potential. They place this in the background of the rise of Prozac in the treatment of depression which opened the door for adults to seek medical treatment for life problems. Dehue (2014) illustrates the same point by showing how successful individuals perceived ADHD to be in the way of their careers and how, by acknowledging their ADHD and seeking treatment, they took control over their life and became successful. She further provides an elaborate discussion on how the responsibility for a person's own failure and success is increasingly placed upon individuals, at least in the Netherlands. That is: if one fails in life, it is your own fault and, thereby, also your own responsibility to create success for example by seeking medical attention. Together with an increasingly biological conceptualization of ADHD, this sense of responsibility may drive individuals to seek solutions in the biological domain, which further legitimizes pharmacological treatment. In other words, people are increasingly expected to take responsibility for current or future underachievement, which is more and more perceived as inherently biological, by seeking medical (pharmacological) treatment.

At the same time, governments across the West implement major healthcare reforms to contain the ever increasing costs of healthcare by promoting prevention strategies and self-management (Dehue 2014). The Dutch Health Council and the Minister of Health expressed their concerns over the increases in stimulant use and are looking for ways to control it. These politics, according to Dehue, are paradoxical. The government makes its citizens responsible for their successes and failures, but tries to limit the ways in which its citizens can achieve that: mental healthcare.

In a further attempt to curb rising healthcare costs In the Netherlands, health professionals have to work according to Diagnosis treatment combinations (DBC; "Diagnose Behandel Combinaties") in order to get healthcare costs reimbursed by insurance for both health professionals and patients. These DBCs match a diagnosis with a predefined treatment protocol, which according to Sambeek, Tonkens et al. (2011) stimulates precipitous diagnostics in order to be able to provide care to patients. This runs the risk of misdiagnosis and over-diagnosis. Moreover, the diagnostic label itself, and not the patient, becomes the centre of predefined treatment protocols and evidence-based guidelines. These guidelines are criticized for having an overly narrow vision of the treatment of ADHD as they strongly emphasize pharmacotherapy as the preferred treatment (Garfield and Garfield 2000, Moncrieff and Timimi 2013). Moreover, evidence-based guidelines may present conflict of interests, be based on faulty or selective evidence or evidence that is based on the opinions of a small group of experts and not the broader group of health professionals and patients (Feinstein and Horwitz 1997, Goldenberg 2006). More

importantly, the DBC structure is at odds with another trend in healthcare. In most (Western) healthcare systems, patient-centred care (PCC) has become central to recent and probably future health care reform (Robinson, Callister et al. 2008, Scambler and Asimakopoulou 2014). Reasons for the popularity of patient-centred care are twofold. Firstly, it is grounded in moral or ethical belief that it is the right thing to do regardless of its influence on health outcomes (Duggan, Geller et al. 2006). According to medical ethics, the autonomy of patients should be respected and they should be treated with respect and dignity (Epstein, Fiscella et al. 2010). Secondly, the delivery of PCC is associated with improved health outcomes, satisfaction with care and reduced healthcare costs (Mead and Bower 2000, Mills, Frost et al. 2014). PCC is defined by the Institute of Medicine (2001, p7) as:

partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patient's wants, needs and preferences and that patients have the education and support they need to make decisions and participate in their own care.

This should apply to every stage of healthcare, from entry to discharge. This leads to the paradoxical situation where health professionals, on the one hand, are obliged to diagnose their patients and offer the treatments predefined for a given disorder whilst, on the other, they are supposed to provide care that is tailor-made for individual patients.

ADHD is the subject of increasing public debate, controversy and even ridicule. In contrast to the general belief that the debate surrounding ADHD is a recent phenomenon, the first public concern with the stimulant treatment dates back to the 1970s. In Omaha, Nebraska, school children allegedly were subjected to 'behaviour drugs' without adequate medical attention. This resulted in new regulation to control the production and prescription of stimulants, which was then tracked by Drug Enforcement Administration (DEA). Already at that point, critical scholars accused the pharmaceutical industry of marketing hyperactivity for their behavioural drugs (Conrad 1975). Another finding in the late 1970s further complicated the use of Ritalin for behavioural problems. Rapoport (1978, 1980 as cited in (Rafalovich 2005)) showed that not only children with problematic behaviours but also their 'healthy' peers showed improvement of attention span when using Ritalin. This indicated that there is no hard boundary between those afflicted with the disorder and those who are not, which creates the possibility of medicalizing normality or enabling human enhancement.

Nowadays, it is increasingly questioned if ADHD is a *real* disorder. There are no clear boundaries between normal and abnormal. There are vast differences in prevalence within and between countries. Biomedical research has not lead to a decisive laboratory test. Stimulant prescriptions increase worldwide. In the public media, parents are increasingly blamed for *drugging* their children instead of raising them (Horton-Salway 2011). Moreover, health professionals are blamed for being too casual in diagnosing and treating the disorder. Others contend that ADHD, or at least the expansion of the disorder, is the work of the pharmaceutical industry, creating a flourishing market. All in all, it seems that ADHD serves as a symbol of the normalization of individuals in a society that is becoming less and less tolerant of deviation, or even as a form of social control, with the use of psychiatric labels and accompanying pharmacological treatment. The influences of this controversy on the clinical encounter and future health policy and research are unknown. It can, however, be theorized that these influences are substantial. For example, both the Dutch Health Council as well as the Minister of Health have expressed their concerns about ADHD specifically. The controversies on ADHD are typically rebutted with more research on the genetic and neurological causes of ADHD. However, solid evidence for genetic and neurological causes remains to be delivered and, as a result, ever more efforts are made to uncover the biology of ADHD in order to validate its status as a 'real disorder'.

2.6 Evidence, experience and expertise

In the previous sections I addressed the biomedical perspectives on ADHD and placed the disorder in a broader social, political and economic context. I showed, on the one hand, how ADHD has become increasingly medicalized as the biological underpinnings of the disorder and its treatment are investigated, and, on the other hand, how the evolution of ADHD, from a moral defect to a disorder of inattention, its treatment and the accompanying societal controversy question this medicalization. At the same time, the Dutch government is trying to contain the increase in diagnoses and treatments. It is striking that, in these processes, the experiences and perspectives of patients and health professionals are hardly explored and even more rarely are an integral part of biomedical research. Moreover, it remains unclear how these perspectives align with the recommendations presented in clinical guidelines.

In this section, I discuss why the perspectives and lived experiences of patients are essential to medical research and to the provision of healthcare. I use the original definition of Evidence-Based Medicine

(EBM) as proposed by Sackett, Rosenberg et al. (1996) to show that its delivery is only possible if the experiences, perspectives and needs of patients as well as the expertise of health professionals are part of clinical practice. I will use this operationalization of evidence-based practice and combine it with the ecological model as proposed by Bronfenbrenner (1992), in order to take a transdisciplinary perspective on ADHD and its treatment. For conceptual clarity, I will use the word 'perspective' to refer to the experiences of adults with ADHD and health professionals, the meaning they attribute to these experiences and the resulting needs.

In the last decades, EBM has become the cornerstone of medical practice. The basis of EBM is straightforward: health professionals should base their decisions on the best available evidence. However, the following questions remain: What constitutes the best available evidence and how should health professionals use this in clinical practice? And, most importantly, how does this evidence align with the experiences, needs and perspectives of patients? The nature of evidence, the multiple forms of evidence and the different utilities of evidence form a very live area of study, as are the various ways their value to aspects of healthcare can be mapped. In this section, I provide a brief outline of different forms of knowledge and how they could inform day-to-day clinical practice if they were available.

What is research evidence and why does it matter?

In the medical literature, the word research evidence typically refers to meta-analyses, systematic reviews and Randomized Controlled Trials (RCTs) as the 'highest' form of evidence (Evans 2003). These methods use large numbers of patients to compare new treatments to either existing treatments or placebo. The basic assumption is that delivering a new treatment to a group of patients and comparing the outcomes with a comparable group of patients that received placebo or an already existing treatment will show which treatment is more effective. Meta-analyses and systematic reviews combine multiple RCTs of the same treatment to validate whether the positive effects are reproducible. RCTs and meta-analyses draw on statistical methods to prove the effectiveness of one treatment over the other or demonstrate clinical relevance by showing a similar same effect but with easier administration or fewer side effects (Sackett and Rosenberg 1995). The use of RCTs has yielded a large number of successful therapies and rejected unnecessary or ineffective treatments. This has all contributed to the safety and wellbeing of patients (Paley 2006).

Nevertheless, the critiques on RCTs and the (over)reliance on quantitative methods in health research are numerous (Goldenberg 2006, Lambert 2006, Greenhalgh, Howick et al. 2014). Two of those are

especially important to this thesis: (1) research evidence may not be in line with (individual) patient experiences preferences and values; and (2) there may be difficulties translating research evidence into clinical practice. For the former, patients are the final recipient of the therapies investigated by RCTs, but patients themselves may have other priorities in their treatment than those investigated in the RCT. For example, patients may prefer a treatment with a lower chance of success but with less chance of unwanted side-effects (Pols 2013). For the second critique, the translation of evidence to clinical practice may be complex because of issues of generalizability – RCTs present information that may hold for the general group of patients but not for individuals. For example, many RCTs have only used male participants and may, therefore, be less applicable to female patients (Goldenberg 2006). Moreover, patients may present complex problems that are not comparable to those under investigation in RCTs, such as multi-morbidity where patients take multiple medications for multiple health problems. In sum, clinical decision cannot rely on the best available scientific evidence only.

In defence of these critiques, proponents of EBM contend that it was never intended as its basic tenet that clinical evidence from systematic research be promoted as the dominant factor in clinical practice. Sackett, Rosenberg et al. (1996, p771) state that:

Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual health professionals acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care.

In other words, the practice of EBM requires that health professionals use their expertise to apply the best available research evidence to individual patients. The best evidence, according to Sackett and his colleagues, is the newest and most rigorous research showing the highest power of diagnostic markers and the most efficacious and safe therapeutic interventions – research that, with the progress of science, can be invalidated and replaced with new 'best' research evidence. However, to align this evidence with the “predicaments, rights, and preferences” of patients, accumulated clinical expertise is imperative as well as knowledge about the perspective of patients.

Perspectives of patients, why do they matter?

The lived experience of patients refers to what it is, and feels like, to be struck by illness, living with the disease, receiving care and treatment and getting cured or not. In the course of the history with their disease, patients accumulate knowledge and habits that are specific to their disease in their context. In the end, only patients know what it *feels* like to get diagnosed with cancer or to take stimulants to address the symptoms of ADHD. This knowledge is unique to patients and is tacit: patients do not necessarily explicitly think or talk about it, but it rather lies enclosed in day-to-day habits and practices to deal with their bodies and diseases (Caron-Flinterman, Broerse et al. 2005). That is, patients can identify aspects of their disease, daily life with their disease and the care they receive. This knowledge can be used to translate research evidence into, or to fine-tune already existing, clinical recommendations that align better with the perspectives and needs of patients (Harding, Pettinari et al. 2011). This can, in turn, help explain and prevent patient non-adherence to clinical treatments. This is an important problem for medicine in general and ADHD in particular (Kooij, Bejerot et al. 2010), as people can have valid reasons for not complying with the treatment regimen prescribed by their doctors (Donovan and Blake 1992). Moreover, understanding patient perspectives can illuminate new paths of research that matter to patients (Caron-Flinterman, Broerse et al. 2005, Greenhalgh 2009). However, as Lambert (2006, p2650) stressed:

For although in evidence-based clinical practice the starting point for selecting what population-based evidence is relevant is always the individual patient (or ‘case’), patient narratives are not themselves usually regarded as ‘evidence’ within EBM.

Lambert (2006) and other scholars, such as Rycroft-Malone, Seers et al. (2004) and Misak (2010) conclude that the perspectives of patients should become an integral part of medical evidence to support clinical practice and clinical guidelines. They suggest using qualitative methods as the starting point for investigating the narratives of patients, which by means of explication and critical appraisal can be transformed into new evidence (Sandelowski 2004).

What is clinical expertise and why does it matter?

Health professionals who work with patients on a day-to-day basis, along with patients themselves, acquire practical knowledge of *doing* medicine. Moreover, health professionals do not work in a vacuum but operate in a context where they are influenced by patient preferences, organizational and health system factors (Rycroft-Malone, Seers et al. 2004, Rafalovich 2005). Accordingly, the controlled

laboratory environment in which RCTs are executed cannot always be translated directly into the treatment of individual patients. In other words, in order to use research evidence in clinical practice, the acquisition of expertise is necessary.

Understanding clinical expertise is important for numerous reasons. It can provide a context in which to make good use of other information. For example, Greenhalgh, Flynn et al. (2008) shows how the use of a screening list for rehabilitation becomes a tacit form of knowledge, that has to be acquired by new team members in order to be able to understand it and use it properly. In addition, Struhkamp, Mol et al. (2009) discuss how the objectives that are measured by a screening list do not incorporate all aspects that are important in the clinic and in the context of patients' lives. It provides equal importance to all items whereas in real life some items are deemed more important than others. In both these cases, performed in rehabilitation care (a clinical field with high uncertainty), it was clinical experience and patient preferences that were decisive for future action rather than the score produced by the screening tool. These studies help to understand how a tool is used and how this tool may be amended to better support clinical practice. Relying on guidelines alone can also mask more complex medical problems. For example, multi-morbidity or symptomatic overlap may confuse the logical flows of the guidelines and subtle observations, usually acquired through clinical experience, may be needed to set one on the right track again (Garfield and Garfield 2000). Moreover, newly developed interventions may require a substantial change in day-to-day practice which may be infeasible to implement. Alternatively, clinical guidelines may provide recommendations that are too general to easily translate into practice. Finally, clinical practice is often surrounded by uncertainty which is further complicated by local and organizational factors which may restrict the time health professionals have to find the best evidence or which may obfuscate the starting points and end goals of treatment. Thus, as Rycroft-Malone, Seers et al. (2004, p84) propose:

The delivery of individualized evidence-based health care not only requires professional craft, knowledge and reasoning, but requires such knowledge and reasoning to integrate (...) different types of knowledge (...) within the contextual boundaries of the clinical environment.

2.7 Transdisciplinary model of Evidence-Based Medicine

Transdisciplinary research typically addresses problems that are highly complex or ‘messy’ and exist in the interplay of society, science, technology and environment (Wickson, Carew et al. 2006, Carew and Wickson 2010). These problems exist in the ‘real world’ and cannot be understood by one or a few scientific disciplines. To fully understand these problems other actors need to be included, such as practitioners, policy makers, entrepreneurs, consumers and so forth, depending on the problem at hand. In this sense, transdisciplinary research transcends academic disciplines to include diverse forms of knowledge to study and address these complex issues. Even though ADHD is predominantly perceived as a medical phenomenon, I previously showed that there are a myriad of other factors that influence those living with ADHD and those who diagnose and treat it. Since this thesis focuses on perspectives *other* than those dominant in the scientific discourse and the wish to understand the complexity of ADHD within the current specific socio-political landscape, I take a transdisciplinary perspective on adult ADHD.

Transdisciplinary research is characterized by the integration of two types of knowledge, namely propositional knowledge and tacit knowledge². Propositional knowledge is acquired through research and scholarship and is standardized and generalizable. Tacit knowledge is practical and personal and is acquired through practice and experience (Greenhalgh, Flynn et al. 2008). The former one is explicit and is recorded in scientific publications, practice guidelines, electronic databases. The latter form of knowledge is implicit and lies enclosed in day-to-day practice: it is know-how that enables people to function in their daily work and lives. Tacit knowledge, however, can be made explicit and be transformed into new propositional knowledge. Contrary to hierarchies of evidence that place systematic reviews and meta analyses at the top, downgrade qualitative methods as ‘poor’ evidence and completely disregard evidence based on tacit knowledge (Sandelowski 2004), transdisciplinary research acknowledges that the various forms of knowledge should be valued equally as evidence with their own validity criteria and can mutually reinforce one another.

Transdisciplinary research also explicitly takes a multi-level perspective, including the micro, meso and macro levels. In the past most research into interactions between patients and health professionals was mainly restricted to what happened in the consulting room (Haynes, Devereaux et al. 2002). As it

² These forms of knowledge have different names: propositional, explicit, codified on the one hand and non-propositional, tacit and personal. In this thesis I use propositional and tacit to address this separation.

became clear that these encounters may *happen* as isolated events but were also influenced by external factors, new models for disease management arose that incorporated external influences on what happens in the consultation room (Greenhalgh 2009). Patients and health professionals do not function and interact within a vacuum but are influenced by factors in local contexts related to the broader social, political and economic landscape. (Satterfield, Spring et al. 2009) already suggested that a model of EBM should also include the environment and the organizational context. In this thesis, I will further this idea by placing the EBM Venn-diagram within a social-ecological model. The social-ecological model, originally developed by (Bronfenbrenner 1992), discriminates between micro-, meso- and macro-levels that mutually influence each other. It is beyond the scope of this thesis to provide a full discussion of Bronfenbrenner's model but I use his idea that individuals are influenced by factors in both their close and their distant contexts.

Patients, health professionals and their interactions are placed within the micro level. Both are social actors who make decisions about their lives and have direct interactions with others such as family members, employers, or the local organizational context, wherein healthcare provision takes place. However, these actors operate within a larger system, the meso-level, where organizations, such as health-insurers, universities, pharmaceutical companies, determine what treatments are available and what constitutes best evidence for evidence-based practice. This meso-level is placed in the larger social, economic and political landscape, the macro-level, in which the health-system as a whole, with all its rules and regulations, plays a significant role. Economic trends, such as the reactions of governments in order to keep healthcare affordable, are also placed at this macro-level.

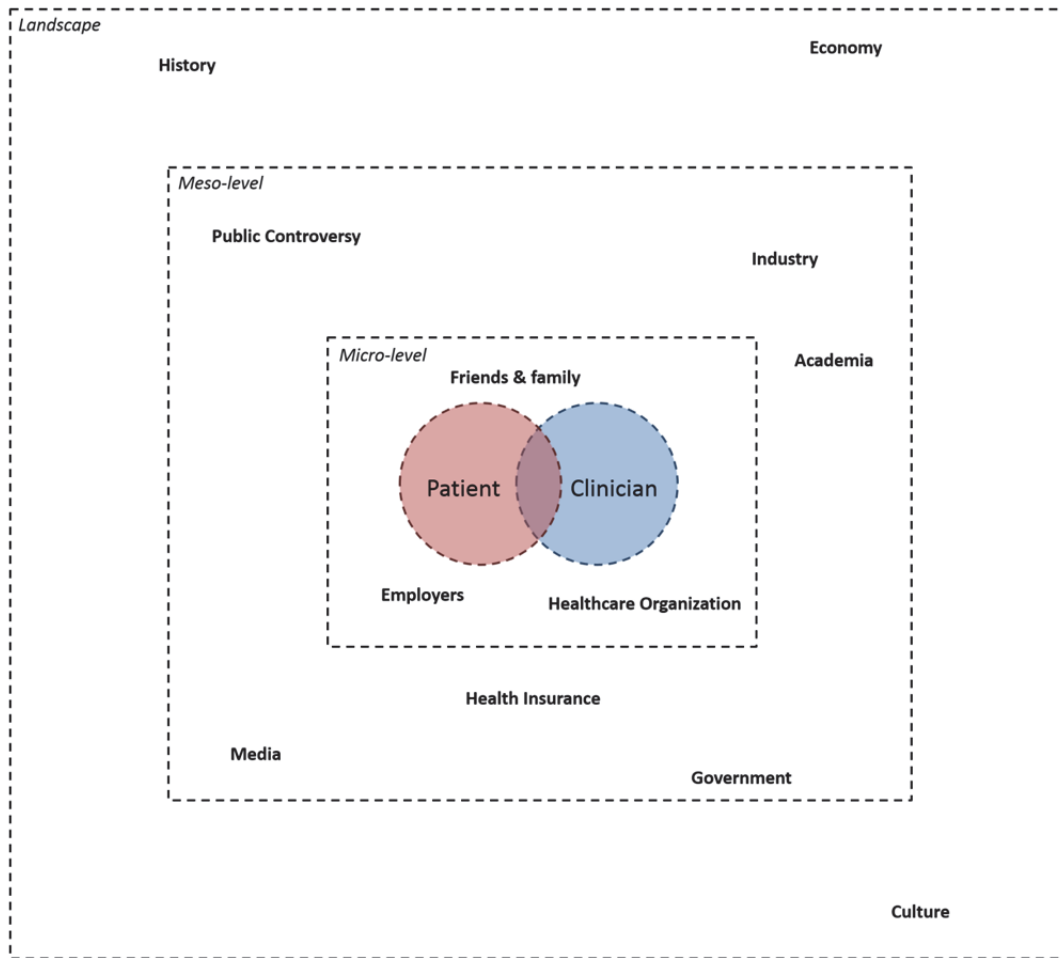


Figure 2. The integration of the transdisciplinary model for EBM and the ecological model which serves as a basis for this thesis

Chapter 3: Research design

3.1 Research aim and research questions

This thesis aims to acquire insight into the perspectives of patients and health professionals on adult ADHD and ADHD care in order to contribute to continuing efforts to increase the quality of care and the well-being of people with ADHD. This aim has been translated into two research questions that address the gap of knowledge in the micro-systems of the model as depicted in figure 2:

1. What are the perspectives of adults with ADHD towards ADHD and adult ADHD care?
2. What are the perspectives of health professionals towards ADHD and adult ADHD care?

In order to understand the complex nature of adult ADHD in a wider context, two research questions are formulated that address the higher levels in the model.

3. How do the perspectives of patients and health professionals relate to the broader ADHD debate?
4. What lessons can be learnt in order to contribute to a more person-centred care for adult ADHD?

In this thesis chapters 4, 5 and 6 address the first three research questions and explore the experiences of patients of daily life with adult ADHD and of the care they received. Chapter 7 explores the experiences and ideas of health professionals towards adult ADHD and the diagnostic process and treatment of the disorder. Chapter 8 functions as a stepping stone to answer the fourth research question by drawing upon the data presented in the first part combined with data from a similar study that explores the perspectives of people with bipolar disorder. Finally, chapter 9 comprises the concluding sections where I discuss my findings according to my research questions and in relation to the relevant literature. I close my thesis by giving recommendations for further research.

3.2 Research approach

This thesis mainly uses a qualitative, exploratory approach. Qualitative methods can give an in-depth understanding of the experiences, and the meaning of those experiences, of individuals who encounter

certain phenomena, such as getting sick and receiving treatment or being a physician who encounters and treats patients. Moreover, qualitative methods give people the space to elaborate and explore topics that are of prime importance to them. Qualitative research can thus access the narratives of patients regarding their illness and received treatments. Another major strength of qualitative research is that it is contextual (Sools 2013). It moves beyond physical measures of health and illness and provides insights into the meaning patients and health professionals attribute to health, illness and treatment in the context that is important to them (Upshur, VanDenKerkhof, and Goel 2001, Misak 2010).

Perspectives of adults with ADHD

There is a substantial literature on the problems of adults with ADHD and on how treatment contributes to alleviation of those problems from a biomedical or clinical perspective. This is mainly based on topics derived from the DSM or based on societal or economic perspectives (such as symptom severity or loss of productive labour output), rather than on a bottom-up approach wherein adults with ADHD themselves define the topics of importance and the meaning they attribute to them. Since, in the end, it are the 'patients' who live with the disorder and are subjected to medical investigation and treatment, this thesis specifically investigates these issues from the perspectives of the adults with ADHD themselves. This thesis includes three studies on: (1) the daily life experiences of adults with ADHD; (2) the experiences, needs and perspectives of adults with ADHD towards adult ADHD care; (3) the experiences of adults with ADHD in relation to a strength-based coaching methodology provided by a private coaching centre in the Netherlands. The first two studies are what Merriam (2014) coins *basic qualitative research*. These studies aim to uncover how adults with ADHD experience their lives and the care they received and how these experiences underlie their needs and perspectives towards adult ADHD care in the public sector. The third study is a qualitative case study. I will address these studies in more detail below.

Study 1

In the first study we focused on the experiences of adults with ADHD in daily life. We posed the following sub-questions:

- What are the experiences of adults with ADHD of living with ADHD?
- What problems do adults with ADHD face in daily life?

- What are current needs and wishes for the future of adults with ADHD with regard to their life with adult ADHD?

For this study, eight Focus Group Discussions (FGDs) were held with adults, aged 21 and over, with a primary ADHD or ADD diagnosis (n=52). The FGD method was chosen because it is an appropriate method for understanding the perceptions and concerns of groups of people (e.g. patients), exploring diverse views, values and attitudes (Morgan 1998). From the perspective of social psychology, perspectives and opinions are individually constructed but can be further explored through interaction with others (Ryan, Gandha et al. 2014), since shared and conflicting ideas become more visible through participant interaction (Kitzinger 1995, Belzile and Öberg 2012, Ryan, Gandha et al. 2014). A script was used with questions and exercises to guide the discussion, aiming to create a balance between encouraging participant interaction and staying on topic. FGDs were audio-recorded and transcribed verbatim. Transcripts were analysed using conventional content analysis as proposed by Hsieh and Shannon (2005) with the support of MaxQDA data analysis software version 11. For more details on the methodology, I refer to chapter 4.

Study 2

In a next study we explored experiences of adults with ADHD with adult ADHD care as well as their care needs. Specifically, we explored the needs of adults with ADHD with regard to care and how this care addresses the problems that are important to them. This study, therefore, addressed the following three sub-questions:

- What are the healthcare experiences of adults with ADHD?
- What are the healthcare needs of adults with ADHD
- To what extent are the healthcare needs of adults with ADHD met?

For this study, 30 adults, over age 21, with a primary ADHD diagnosis participated in four focus groups. Focus groups were again chosen as the preferred method for the reasons mentioned above. Again audio-recordings were transcribed verbatim and transcripts were analysed using conventional content analysis and MaxQDA data analysis software. More details can be found in chapter 5.

Study 3

In the Netherlands, an increasing number of private ADHD clinics have emerged, some of which promote themselves as using a strength-based approach. As they are private, they are not reimbursed by health insurance and thus clients have to finance it out of their own pockets. As these clinics are increasing in number and treat a growing number of clients, they can be assumed to address a need of adults with ADHD (after all people are willing to pay for it over fully reimbursed public care) that may not be addressed in formal adult ADHD care. For this study we explored the experiences and perspectives of adults with ADHD with a strength-based coaching treatment.

- Why do adults with ADHD choose for private coaching over public mental healthcare?
- What, according to clients, is the added value of private coaching?

A quickly growing coaching service was selected in Delft, a medium-sized city within the metropolitan area of The Hague. When founded in 2007, the centre had one facility. By 2015, it had grown to 13 facilities throughout the country. Its client base has steadily increased over the same period of time, with 186 invoiced ADHD coaching sessions in 2007 and 1907 in 2013. At the basis of the centre's approach is the vision that the problems of adults with ADHD, in addition to their symptoms, stem from the 'collateral damage' of having ADHD; namely, the negative coping strategies that one may have developed over the years as a result of living with ADHD. It argues that addressing this collateral damage can quickly lead to improvements in wellbeing and daily functioning.

For this exploratory study 22 clients were interviewed using a semi-structured design. Semi-structured interviews were chosen for this study since this method allows study participants to further elucidate on topics that are of great importance to them while maintaining focus on topics of interest for the researchers (Britten 1995). Interviews were audio-recorded and transcribed verbatim. Transcripts were analysed using open coding in line with the content analysis of Hsieh and Shannon (2005). The methodology is more elaborately described in chapter 6.

Perspectives of health professionals

Research question 2 concerns the experiences and needs of health professionals treating adults with ADHD. In order to answer this question, a fourth study was conducted.

Study 4

It has been argued before that the clinical experience and tacit knowledge of health professionals is an important part of clinical practice. Their perspectives also need to be explored and made explicit as part of the delivery of Evidence-Based Care, as originally conceived. This allows a better understanding of what and how research evidence is used in medical practice and also the transformation of tacit knowledge into explicit knowledge and new evidence. In the case of adult ADHD specifically, their perspectives are of importance because it can be substantially troubled by comorbid disorders, symptomatic overlap and problems that adults with ADHD may develop due to living with undiagnosed ADHD. Moreover, the diagnosis and treatment with stimulants remains a controversial topic and is surrounded by societal and political debate. Therefore, in this study we explore how health professionals deal with adult ADHD in their day-to-day clinical practice. We posed two sub-questions:

- What are the perspectives of health professionals towards the diagnostic process and treatment of adult ADHD?
- How do health professionals relate to the public debate that surrounds ADHD?

For this study, a qualitative approach was employed since this allows the study of how participants interpret, perceive and ascribe meaning to phenomena in the real world (Smith 1996, Biggerstaff and Thompson 2008), and gives in-depth understanding of these processes from the perspective of the participants (Green and Thorogood 2009). Semi-structured interviews were considered appropriate for this approach as they provide structure to address topics of interest of the researcher as well as leave room for individual respondents to elaborate on topics that they deem important (Biggerstaff and Thompson 2008). In total, 23 interviews were conducted with mental health professionals, who work with adults with ADHD, from different disciplines. Interviews were held with psychiatrists (n=14), psychologists (n=4), mental health nurses (n=4) and a coach (n=1). Interviews were audio-recorded and transcribed verbatim. Conventional Content Analysis approach proposed by Hsieh and Shannon (2005) was applied and MaxQDA v. 11 analysis software was used. For more details on the research methods, I refer to chapter 7.

Perspectives on patient-centred care

As mentioned before, patient-centred care is increasingly seen as central to the healthcare systems of modern states. Research on that takes a patient's perspective on PCC is sparse. This is striking as the

core idea of PCC is that the patient should be placed at the centre of health care provision (J. H. Robinson et al., 2008). Research into patient-centred care has proliferated but little is known what patients of outpatient psychiatric services need with regard to 'good care'. Study 5 sought to address research question 4 (about PCC) on the basis of the perspectives of patients. We argue that patients' stories are needed to give meaning to the concept of PCC discussed in the literature and to see if this conceptualization matches the perspectives and experiences of psychiatric patients.

Study 5

To that aim, we explored the perspectives of patients with adult ADHD and bipolar disorder on good quality of care, in order to answer the following questions:

- What are patients' perspectives on 'good care' in outpatient psychiatry in the Netherlands?
- How do these perspectives relate the conceptualization of PCC in the scientific literature?

The method for this study was twofold: (1) a systematic review was conducted in order to synthesize a conceptual model of patient-centred care; (2) this model is contrasted with the findings of the focus groups conducted for study 2 (see above) as well as a similar qualitative study on the perspectives of adults with bipolar disorder towards mental healthcare in the Netherlands (which was conducted by a colleague at the Athena Institute). The 'bipolar study' used six focus groups (n=35) as well as interviews (n=9) to explore the experiences and needs of adults with bipolar disorder on health care. For further elaboration on the methods used and the results of this study, I refer to chapter 8.

Research ethics

Because of the non-invasive nature of the exploratory studies conducted in this thesis, no formal approval was needed from a medical ethical committee according to Dutch regulations. The studies did not ask for personal-sensitive data such as medical history or questions regarding medical dossiers. All participants gave verbal or written informed consent at the beginning of interviews and focus groups for the audiotaping, analysis and publication. They were given the option to retract from the study at any given point without explanation or consequences. Data were handled with care and were made anonymous for analysis and publication and no information appears that can be related to the identity of individual participants. Names that appear in the thesis are pseudonyms.

3.3 Validity

Various strategies were employed to ensure validity and rigour of the results and the conclusion.

Rich data: The primary data of the studies, mainly interviews and focus groups, were extensively documented. Field notes for the interviews and focus groups were made and documented. For the focus groups one or two monitors (master students and/or other researchers from our research group) were present at every meeting taking notes and supporting the discussion where needed. All conversations and discussions were audiotaped and transcribed verbatim to prevent loss of data.

Member check: All participants and respondents were sent summaries of the conversations and summaries of the conclusions in order to check whether the researchers grasped the messages they conveyed and whether the conclusions drawn from the data resonate with the participants. After the interviews and focus groups there was time to discuss the process of the conversation and participants were asked to reflect on the process itself, whether there was enough room and the right atmosphere to talk about their experiences and whether they felt understood by the researcher, neutrality of the researcher and the applicability of the research design.

Triangulation: Throughout the process, multiple researchers were involved in the project who regularly reflected on decisions made with regard to design, analysis and presentation of the results. Findings of the studies were regularly compared to the relevant literature in order to analyse similarities and differences.

Researcher – Patient

An important validity aspect is that I, myself, have been diagnosed with ADHD and have received treatment for it. This is by no means exceptional; there are numerous examples where the research topic is directly related to the personal situation of the researchers. For example, Patricia (Deegan 1988, Deegan 1997, Deegan 2002, Deegan 2007), who after experiencing a schizophrenic episode started investigating how to support people with schizophrenia in their recovery process. Additionally, she published a number of papers elaborating on her experiences of getting a diagnosis, feeling lost and helpless, taking medications and finally how she managed to create a meaningful life despite of having schizophrenia. Another example is Truus Teunissen who, on basis of personal experiences, questioned the ability of patients with chronic disease to act as independent consumers and to take the responsibility to manage their disease (Teunissen, Visse et al. 2013). Furthermore, Schipper, Abma et al.

(2010) present a personal elaboration on the experiences of Karen Schipper as a patient research partner, working together with researchers and professionals in various stages of the research process, from agenda-setting to interpretation of study findings.

Gerrits (2012) provides a number of reasons why people who have experienced misfortune, for example in the form of disease, choose to study and write about it: (1) the realization that hardly anything had been published about the topic when they wanted to learn more about it; (2) their disagreement with the way the topic was represented in the literature, (3) the fact that literature did not provide insights from the perspective of the people involved; and/or (4) the wish to make a contribution to the political or public debate about the issue, or to provide health professionals with the patients' perspective. For me, all these were reasons to choose this topic for my PhD research, but two of them really stand out, namely the second and third reason.

Being a researcher and patient poses advantages as well as challenges with respect to validity. One of the advantages is that researchers who share experiences with their informants might be better equipped to understand those experiences (Rothman 1986, Reis 1998). However, there is also a risk for researcher bias since people with shared conditions, such as the same diagnosis, do show a variety in experiences, views, needs and so on (Anderson 2006, Gerrits 2012). The pitfall exists of reproducing personal experiences while rejecting or ignoring experiences that are not shared by the researcher, thereby creating respectively over-emphasis on certain aspects and blind spots on others. In order to prevent this, I actively searched for experiences of adults with ADHD that deviated from my personal story. Data was collected by at least two researchers (of which I was one). In addition, I extensively reflected on my own experiences and data analysis with other researchers in order to explicate my own position and to ensure that the full variety of perspectives, whether shared or conflicting, was reviewed in an unbiased manner. Furthermore, I will disclose my own history with ADHD in box 3 so the reader is aware of my own experiences with living with ADHD and ADHD care.

Box 3. Personal history with ADHD

I was not diagnosed in childhood because there were no substantial problems with my schoolwork. According to teachers I was hyperactive but there was no real suspicion of attention problems as my grades and my development were comparable to other students. The divorce of my parents, however, had a large impact on me; I grew up between two families. Also, because of being "different", I was often bullied at school.

In early adulthood, I was troubled by problematic finances and I had a lot of problems with planning and finishing things I started. I was constantly fiddling with my hair, could not sit still, and was impulsive in making big decisions like switching jobs or quitting my university programme. Another typical trait was the chaos I had in my head: I

could not keep my attention on one thing but was always “on the go” switching between tasks for work, my private life or just doing things out of plain curiosity. At that time, my self-image was very low.

I only sought professional help for the first time, when I was 24 – a time when I experienced severe personal distress. I found out that the field I had chosen for my academic career (master programme medical physics) was not right for me and I noted that it was impossible for me to finish my education even though it was just one step away. After seeking assistance from the mental health services at my university, I was referred to a psychiatrist with suspected ADHD. After a couple of conversations he confirmed ADHD and started treatment with Ritalin. However it did not work for me since it exaggerated depressive complaints I, apparently, also suffered from at that time. When I stopped taking Ritalin, the depressive complaints disappeared. From then on, because I still experienced substantial problems and impairment, treatment was on and off and I had a number of unpleasant experiences and unsuccessful therapies. One psychiatrist did not want to treat me for ADHD unless I would, in addition to Ritalin, take antidepressants. The side effects of the antidepressants were substantial and, eventually, I discontinued treatment again.

In most mental health institutes (GGZ instituten) in The Netherlands therapy comprises pharmacotherapy combined with ADHD coaching, which I also received. The coaching therapy, which aimed to help me create more structure in my life, was not very effective. It consisted of strict day planning and predefined coaching in order to get my finances and housekeeping under control. For me, however, it did not address the underlying problems; it rather made me feel even more incompetent, further reducing my low self-image. For example, I regularly lost my keys. During coaching, I was told that a hook for the keys in the kitchen would help me not lose my keys. However, the hook did not help me not lose my keys since the keys would only rarely make it to the hook before I lost them. I repeatedly told my coach that the problem was not that I did not understand that if I put my keys in one place, say a hook, I would not lose them. The problem rather was that the keys never ended up on the hook even though I intellectually understood the concept of a key-hook. As a result, my self-image was negatively influenced. Why could I pass my university exams but was unable to perform even the simplest task such as hanging my keys on a hook?! This is just an example, but there were numerous instances where ADHD coaching mainly reinforced my negative self-image. In other words, the psychosocial treatment offered for adults with ADHD did not work for me. The focus on strict day planning felt superficial and it did not address, in my opinion, the complexity of the problems I experienced.

For some time, I had been hopping jobs in restaurants, not finishing my education and being lost as to what I wanted in life. Mainly because of pressure of my friends, who found it a waste that I did not finish my university, I decided to register for a master’s programme again. Aware of my previous failures with education, I wanted to prevent the problems I had been through before and sought professional help again. This time I got treatment – medication and psychotherapy for the underlying problems with my self-image and emotion-regulation – that was effective. Things started to work out again and in 2009 I graduated Cum Laude for my MSc. After seeing the substantial benefits that psychosocial therapies can have, I also had successful periods without medications, which enabled me to believe that it can be possible, at least for me, to function without medications at certain stages in my life. Eventually, I have understood that the symptoms of ADHD are at its worst, when my context is really difficult (such as the break-up of an intimate relationship or the stress of finalizing a PhD study). During those times, medication can reduce my ADHD symptoms and thus provide me with the extra support I need to successfully bring things to an end.

Chapter 4: 'Do I need to become someone else?' A qualitative, exploratory study of the daily lives of adults with ADHD

Abstract

Background: Attention deficit/hyperactivity disorder (ADHD) is a common psychiatric disorder in childhood which has recently been acknowledged to persist into adulthood in two-thirds of cases. However the problems faced by adults with ADHD in their daily lives remain largely unexplored.

Objective: To assess the perspectives, problems and needs of adults with ADHD.

Design and Participants In this exploratory qualitative study, adults (n = 52) with a primary ADHD or ADD diagnosis, aged 21 years or older, participated in a eight focus groups in five cities in The Netherlands.

Results: Although core symptoms of ADHD were perceived as a problem, participants placed greater emphasis on social problems that arise from living with ADHD and their subsequent effects on self-image. Accompanying problems were feelings of powerlessness, lack of acceptance by their social environment, and poor self-image. Adults with ADHD would like to see greater acceptance of ADHD and its accompanying problems, together with appreciation for personal competences and strengths in certain domains, such as creative or associative thinking.

Conclusion: Our study adds to previous research by providing insight into how these problems are interrelated and their strong link to the social environment. Perceived powerlessness, failure and negative reactions of the social environment leads to a persistent low self-image. This merits substantial attention in future research, particularly when considering ongoing care options.

4.1 Introduction

Attention deficit/hyperactivity disorder (ADHD) is a common psychiatric disorder in childhood which persists into adulthood in two-thirds of cases (Wender, Wolf et al. 2001, Kooij, Bejerot et al. 2010). The prevalence of ADHD in children has been estimated to be 5.29% (Polanczyk, de Lima et al. 2007) and 2.5% (Simon, Czobor et al. 2009) in adults. According to the Diagnostic and Statistical Manual of psychiatric disorders text-revision (DSM-IV-TR), there are three different ADHD subtypes: the mainly inattentive type better known as Attention Deficit Disorder (ADD), the mainly hyperactive/impulsive type and the combined type (APA 2000). The classical symptoms are clustered in the three categories of inattention, hyperactivity and impulsivity (Davidson 2008, Kooij, Bejerot et al. 2010). However, these symptoms have been defined for children and there is no consensus regarding the applicability of these criteria to adults (Kooij, Bejerot et al. 2010, Matte, Rohde et al. 2012).

Adults with ADHD often additionally suffer from a wide range of social, emotional and psychological problems (Biederman and Faraone 2005). For example, on average, adults with ADHD experience higher rates of unemployment and underemployment; underachievement in academic careers (Murphy and Barkley 1996, Biederman, Petty et al. 2008); and relational, marital and family problems (Biederman, Faraone et al. 1993, Murphy and Barkley 1996, Eakin, Minde et al. 2004, Harpin 2005). Thus, adult ADHD negatively affects multiple facets of life and is responsible for considerable impairment in social functioning.

Although the diagnosis and treatment of ADHD has been extensively studied from a clinical or a psychiatric perspective, the perspectives and experiences of adults with the disorder remain largely unexplored with the exception of three qualitative studies (Young, Bramham et al. 2008, Brod, Pohlman et al. 2012, Fleischmann and Fleischmann 2012). First, Brod, Pohlman et al. (2012) compared the burden of disease of ADHD in a seven Western countries using focus group discussions, demonstrating that core ADHD symptoms cause substantial dysfunction in the lives of adults and that the burden of disease did not significantly differ between countries. Second, Young, Bramham et al. (2008) explored the experience of receiving a diagnosis and care for adult ADHD, establishing that participants had to reframe their past in the light of their ADHD diagnosis and went through a period of emotional acceptance in order to form a vision of their new future with ADHD. Additionally, they found that most of the interviewed adults recognized the positive impact of stimulant medications on their functioning. Finally, Fleischmann and Fleischmann (2012) analysed online accounts of adults with ADHD and found

that some adults can see the positive side of their disorder if they have had successful therapy to address the problems resulting from ADHD. Although these studies provide valuable insights into the burden of symptoms, the diagnosis and treatment of adult ADHD, there remains limited insight into the perspectives, problems and needs of adults with ADHD in daily life. In an effort to fill this knowledge gap, this study explores the perspectives of adults with ADHD with respect to the following questions: (1) what are their experiences of living with ADHD? (2) What problems do they face in daily life? And (3) what are their current needs and wishes for the future with regard to life with adult ADHD?

4.2 Methods

Due to the exploratory nature of this study, a qualitative approach was employed. Focus groups were chosen as a means of data collection because they are a suitable method for understanding the perceptions and concerns of groups of people (e.g. patients), exploring diverse views, values and attitudes (Morgan 1998). From the perspective of social psychology, perspectives and concerns can be individually constructed and expressed. In a focus group discussion (FGD), shared and conflicting ideas become more visible through a process of participant interaction (Kitzinger 1995, Belzile and Öberg 2012, Ryan, Gandha et al. 2014). The moderator uses a protocol with questions and exercises to guide the discussion, aiming to creating a balance between encouraging participant interaction and staying on topic (Ryan, Gandha et al. 2014).

Two overlapping FGD protocols were used for a total of eight focus groups. The first five focus groups explored the daily life experiences and problems of adults with ADHD. Activities in these focus group were structured as follows: (1) a brainstorm phase to identify a broad variety of important topics and problems considered important in living with ADHD; (2) a discussion phase to further elaborate two central topics and their effects on daily life; and (3) a discussion phase in which possible solutions to the problems were considered. The second FGD protocol, used in three focus groups, also consisted of three phases: (1) a reflection phase in which a summary of the findings of the previous five focus groups was discussed; (2) a creative phase in which participants were asked to visualize their current situation and their desired situation, and how they could achieve their desired situation; and (3) an exercise to identify real world solutions for reaching the desired situation. Focus groups were held at five different locations throughout the Netherlands to ensure diversity in participants. Substantial saturation was reached as no new topics emerged in the third focus groups for both designs which suggests that the full

variety of themes relating to the research topic have been observed in the study. Consequently, no additional FGDs were planned.

In the FGD design, initial time was allocated to give the participants the opportunity to become acquainted with each other. Participants quickly discovered that they had much in common and they often recognised each other's perspectives. This enabled in-depth and personal discussions. In many cases, participants were eager to stay longer than the planned duration of the sessions, discussing their experiences of ADHD and related problems.

Participants were recruited through two channels: a notification e-mail to a national forum for adults with ADHD; and an announcement on the website of the Dutch patient organization for adults with ADHD. In both cases, potential participants were also asked to invite peers. Contact information of the researchers was provided and adults interested in participating could seek further information from the researchers. Respondents with a primary ADHD diagnosis were eligible to participate. Given that comorbid disorders are common among people with ADHD.¹ Only respondents aged 21 years or older were eligible so that all participants would have experience with employment or higher education

During the recruitment phase, 138 potential participants responded to the announcements of the study. Subsequently, 73 participants were excluded because they did not meet the inclusion criteria (n = 3), did not reply to invitations for particular dates and locations (n = 68), or were unable to attend the planned focus group sessions (n = 2). In total, 65 participants were assigned to one of the eight focus groups. There was a no-show rate of 20%, leaving a total of 52 actual participants. On average, there were 7 participants per FGD, with the exception of one focus group which only had 3 participants.

All FGDs were recorded and transcribed verbatim, with summaries of the individual discussions sent for respondent check to all participants of the FGD. After the analysis, the main findings of the study were sent to respondents for member check to support the validity of the conclusions. The reactions of the participants were positive, indicating that reporting was consistent with the views of the study participants; no amendments were necessary. In order to ensure rigour, two researchers were involved in the design and analysis. Their reflections were regularly discussed with a third researcher.

The coding process followed the structure of Conventional Content Analysis as described by Hsieh and Shannon (2005) Transcripts were read and re-read to develop familiarity with the data. In the first phase of coding, the two researchers read the transcripts independently and developed two separate coding schemes. The two coding schemes were then compared and discussed, prior to developing a final joint

coding scheme based on agreement in terms of the code name, definition and description. All transcripts were then re-coded using the final coding scheme in Atlas.ti software. Relevant quotes to underpin the analysis and results were checked and discussed within the research team.

Ethical considerations

Given the non-invasive nature of the study, medical ethical approval was not required. All participants received verbal information about the aim and scope of the research; anonymity was ensured by using pseudonyms in the reporting of the research; and participants were informed that they could withdraw from the study at any time without penalty or questions. During the recruitment phase, contact information of the researchers was provided so that potential participants could seek further information from the researchers. Verbal informed consent was acquired for recording, transcribing and analysis of the FGDs.

Table 1. Demographic variables of the study participants

# of participants	52
Age ^a	43 ± 9.5
<i>Male</i>	24
<i>Female</i>	28
Diagnosis	
<i>ADHD</i>	33
<i>ADD</i>	14
<i>Combined</i>	4
Current treatment	
<i>Pharmacological</i>	37
<i>Psychosocial</i>	17
<i>Other</i>	4
<i>No treatment</i>	7
Education and employment	
<i>College</i>	7
<i>Higher vocational education</i>	27
<i>Intermediate vocational education</i>	11
<i>High school</i>	5
<i>Other</i>	2
<i>Unemployed</i>	10

^a Years Mean ± SD

4.3 Results

Demographic characteristics of the participants are presented in Table 1. Some 52 participants took part in eight focus group discussions. The mean age was 43 (range: 23-55) and 54% of the sample was female, with a mean number of 2 years since receiving an ADHD diagnosis. Problems identified during the focus groups were divided into three categories: powerlessness, perceived lack of understanding from the environment with regard to specific ADHD problems, and poor self-image. In the next subsections, these categories are discussed from the perspective of the participants. Finally, future visions and desires are described.

Powerlessness: 'I want to but I can't'

The vast majority of participants felt limited in their ability to undertake everyday activities. The word 'powerless' was often used to describe their inability to control their thoughts and emotions. Thoughts, emotions and behaviours were out of their control and could change abruptly, almost like they had 'lives of their own.' As Alice explained:

Sometimes you wake up and you're on top of the world, and only one thing happens which is actually quite small, and suddenly you're down as hell.

In addition to the perceived inability to control thoughts and emotions, participants explained that they felt unable to behave in the way that they would like to. This mainly revolved around the inability to perform behaviours that are considered necessary or desirable in social situations, such as tidying the house, and refraining from behaviours perceived as inappropriate, such as speaking loudly in public places. Participants attributed the cause of poor behavioural control to the gap between the intention and the performance of a behaviour, and to a lack of interest in performing certain tasks or activities. Participants explained that they understood socially acceptable behaviours, felt that they had the competencies and attributes to behave in socially acceptable ways but nevertheless felt unable to act or change behaviour patterns. Some participants explained that they were able to modifying their behavioural patterns but that these efforts were short-lived:

And every time you start again with the idea 'this time I am going to do it right', and you start off in the right way, but in the end it doesn't work out that way. *(Peter)*

I can talk on and on, and there is a little voice in my head telling me to shut up, but I just can't stop, I just can't stop [talking]. *(Margreet)*

Maintaining focus on uninteresting tasks or activities was perceived as difficult by most participants, often leading to postponing, forgetting and not finishing tasks. Novel tasks and activities were perceived as interesting to participants but, with increasing familiarity, focus dwindled. Novelty was perceived to be advantageous by some participants because it stimulated interest in undertaking new and multiple activities simultaneously. Novelty had negative connotations for others because it contributed to avoidance behaviour or served as an escape from uninteresting, annoying obligations. Interestingly, this behaviour, both positively and negatively formulated, led to postponing, forgetting and not finishing other, more important or urgent things:

If I don't see use and necessity, even for the simplest things, then it just doesn't happen. The necessity will be there surely, some things need doing, but the simplest things become the biggest barriers. *(Mark)*

Some participants described that they find it more difficult than people without ADHD to 'filter out' irrelevant stimuli or thoughts that spring into their mind. As a result, every new stimulus, emotion or thought needs immediate attention and action, making it hard for them to focus on one task.:

If too many stimuli enter your head, you are unable to filter them which makes it impossible to prioritize them. *(Ingrid)*

Lack of understanding: '[They think] you can but you don't want to'

Participants were of the opinion that their immediate social environment (family, colleagues and friends) expects that they should be able to perform organizational tasks, whereas these are precisely the tasks that participants found difficult to focus on and complete. For some participants, this was further complicated by the ease with which they could perform highly complex tasks. This paradox of the inability to do easy tasks, for example simple book-keeping, and the ability to do highly specialized tasks, for example process engineering, was difficult for their social network to grasp and accept:

On the one hand, in some things you are a real perfectionist ...on the other hand, you don't understand the most simple things. Then you have to ask help for 20 times and then people think that you are a complete idiot. *(Anna)*

In response to mismatched societal expectations, participants felt forced to adapt to meet these societal expectations, such as having a tidy house or being structured and organized. Participants explained that

they were convinced that something was wrong with them and that they were expected to act in a different way. In a sense, they felt they had to be someone else:

Well, adaptation really is a big one [problem] for me. For thirty years, I have tried being a blue square while I actually am a red circle. I try very hard to be like everybody else.
(Cees)

The pressure to adapt and high self-expectations often gave participants the feeling of having to perform to the highest standards at all times, inevitably leading to disappointment and failure when these standards could not be met. Participants frequently made statements like 'I want to but I can't' where they felt judged by their social environment as people that 'are able [to do certain things] but don't want to.' This spiral of failure and lack of understanding from their social environment led to feelings of low self-worth and to low self-image.

Low self-image: 'I come from a different world'

The perceived inability to think and act as they would like to, coupled with the lack of understanding from social networks, has a negative impact on the self-image of many participants. Many explained that the phrase 'you can do it but you don't want to' was carved into their minds, reinforcing repeated feelings of not being good enough and of underachievement:

Continuously trying so hard, and then you feel disappointed in yourself, because by trying so hard all the time, sooner or later, you get a setback; you can't do your best all the time. And then people tell you: you are worthless or you are no good. (Mark)

Mark, quoted above, wanted to behave optimally all the time and in all circumstances, an aspiration which was unrealistic, easily leading to a sense of failure and lack of acceptance by his social environment. Although social influence was important in shaping the feeling of having to perform optimally, many participants admitted that they had high expectations of themselves, were frequently unsatisfied with their achievements, and always thought they could do better. Moreover, they explained that the feeling of striving to be perfect becomes compulsive with time:

I am such a perfectionist with what I want, because I really want everything to be tidy and I am looking for the structure to do so, but I can't give myself that. (Margreet)

Expectations ranged from the every mundane tasks (e.g. having a tidy house) to professional and employment expectations (e.g. being the best at a very specialized job). Regardless of the type of task or life event, the negative impacts on self-esteem were similar. In most cases, not living up to one's own expectations led to a sense of underachievement and experience of failure. The continuous, common feeling of underachievement, in turn, contributed to low self-worth:

For me, perfectionism is different from procrastination . . . No, not always, sometimes my targets are too high and then it is difficult to get started with my tasks and the consequence of this procrastination is shame: shit, I've done it wrong again... A vicious circle. (*Karin*)

Participants explained that, regardless of the repeated experiences of failure, they tried to start again 'the right way' and make a 'new start' for themselves but they were often confronted with the inability to maintain this new way of doing things. This was often perceived as proof of inability to change or to do things better. In this 'cycle of failure', it was difficult to start challenging tasks due to the fear of continuous failure:

I don't have faith it will work out but I try every time. And that causes my self-image to stay low because you keep on failing all the time. (*Yvette*)

Some participants explained that they felt they 'came from a different planet' as they continuously try to adapt to their environment. This, sometimes, led to feelings of alienation such as illustrated by Masha and Peter respectively:

It seems like you can't be yourself in this world

I already said it, we are beavers in the world of squirrels!

Not all participants interpreted the feeling of being different as a bad thing. Being different was described as a reflection of human diversity, including different qualities, competences and weaknesses. Some participants indicated they even perceived ADHD as an advantage, arguing that they were, for example, able to think faster, more creatively and more 'out of the box' than people without ADHD. Participants explained that they felt gifted in certain areas that are less developed in individuals without ADHD, for example as associative and creative thinkers and, to lesser extent, as faster thinkers as can be illustrated by the discussion excerpt:

You just understand, or see through, a lot of things more quickly than other people. For example, in a meeting when you come up with a certain solution, then people say: Huh where does that come from? And then, two weeks later, those people come up with exactly the same solution. *(Martijn)*

That is because we can think out of the box! *(Peter)*

This was often extrapolated to the ability to be extremely powerful in designing more creative solutions for difficult problems. Associative and unconventional thinking was linked to successful careers requiring such traits, such as entrepreneurship.

Needs and future desires: 'We are a beautiful colourful world'

When future aspirations and desires were discussed, many participants visualized a world of harmony in which everyone is accepted for who they are, including shortcomings, and appreciated for their gifts and competences. In order to achieve this harmonious world, four steps were identified by participants: self-knowledge; acceptance and understanding; two way communication; and appreciation.

Many participants explained that self-knowledge is an essential step to enable people with ADHD to function better in daily life. Self-knowledge would allow individuals to see their own weaknesses and understand where others might have problems with their behaviour. Ultimately, self-knowledge would make it possible to deal with or circumvent one's own behaviour:

It is just like shooting with a gun at a fair. If you know the inaccuracy of your gun, it is possible to hit your targets. *(Alice)*

Moreover, several participants explained that awareness of their own weaknesses means that they know when to ask for help from others and how to instruct people in their social network to deal with their behaviour in specific situations. Asking for help, in turn, prevented failures and also lack of understanding from the social environment:

Well, that understanding increases, the more you know who you are, the more your environment positively reinforces that and the more you find the setting in which you function best. *(Jan)*

Another important benefit of self-knowledge was that it helps to find an environment that best fits an individual's personality. If you know yourself, they explained, it is possible to find the people that accept

you for who you are and that give you energy, instead of draining energy. Additionally, knowing yourself enabled participants to look for jobs that better aligned with their desires and competences:

It is a quest. For example, last year I had a job, I have a new job every year, and I thought: 'Oh no, I am going to die here, I have to leave or I will kill myself!' And every time I think: and now I am going to find a job that suits me better, and I am not there yet, but I made one step in the right direction and I won't jump off my roof that soon anymore. *(Anna)*

Two pathways to acquiring self-knowledge were described: professional therapy and coaching; and having a 'mirror', namely contact with other people with ADHD. Indeed, the focus groups themselves were seen as an example of the latter. They helped the participants to reflect on their behaviour, how they function and the extent to which they are similar or different to others. Moreover, it sometimes helped them to gain self-knowledge as they saw their behaviour through the eyes of others. This, in turn, made them realize how difficult it can be for their own social environment to live with someone who has ADHD:

You know how you can get that extra self-insight? By looking around in this [focus] group, for me it was really nice to recognize my own behaviour in others. It enables me to see when I behave in this way. Just what you said [other participant]: a lot of thoughts and immediately start talking, no matter who is talking at that moment. So, we see, from each other, how we behave, and that is very nice for self-knowledge. *(Peter)*

Most participants also wanted adults with ADHD to be accepted by their social environment as individuals with strengths and weaknesses. For this to happen, society should first accept that 'ADHD is a real thing and can cause real problems' for people with the disorder. One particular difficulty, according to participants, is that ADHD is not something which can objectively be proven to exist by, for example, a photograph or a scan:

Because you can't see it [ADHD], that makes it so difficult. You can't see it. If you break your legs they think: well, that's sad, we'll help you with that. And if you have something wrong in your head, that they can't see, that they think what a freak. *(Angelique)*

Third, participants stressed that open, non-prejudicial communication with people in their social networks was crucial. This communication should be mutually open: person with ADHD could explain

openly how they feel or what there are experiencing; and people in their social network could identify their boundaries or describe their feelings about living with someone with ADHD. In this way, an open and accepting environment could be created and this, in turn, would enable adults with ADHD to function better socially.

Finally, the greatest desire of the participants was concerned with their need for appreciation. Many participants explained that their characters also have positive, worthwhile characteristics from which the world could benefit and for which they would like to be appreciated. This goes beyond their desire to be accepted for their weaknesses:

Well, I like to paint sometimes, and then I think: 'What if you have a painting where all colours blend into each other because we actually are a beautiful colourful world.' Then I think: 'Beautiful, that is where our strength is, that is where we complement each other.' If there is a little acceptance and everyone can live to his or her own competences, then together we stand strong. That not only the other is different but we see we are all different. (*Johan*)

4.4 Discussion

In this exploratory study, focus groups were conducted to better understand the problems faced by adults with ADHD in their daily lives, and their visions and needs for the future. We found that there were three interrelated categories of problems that the participants perceived to be particularly detrimental, namely the inability to control their thoughts, emotions and behaviours; the lack of understanding of their social environment; and the combination of high self-expectations and poor self-image. Their visions and desires for the future included improving self-knowledge, increasing social acceptance of the individual and his or her shortcomings; and appreciation of one's own gifts, talents and competences. Although symptoms, such as inattention, impulsivity and hyperactivity were mentioned, priority was given to the social implications of these symptoms and the effect of these social implications on self-image. Few participants wanted to get rid of the symptoms completely because that would mean that they were not themselves anymore. Instead, they wanted the world to accept them for who they are and to appreciate them for their gifts and competences.

Adults with ADHD appear to consider that nothing works out the way they want and that even the most easy tasks will, for them, result in failure. This underperformance is often misinterpreted by those in their social environment, such as colleagues or spouses, as unwillingness. This leads to a lack of understanding, which, in turn, results in feelings of poor self-image and feelings of rejection. In other words, daily life with ADHD becomes problematic in relation to the broad social context, rather than ADHD and its symptoms being a problem in themselves.

Our study confirms findings that have been reported earlier. Experiences of adults with ADHD were comparable with those identified here, namely problems with interpersonal relations and feelings of being different from normal people; and repeated experiences of failure, and their effects on the self-image (Kooij et al. 2010, Young et al. 2008, Fleischmann and Fleischmann 2012, Brod et al. 2012). However, our study adds to previous research by providing an insight into how these problems are interrelated and strongly linked to social context. We hypothesize that it is the repeated and reinforcing interaction between problems with self-image and typical ADHD symptoms and the negative or even rejecting reactions of the environment that creates the tremendous impact of ADHD has on the daily lives of adults with the condition. Additionally, this is the first study to provide insights into the desires of adults with ADHD with regard to the future: namely, their desire for more societal acceptance of ADHD, for support from within their social environment, and for appreciation of personal strengths.

The findings of this study reinforce the importance of person-centred care for people with ADHD. From the person-centred care perspective, therapies and 'doctor-patient' communication need to look beyond the disorder and consider the individual as a whole, including his or her context, emotional needs and life issues (Pulvirenti, McMillan, and Lawn 2014, Stewart 2001). Our study highlights the need to pay more attention to problems specific to adult life with ADHD, particularly in relation to the social environment. Moreover, participants expressed the need for more positive acceptance of adults with ADHD and a stronger focus on personal strengths. Currently, neither of these perspectives have an explicit place in standard practice for the treatment of adult ADHD, as recommended by Kooij et al. (2010) or the guidelines from the National Institute of Health and Care Excellence (NICE 2008).

In this context, and also reflecting Brod et al's (2012) proposal of the need to further investigate the role of social stigma on wellbeing of adults with ADHD, we propose that future research should investigate the role of the social environment and social stigma on the quality of life of adults with ADHD. Future research should investigate how therapeutic interventions can be adapted or supplemented to address the role of the social environment. Moreover, participants highlighted the need for positive acceptance

and recognition of personal strengths, possible paths for research which focuses on person-centred therapies.

This study has two limitations. First, most participants had received their diagnosis relatively recently with a median of 2 years, which may indicate that they were still coming to terms with their condition. Second, groups were heterogeneous with respect to diagnosed type of the disorder, namely ADHD, ADD or the combined type, and comorbid disorders, which could have disguised differences between these groups of adults with ADHD.

4.5 Conclusions

The symptoms of ADHD in themselves were not seen as a problem by most of the participants. Although coping with ADHD was a struggle for some, ADHD appears to become most problematic in the social environment with symptoms, self-image and social environment all playing central roles. Adults with ADHD appear to have low expectations of what they can achieve and expect failure. This underperformance is often interpreted by those in their social environment, such as colleagues or spouses, as unwillingness. This lack of acceptance results in feelings of not being good enough and feelings of rejection. The role of the social environment should be investigated in future research so that suitable therapeutic strategies can be developed to integrate the environment in the treatment process.

Chapter 5: 'How should I take my medicine?'

Experiences with and needs for mental healthcare of adults with ADHD

Abstract

Adult ADHD is a topic of substantial scientific and societal debate; however, the perspectives of adults who are diagnosed and treated with ADHD are rarely investigated. Therefore, this article explores the healthcare experiences and needs of adults with ADHD, in the Netherlands, in order to strengthen their voice in the debate and to contribute to quality of care. To this end, we conducted four focus groups (n=30) with adults with ADHD. Participants explained that adequate diagnosis and treatment can substantially relieve suffering and improve functioning but that it often was a long and frustrating process to get their ADHD acknowledged. They experienced care to be too disease- and treatment-centred because of the strong focus on pharmacotherapy combined with the enforcement of strict planning and structure in their daily lives. More person-centred care, taking into account their unique personalities and contexts, would be of benefit to adult ADHD care. Participants expressed concern that the scientific and societal debate would reduce access to care for adults with ADHD.

5.1 Introduction

Initially being defined as a childhood disorder, adult ADHD is a recent phenomenon (Wender, Wolf et al. 2001). Only since the turn of the Millennium it is medically acknowledged that ADHD may persist into adulthood and is estimated to affect 1.2-7.3% of adults worldwide and about 5% of Dutch adults (Fayyad, De Graaf et al. 2007, Kooij, Bejerot et al. 2010). ADHD is generally considered a neurodevelopmental disorder which may be correlated to abnormalities in the dopaminergic systems in the brain (Tripp and Wickens 2009, Cortese 2012). As defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), the symptoms of ADHD typically include inattention, impulsivity, restlessness, disorganisation and forgetfulness (APA 2000, Faraone, Biederman et al. 2000, Wender, Wolf et al. 2001, Spencer, Biederman et al. 2007). These symptoms can result in impairments across multiple areas of adult life such as interpersonal relationships, family dynamics, education, occupation and overall health-related quality of life (Murphy and Barkley 1996, Eakin, Minde et al. 2004, Harpin 2005, Biederman, Petty et al. 2008). Adult ADHDs' far-reaching effects make it a serious disorder that requires early and adequate diagnosis and treatment. The number of adults treated for ADHD in the Netherlands has steadily risen (Stichting Farmaceutische Kerngetallen 2014), but diagnosis and treatment remain complicated and there are indications that patient needs are insufficiently met (Matheson, Asherson et al. 2013, Schrevel, Dedding et al. 2015).

Since the 1990s, there has been growth in the amount of research into the diagnosis and treatment of adult ADHD and treatments have become increasingly accessible to patients (Kooij, Bejerot et al. 2010). Pharmacological treatment of ADHD has proven effective in reducing symptom severity in several Randomized Controlled Trials (RCTs) (Mészáros, Czobor et al. 2009, Surman, Hammerness et al. 2013). In spite of addressing symptoms, pharmacological treatment alone may not sufficiently improve negative impacts of ADHD, and many scholars and health professionals recommend a combination of pharmacological and psychosocial interventions as treatment (Murphy 2005, Kooij, Bejerot et al. 2010, Emilsson, Gudjonsson et al. 2011, Weiss, Murray et al. 2012). Treatment for adult ADHD in the Netherlands generally involves a combination of two approaches: pharmacotherapy, mainly in the form of psychostimulants such as methylphenidate (Ritalin), and psychosocial interventions such as psycho-education, skill training and Cognitive Behavioral Therapy (CBT) (Kooij, Bejerot et al. 2010).

From its conception, ADHD in both children and adults has received substantial criticism from within the scientific community, particularly the social sciences (Conrad and Potter 2000). Critics point at social and

cultural explanations for the emergence of ADHD and the dramatic increase in stimulant prescriptions (Conrad and Potter 2000, Mayes and Rafalovich 2007, Mayes 2008). Scholars have especially focused on the medicalization of 'normal' childhood behavior (Conrad 1975), the expansion of medical categories (Conrad and Potter 2000, Batstra and Frances 2012), definitions of what counts as a disorder and whether the brains of individuals are 'sick' or whether it is caused by societal changes (Timimi and Taylor 2004, Bowden 2013). Most of these critiques raise doubts whether people who have received the diagnosis ADHD have a 'real disorder'; they thus question the validity of the diagnosis and its accompanying pharmacological treatment (Moncrieff and Timimi 2011). Public concerns have been raised as well, pointing at the marketing strategies of the pharmaceutical industry, rising healthcare costs and the use of psychostimulants for ADHD by 'healthy' people for human enhancement (Levinson and McKinney 2013, Singh, Filipe et al. 2013, Dehue 2014).

Against this backdrop, there is a group of people who live with the diagnosis and who are treated for it. Only recently, some scholars have explored the perspectives of adults with ADHD towards the impact of ADHD on their lives and how they experienced treatment. The major challenges faced by adults with ADHD emerge in interaction with their social surroundings and as a result of negative societal judgments; they internalize these negative judgments which causes feelings of rejection, alienation from society and low self-worth (Fleischmann and Miller 2013, Schrevel, Dedding et al. 2015). However, adults with ADHD also attribute positive characteristics to their ADHD such as high levels of energy and quick wittedness (Fleischmann and Fleischmann 2012). In the UK, two studies investigated the experiences of receiving a diagnosis and treatment; after the diagnosis, adults with ADHD had to reframe their past in the light of their diagnosis and went through a period of emotional acceptance to form a vision of their new future with ADHD (Young, Bramham et al. 2008, Fleischmann and Miller 2013). Additionally, most of the adults recognized the positive impact of stimulant medications on their functioning; however, adults experienced a gap between their needs and adequate services despite the existence of policy measures and clinical guidelines (Matheson, Asherson et al. 2013).³

In other words, there is a growing body of literature that explores adult ADHD from the perspectives of those who have it and conclude that there is substantial suffering and treatment may provide relief.

³In the UK, the Nation Institute for Health and Care Excellence (NICE) published a guideline for adults with ADHD specifically (NICE 2008). In the Netherlands no multidisciplinary guideline for adults is published, therefore health professionals could base their decisions on the NICE guidelines or on the European Consensus statement by Kooij et al. (2010).

Moreover, it is increasingly acknowledged that ‘patients’ acquire substantial knowledge about their disease and how treatment does or does not work and can, therefore, contribute greatly to medical science and clinical practice (Lambert 2006, Pols 2014). Multiple scholars stress the need for empowering patients in order to question the medical model of psychiatry where ‘patients’ become the passive recipient of diagnosis and standardized treatment decided upon by ‘the doctor’ (Heenan 2006, Russo and Beresford 2014). Especially since adult ADHD and its pharmacotherapy is a controversial topic, the perspectives of those who are diagnosed with and receive(d) treatment are important to take into account. Moreover, the studies described above provide a solid base for understanding ADHD from the perspective of survivors, but provides limited insight into the healthcare needs of adults with ADHD. Therefore, this article aims to expand our knowledge of patients’ healthcare experiences, how they relate to their healthcare needs, and to what extent current care meets those needs in order to contribute to continuing efforts to increase the quality of care and the wellbeing of people with ADHD.

5.2 Methods

For this exploratory study, the Focus Group Discussion (FGD) was chosen as a means of data collection because it is an appropriate method for understanding the perceptions and concerns of groups of people, exploring diverse views, values and attitudes (Morgan 1998). From the perspective of social psychology, perspectives and opinions are individually constructed but can be further explored through interaction with others (Ryan, Gandha et al. 2014). Therefore, in a FGD, shared and conflicting ideas become more visible through participant interaction providing thorough insight into the perspectives of the study participants (Kitzinger 1995, Belzile and Öberg 2012, Ryan, Gandha et al. 2014).

Participants were recruited through a notification on a national Internet forum for adults with ADHD and an announcement on the website of the Dutch patient organization for adults with ADHD. In both cases, potential participants were also asked to invite peers who were non-members of the forum and of the patient organization. Adults interested in participating could seek further information from the researchers. Respondents with a *primary* ADHD diagnosis were eligible to participate, given that comorbid disorders are common among people with ADHD.¹ Initially, 67 people contacted the researchers with an interest in participating. 37 participants did not participate because of inability to attend at the specified time or place or because they became absent during follow up, leaving 30 participants in four FGDs lasting two hours.

A structured script with exercises and probe questions guided the discussion, aiming to create a balance between individual contribution, encouraging participant interaction and staying on topic (Ryan, Gandha et al. 2014). FGDs started with a short introduction round where some initial time was allocated to give the participants the opportunity to become acquainted with each other. In the first exercise, the participants were asked to discuss and write down their experiences with the diagnostic process and treatment of adult ADHD in small parallel groups of three participants; after which the papers were collected and discussed plenary. This exercise aimed to obtain a broad overview of topics that patients encounter during care and to start a process of reflection on personal experiences. In the second exercise, participants were asked to identify two key topics with respect to adult ADHD; these were collected one-by-one and the moderator asked for further elaboration and whether other participants had similar or different experiences. For the third exercise participants formulated specific needs for adult ADHD care in groups of three participants and then presented their topics to the other group members for further discussion.

All FGDs were recorded and transcribed verbatim; summaries of the discussions were sent to the participants for respondent check. Transcripts were read and re-read to develop familiarity with the data. Coding followed two stages, firstly thematic coding was used to categorize the experience under 'diagnostic process', 'treatment' and 'organization of care' as advised by Ritchie and Spencer (1994). Within these categories, and open (inductive) coding was used to unravel the full range of healthcare experiences and needs relevant to the category. The open coding process followed the structure of Conventional Content Analysis as described by Hsieh and Shannon (2005). The two coding schemes were compared and discussed, prior to developing a final joint coding scheme based on agreement in terms of the code name, definition and description. All transcripts were then re-coded using the final coding scheme in MaxQDA 11 software. The reflections of the two researchers were regularly discussed with a third researcher. Relevant quotes to underpin the analysis and results were checked and discussed within the research team.

Ethical considerations

Given the non-invasive nature of the study, medical ethical approval was not required according to Dutch law. All participants received information about the aim and scope of the research, and were informed that they could withdraw from the study at any time without penalty or questions. Anonymity was ensured by using pseudonyms in the reporting of the research. Verbal informed consent was acquired for recording, transcribing and analysis of the FGDs.

Table 2. Demographic characteristics of the study participants

Characteristic	No. of Participants (n=30)
<i>Age^a</i>	43±12
<i>Female</i>	22
<i>Male</i>	8
Diagnosis	
<i>ADHD</i>	25
<i>ADD</i>	5
Time since diagnosis	
<i>Min</i>	1
<i>1st quartile</i>	2
<i>Median</i>	3
<i>3d Quartile</i>	5.25
<i>Max</i>	23
Treatment^b	
<i>Medication</i>	20
<i>Psychosocial therapy</i>	26
<i>No Treatment</i>	3
Education	
<i>University</i>	2
<i>Higher vocational education</i>	16
<i>Intermediate vocational education</i>	5
<i>High school</i>	5
<i>Student</i>	2
Employment status	
<i>Employed</i>	13
<i>Self Employed</i>	6
<i>Student</i>	2
<i>Unemployed</i>	6
<i>Sick leave</i>	2
<i>Retired</i>	1

^a Years MEAN±SD

^b Because there was overlap in treatments the sum of these numbers exceeds the number of study participants

5.3 Results

A total of 30 participants participated in four focus groups, 22 participants were female (see table 2). The average age was 43 ± 12 years. All participants mentioned experiences with medications in the past and 20 participants indicated that they were using medication at the time of the FGD. The time since

diagnosis was on average three years before the FGD. In this section, we describe the experiences with the diagnostic process and treatment as well as their needs and suggestions for change.

The diagnostic process: a long and twisting road

In the Netherlands, the general practitioner (GP) is the gatekeeper for specialist secondary care and therefore the first point of contact when people encounter problems with their mental health. When going to their GP, participants often mentioned they did not seek help for the symptoms of adult ADHD, such as a lack of concentration or impulsivity, but rather for help with issues relating to work, marital problems or burnout complaints. According to many participants, the GP generally did not recognize these problems as relating to ADHD:

Rick: In the conversations I had with him [GP] (...) he never said 'You talk so fast' or something like that; apparently the GP is not (...) trained for that. (FG2)

Sara: So I first had to go to the GP but since I'm 50 plus they automatically think it's a burnout, and it wasn't going well with work so I went to a psychotherapist for two years. (FG3)

Given that ADHD was often missed in primary care by GPs and psychologists and sometimes also in secondary care by specialists, 22 of the 30 participants became acquainted with ADHD by coincidence and recognized the symptoms themselves. Examples are the ADHD diagnosis of a child, someone in their personal sphere (spouse, friend, family member) who had encountered ADHD, a radio interview with an ADHD researcher or a newspaper article. As Gwen and John pointed out:

Gwen: Well, if my son never got the diagnosis I would never have found out that I have it myself, I would never have looked up information about it. (FG2)

John: My friend from scuba diving works with children and adolescents with ADHD and he told me that he thought I had it too. (FG3)

After this 'auto-diagnosis', sometimes early in the process and sometimes after years, some participants started a search for a health professional who was willing to seriously consider the possibility of ADHD. According to the participants, this often involved difficulties because some professionals stuck to their first diagnosis. For example, Moira had episodes of depression and, after recognizing ADHD herself, had to put a lot of effort into convincing professionals that she also had ADHD:

Moira: Well, I am one of those people who kept on trying to convince everyone, for ten years, that I *do* have ADHD. But according to them I was a hyperactive woman with episodes of depression (...) eventually ADHD was diagnosed but it took some time. (FG3)

Due to living with undiagnosed ADHD, often for a long time, most participants experienced multiple problems in various domains of life. These struggles tended to be unique to the individual and interrelated with their history and contexts. In other words, even though the 'official disorder' may be the same, participants quickly found out that the way each one of them experienced their disorder is unique. Even though some understood that this makes the diagnostic process highly complex for health professionals, many participants felt that their personality, individual problems and their individual contexts were not sufficiently taken into account. Susan, for example, was first diagnosed with Borderline Personality Disorder (BPD), but explained her behaviour as follows:

Susan: I had a lot of difficult things to deal with [at that time] and I pushed myself to the limit; I just couldn't take it anymore, no wonder I freaked out sometimes, but that's not Borderline! (FG1)

In addition to unwillingness to seriously consider ADHD and the under recognition of ADHD among health professionals, some participants also referred to the guidelines for ADHD diagnosis that complicate a diagnosis in adults. In the Netherlands, hetero-anamnesis is a prerequisite, requiring the presence of a parent to give the medical history and only a few health professionals are willing to divert from this guideline. Carolyn, for example, put forward she visited three different healthcare providers until she found one willing to start the diagnostic process of ADHD without hetero-anamnesis with her mother:

Carolyn: I didn't want to bring my mother because she thinks I'm completely normal. And I wanted a diagnosis, but that was all complicated, so I went to another clinic and I told them, in advance, that I was not going to bring my mother. They kept on pushing to bring my mother and finally they sent me a letter that I was hampering my own process because I didn't want to bring her. And finally, I found a psychiatrist who said 'You know yourself well enough.' (FG3)

The experience that health professionals often had problems linking the observed symptoms to ADHD, strictly adhered to formal guidelines, did not take contextual factors into account and did not listen to the suggestions of people themselves made many participants feel that they were not taken seriously by

their health professionals. As a result, the search for adequate diagnosis took a long time; participants often attended multiple professionals over a period of up to ten years before the diagnosis adult ADHD was made. Some expressed that the search to get ADHD diagnosed had caused them unnecessary time and suffering which could have been prevented by early recognition, acknowledgement and consideration of their health professionals.

Needs and wishes for improvement: seeing the red flags – Regarding the recognition of ADHD, most patients considered that primary care professionals should be more aware of ‘red flags’ or markers for ADHD, such as recurrent relational and job problems, burnout and repeated depressions. Primary care professionals should take the patients’ own diagnosis of ADHD more seriously, referring patients to specialists with expertise to diagnose ADHD. Furthermore, some participants stressed that specialists should not interact in a top down way with patients or ‘label’ diagnosis with an incomprehensible disorder; rather, professionals should take into account the personality and situational context of patients:

Eric: At the moment you get the official diagnosis (...) it would add a lot if you, from the diagnostic interviews and conversations, could find out what ADHD does with *you*, not ADHD in general, but how ADHD works for *you* as a person and what the problems are *you* face. (FG2)

Participants tended to be more positive about their care if they experienced the diagnostic process as a joint venture with the health professional, where the diagnosis is mutually agreed upon and, additionally, if the diagnostic process took into account psychosocial functioning and context:

Judith: I had a combination of things, very extensive medical psychology, IQ tests, cognitive tests, questionnaires on a computer and conversations. I was there three times for a part of the day and I thought that was very good, you know, that it was regarded from various perspectives. (FG3)

Treatment: feeling hampered by protocolled treatment

As explained in the introduction, treatment in the Netherlands typically involves pharmacotherapy as first-line treatment, often complemented with psychotherapy and coaching. In this section, we first discuss problems participants experienced regarding these two approaches and conclude participants’ therapy needs.

Table 3. Participants' positive and negative experiences with medications. The numbers indicate the number of participants who expressed that experience during the focus group.

Experience	# participants				Relevant quote
	FGD1	FGD2	FGD3	FGD4	
Positive	5	7	4	1	I don't care how expensive it is, it works and that is the only thing that matters. (FG2)
Negative	1	5	5	3	The medications don't work for me. I belong to the 30% of people for whom they don't work. (FG2)
Positive effects					
Clear mind	0	2	1	0	In the morning, my head is full of everything I need to do and that confuses me but when I take Ritalin it all falls into place. (FG3)
Concentration	1	3	2	1	When I took the medications, I functioned normally, I could focus and do my work (...) and it helped me finish school. (FG4)
Control	2	2	0	0	If things go really wrong, I take it, if I need to do a lot of things at the same time. (FG2)
Emotion regulation	1	2	0	0	Emotion regulation is kind of problematic but with the medications that is manageable. (FG1)
Inner rest	2	1	1	0	That restlessness is gone. It doesn't help me to concentrate, it's more that you have the calmness to do something. (FG3)
Other	0	2	1	0	I am very sensitive to noise and with Ritalin that is a bit less. (FG3)
Negative effects					
Negative side-effects	1	0	5	3	When it stops working, I get very restless and (...) it made me very insecure. (FG1)
Difficult timing	2	0	0	1	If I didn't take it at the right moment, I started trembling and sweating and my head became a mess again. (FG4)
Aggression	0	3	0	0	It also made me more aggressive, especially if I didn't take it in time with the rebound. (FG2)
Lost sense of self	1	2	1	0	I was really happy I stopped taking it (...) because I felt like myself again, and I didn't have that with the medication. (FG1)

Pharmacotherapy; how should I take my medicines – All participants in this study had experiences with pharmacotherapy and voiced a spectrum of considerations relating to the costs and benefits of taking medication, summarised in table 3. Weighing of the costs and benefits appeared to be situational: in some situations the benefits, such as better concentration, are found to outweigh the costs, such as anxiety and dependence on drugs, while in other situations the reverse might be preferred.

Louise: With medications I can hold my thoughts and reflect on my feelings and that really helped me (...) but now I try to stop because I don't want to take them my whole life so it's a bit of a contradiction.

Gwen: That is really important what you say; I too think it is contradictory. The first day I felt like a changed person, fantastic, very happy. But now, after one-and-a-half years, I am trying to stop; I feel I changed into someone I'm not. It [the medication] helped me to get to know myself, and now I want to go on. (FG2)

Given this situational aspect of pharmacotherapy, most participants consider the decision to start pharmacotherapy as a personal one. Especially since the diagnosis was perceived by some as a shock, some participants experienced the strong focus on medications as detrimental. This contrasts with the medical protocol for adult ADHD care in which pharmacotherapy is seen as *the* priority treatment. Even though the positive effects of medication were consistently mentioned during discussions, many participants expressed a number of problems with the importance attached to pharmacotherapy and the experience of being on pharmacological treatment, as the conversation between Simone and Philip shows:

Simone: I thought treatment was very standard, according to their theory (...) the starting point is medication and possibly supplemented by group sessions. I understand that it is their philosophy but, for me, that is a very personal decision.

Philip: So [you think] more centred on the person and not centred on medication would be better?

Simone: Yeah, something like that, because when you get more therapy and more tools you might not even need the medications. (FG1)

Psychosocial care: being tired of enforced planning – With regard to psychosocial care, many participants perceived their psychosocial care to be problem-centred and highly protocolled, leaving little room for the incorporation of personal preferences, personality and contexts. Some of the core elements of predefined treatment programmes, such as the emphasis on planning and structure, do not appear to work for all adults with ADHD. For some participants it indeed provided them with tools to manage their lives, but for others it was perceived to be even counterproductive, as illustrated by the following quote:

Dillon: Every time I had to go there it gave me an unpleasant feeling because I knew that (...) I would get told everything that I do wrong and recapitulate all my failures. Then I had to put schedules and planning on the walls throughout my house and had to structure everything (...) but that was completely counterproductive [for me] and at some point it appeared to me that this just doesn't work. (FG4)

The same holds for group sessions: whereas the perceived benefits of peer-contact are acknowledged, strict planning of the sessions may hamper the positive effects, as explained by one of the participants:

Zoey [cynical]: The coach just wanted to push through his protocol from a century ago but we just wanted the acknowledgement and the recognition from each other and nothing more (...) You know, he was pushing on and on, and we just wanted to talk to each other. (FG1)

Conversely, participants who felt that their therapists listened to them, took their problems seriously and took into account their personal situation, context and preferences tended to evaluate their care more positively:

Hetty: I am currently receiving treatment at [clinic], fantastic (...) It is a very good combination of things (...) They really find the core [of your problems] (...) There is a bit of trauma work, because you experienced a lot of problems because you tried to adapt all the time; and you start working on that and I really appreciated that. (FG2)

Needs and wishes for improvement: tailor-made ADHD treatment – Participants' overarching theme was that care should be better aligned to the individual, namely that treatment protocols should allow the incorporation of personal characteristics, situational contexts and personal preferences and allow for more peer learning. Firstly, the role of pharmacotherapy should be aligned with the preferences of patients. Some participants explained that, after diagnosis, they would have liked to have been given other treatment options before starting pharmacotherapy or that they first desired more time to come to an informed decision to take medication. Others contended that pharmacotherapy should play a supporting role instead of being the most important part of therapy:

Thomas: I think you should first look at the needs and then at other issues that need to be taken into account and then somewhere on the fourth place or so should come

Ritalin. But now the psychiatrist first diagnoses ADHD and then immediately *bam!*
Medication. (FG4)

Secondly, psychosocial therapy should address more than just the deficits typically associated with ADHD. During the discussions it emerged that participants have an 'individual ADHD'; that is, even though their symptoms and problems may show overlap, how these problems are experienced and how they relate to their individual context may vary considerably. Therefore, treatment should match individual strengths and weaknesses, but also personal contexts which results in individual needs difficult to generalize to the 'adult with ADHD'. While some participants wanted to include their spouses, others wanted to focus therapy on getting and keeping work. In addition, a frequently voiced desire was the incorporation of strength-based approaches in psychosocial care; an individual is more than just his disorder with its deficits, and personal strengths could be exploited to overcome the problems posed by ADHD:

Dillon: They can also say like "hey, that is going very well" and then start working from that. Look at what is going well and find out how you could apply that to something that isn't going so well. (FG4)

Moreover, more and better use of peer-contact should be made during therapy; the benefits of peer-contact are experienced as substantial. It enables, for example, the exchange of experiences but also tips and tricks based on patients practical 'know-how' acquired through the years of living with the disorder. More generally, many participants considered that interaction with others who experienced the same condition can be soothing and comforting, gives recognition, and can help overcome the 'shock' of diagnosis. Importantly, peers can help in ways that professionals cannot:

Simone: With peers, I found out that they have tricks how to circumvent certain problems or how to ignore them (...) The coaches, however, they just don't understand that when you're really bad at something it may be better to just not do it, they think you have to improve that. (FG1)

A final expressed need is adequate referral. If a therapist is unsure what to do, he or she should refer to another clinician who may be more specialized to treat that specific patient. Adequate referral, according to some participants, also includes alternative therapies, such as mindfulness. Alternative and complementary therapies are seen by some participants as capable of addressing topics that are of importance to individual patients but which remain untouched in treatment provided by the public

sector, such as diet and relaxation. Public mental health providers should, therefore, be aware of these alternative and complementary treatments in order to point these out to patients who might benefit from them:

Zoey: Meditation helped me a lot actually, even though my coach at [outpatient clinic] told me that meditation and ADHD could not go together, that it was not for me. Then, somewhat later, I started meditating and it really helped. (FG1)

5.3 Discussion

This article explores the experiences and needs of adults with ADHD with mental healthcare in the Netherlands. Participants reflected on the signalling of ADHD, the diagnostic process and the various therapies they received. Discussions repeatedly centred on the need for more person-centred care: participants with negative experiences perceived care to be disease-centred, professional-centred or treatment-centred whereas participants with more positive experiences perceived care to take into account their individual personalities, contexts and preferences. Person-centred care aims to identify and include patients' personal preferences, emotional needs and life issues in his or her personal context (Stewart 2001, Pulvirenti, McMillan et al. 2014). Person-centred care also means that health professionals and patients engage in a partnership in which communication is honest and open, and decision power, based on adequate and relevant information, is shared (Mead and Bower 2000). Many participants missed such a partnership in their experiences with professionals. This call for more person-centred care fits current trends for more autonomy and control for patients in healthcare. Moreover, a growing body of literature provides evidence that person-centred healthcare provision correlates with increased health outcomes and higher patient satisfaction ratings (Little, Everitt et al. 2001, Epstein, Fiscella et al. 2010, Lawrence and Kinn 2012, Rathert, Williams et al. 2015).

It can be hypothesized that person-centred care is specifically important for adults with ADHD because they seem to suffer less from the direct symptoms than from the problems they encounter in their daily life as a consequence of those symptoms. Examples are difficulties with employment, disturbed relationships with family and friends, and negative societal judgments (Fleischmann and Miller 2013). Indeed, repeated experiences of failures and accompanying negative judgments from the surroundings lead adults with ADHD to develop negative and dysfunctional coping behaviours and self-concepts (Schrevel, Dedding et al. 2015). Therapy, thus, should take into account that adult ADHD cannot simply

be separated from patients' contexts and that adults with ADHD can suffer from a variety of dysfunctional behaviours and thoughts. These contextual and personal variances can be overlooked if treatment only addresses the symptoms of ADHD and professionally predefined problems, such as a lack of planning and structure.

Pharmacotherapy has been proven to be effective in reducing the symptoms of adult ADHD (Mészáros, Czobor et al. 2009) and the importance of pharmacotherapy from the patient's perspective, also stressed in the FGDs, is substantial (Young, Bramham et al. 2008, Fleischmann and Fleischmann 2012, Matheson, Asherson et al. 2013). However, patients themselves may have a variety of reasons for considering pharmacotherapy as desirable or not. In this study, many participants explained that weighing the costs and benefits of pharmacotherapy is very situational: in some situations the benefits of medications outweigh the costs and in other situations the reverse is true. Instead of providing pharmacotherapy as *the* basis of care, professionals could help patients find out in which situations, and in what way, pharmacotherapy would be most successful for them.

Psychosocial therapy for adult ADHD has received far less attention in the medical literature than pharmacotherapy, and the evidence for its use in reducing the symptoms, especially without the combined use with stimulants, is still limited (Ramsay 2009). However, in the few qualitative studies available, patients put forward the positive effects of psychosocial therapy (Young, Bramham et al. 2008, Matheson, Asherson et al. 2013) and health professionals typically advise psychosocial therapy to address the negative effects of living with ADHD (Kooij, Bejerot et al. 2010). Nevertheless, the participants of this study pointed at ways to improve these therapies by a greater focus on individual strengths. Schrevel, Dedding et al. (2015) found that future needs of adults include acceptance by society and by their social surroundings as being unique and valuable individuals with a specific range of personal strengths, competences but also weaknesses. It is therefore important that future therapies also aim to empower adults with ADHD and explore how strengths can be used to address and circumvent the problems they experience.

This call for more person-centred care may be compromised by the strict use of treatment protocols and organizational regulations, fuelled by recent healthcare reform that aims at reducing costs. In the Netherlands, health professionals have to work according to 'Diagnosis Treatment Combinations' (DBC's), an equivalent of the 'Diagnosis Related Groups' in the USA. According to Sambeek, Tonkens et al. (2011) this system stimulates precipitous diagnostic processes where the diagnosed disorder, rather than the individual, becomes the centre of treatments outlined in standardized treatment guidelines

and protocols. These guidelines have a mainly disease-centred nature and prefer treatments that are supported by RCTs. Moreover, other treatment options, which may be more person-centred or may align better with patient preferences, are rejected or not mentioned in guidelines and protocols (Hutschemaekers and van Kalmthout 2006). The guidelines produced by the British National Institute for Health and Care Excellence (NICE) have also been criticized for using only positive findings with respect to pharmacotherapy whilst ignoring critical literature, thereby reinforcing the dominant view that ADHD is predominantly a physical condition in need of drug treatment (Moncrieff and Timimi 2013). The perspectives of patients proved important to criticize these recommendations as, according to our participants, medication is not a 'one-size-fits-all' treatment for adult ADHD and neither is it desired by adults with ADHD in all cases. Therefore, the call for more person-centred care should be an important topic for future guideline development and design of new treatments for adults with ADHD.

However a point of caution should be made with respect to ADHD. Patient-centred care is underpinned by 'shared' decision making and certainly does not imply unquestionably granting patient wishes (Epstein, Fiscella et al. 2010). Some people might seek an ADHD diagnosis in order to obtain the secondary gains associated with access to stimulants in order to attain the standard imposed upon them by society (Dehue 2014). For example, several studies have shown that university students use, sometimes illegally obtained, stimulants in order to boost concentration and grades (Teter, McCabe et al. 2005, White, Becker-Blease et al. 2006). Just as some participants in this study had to switch different providers in order to obtain the needed diagnosis, people in pursuit of secondary gains may find room in the individual interpretation of the criteria by professionals and the complexity of the diagnosis. For childhood ADHD, health professionals express uncertainty in the specificity of the DSM criteria in relation to the unique context of a child, and the necessity of a diagnosis of ADHD and pharmacological treatment (Rafalovich 2005). If the patient's voice becomes more central in mental healthcare, and professionals are forced to perform quick diagnostics, it can be hypothesized that the number of false-positive ADHD diagnoses might increase rapidly resulting in further medicalization of 'normal behaviour'.

The debate that surrounds ADHD is not ungrounded: from participants' story the ambiguity in the diagnostic process and treatment decisions emerges repeatedly. However, the critiques of ADHD rarely explore feasible alternative solutions to support those who pursue the diagnosis for reasons that may be completely valid from their perspective. That is, these critiques may be important to inform a societal debate on the dangers of medicalization, the ethical problems relating to human enhancement and the

increasing influence of the pharmaceutical industry on health research, but do not yet contribute to address the problems experienced by many who suffer from the symptoms of ADHD. Our results in tandem with an increasing body of literature show that adults with ADHD experience real suffering, find recognition amongst each-other, and see the positive effect that treatment may have. Future research should therefore not only focus on improving person-centred care but also investigate strategies to prevent misdiagnosis and diagnostic inflation.

Strengths and limitations

During the FGDs, participants were very receptive to each other's opinions and were understanding of differing preferences and reasons why people experienced care as positive or negative. Participants experienced the focus groups as pleasant and sometimes therapeutic, and often lingered to continue discussing their experiences with other participants. This enabled an open discussion where, apparently, participants felt free to discuss their personal experiences and views with others.

As a limitation, it is important to note that this is an exploratory study with a restricted group of people and that their experiences might be perceived differently by healthcare professionals. The study is located in the Netherlands with a specific health care setting and findings can therefore not automatically be transferred to another setting. However, since our findings show substantial overlap with findings in the UK, as reported by Matheson, Asherson et al. (2013), they may be transferrable to other countries with comparable mental health systems. Future research should investigate how care is experienced in other countries, preferably also those with systems that differ from the Netherlands and most of the Anglophone countries.

5.4 Conclusion

Most participants mentioned multiple problems with the signalling of ADHD, the diagnostic process and the various therapies they received. Their needs were mostly related to taking into account personal differences and individual problems, contexts and situations, in other words favouring more patient-centred care. It is hypothesized that both pharmacotherapy and psychosocial care could be more effective and more appreciated by patients if the individual and situational nature of adult ADHD is taken into account. Future research should investigate how person-centeredness could become the

standard in healthcare for adult ADHD. International and national guidelines for ADHD could start this process by taking into account the perspectives of patients.

Chapter 6: Why do adults with ADHD choose strength-based coaching over public mental healthcare? – A qualitative case study from the Netherlands

Abstract

In the Netherlands, a growing number of adults with ADHD visit private (out of pocket) strength-based ADHD coaching centres. In an explorative case study we investigated why these adults with ADHD prefer coaching, which is (partially) financed out-of-pocket, over public mental healthcare and what the perceived added value is. To this end, we conducted 23 semi-structured interviews with clients of a private coaching centre. The participants highly valued the optimistic, strength-based and solution-focused approach, which was contrasted with a deficit and symptom-centred framework in public mental healthcare. Coaching was perceived as a joint venture, resulting in a more thorough understanding of how one approaches life and can be better equipped to deal with future problems. In the Netherlands, there is a group of adults with ADHD who feel that their needs are unsatisfactorily addressed in public mental healthcare and who benefit from strength-based coaching. Future research should address the (inter)national prevalence and characteristics of these adults. Strength-based coaching may be a valuable alternative or supplement to public mental healthcare for adults with ADHD.

6.1 Introduction

Attention deficit/hyperactivity disorder (ADHD) is increasingly diagnosed and treated in adults (APA 2000, Fredriksen, Halmøy et al. 2013). In the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) the symptoms are categorized as inattention, hyperactivity and impulsivity (APA 2000).⁴ A growing body of literature addresses the impact of adult ADHD on daily life, including underemployment and academic underachievement (Biederman, Petty et al. 2008, Adamou, Arif et al. 2013), low self-esteem, problems with intimate relationships (Eakin, Minde et al. 2004), and, in general, a lowered quality of life (Able, Johnston et al. 2007, Kooij, Bejerot et al. 2010, Young and Amarasinghe 2010). This evidence suggests that adult ADHD is a serious disorder that requires diagnoses and treatments that address not only an individual's symptoms but also how ADHD affects daily functioning.

Treatment for adult ADHD in the Netherlands generally involves two approaches: pharmacotherapy, mainly in the form of psychostimulants such as methylphenidate (Ritalin) and psychosocial interventions such as psycho-education, skill training and Cognitive Behavioral Therapy (CBT) (Kooij, Bejerot et al. 2010). Pharmacological treatment of ADHD has proven effective in reducing symptom severity in several Randomized Controlled Trials (RCTs) (Mészáros, Czobor et al. 2009, Surman, Hammerness et al. 2013). Pharmacological treatment alone, however, may not sufficiently improve negative impacts of ADHD beyond these symptoms, and, therefore, many scholars recommend a combination of pharmacological and psychosocial interventions as treatment (Murphy 2005, Kooij, Bejerot et al. 2010, Emilsson, Gudjonsson et al. 2011, Weiss, Murray et al. 2012). Despite this, psychosocial interventions remain largely unstudied and lack scientific support (Moriyama, Polanczyk et al. 2013).

In the Netherlands, a growing number of private 'ADHD clinics' and 'coaching' centres offer treatment for adults with ADHD, which differ from services provided in public, reimbursed mental healthcare. Many of these centres describe themselves as 'strength-based coaching centres'.⁵ Strength-based coaching aims to reinforce and utilize innate competences to achieve goals established by both the client and coach (Linley and Harrington 2006). Strengths can be defined as "a natural capacity for behaving, thinking, or feeling in a way that allows optimal functioning and performance in the pursuit of

⁴ Three main forms of ADHD are recognized in the DSM-IV-TR: the mainly inattentive type, also named Attention Deficit Disorder (ADD), the mainly hyperactive and impulsive type and the combined type. During the time of data collection, the DSM-IV-TR was the latest edition and, therefore, we refer to this version in this article.

⁵ Examples in the Amsterdam area are "Up Coaching" (<http://www.upcoaching.nl>), "iQ Coaches" (<http://www.iqcoaches.nl>) and ADHD-Coaching-Amsterdam (<http://adhdcoachamsterdam.nl/>)

valued outcomes (Linley and Harrington 2006, p88).” As of yet, strength-based coaching is not a part of official clinical guidelines in the Netherlands.

The guidelines for mental healthcare in the Netherlands favour treatment options which have been proven effective using RCTs, which are often considered the ‘golden standard’ in evidence-based medicine (Hutschemaekers and van Kalmthout 2006). The focus on evidence-based interventions stimulates new forms of therapy, such as strength-based coaching, to develop outside of the public mental health system. Nevertheless, for mental health there is an increase in the use of complementary and alternative treatments, as well as the scientific enquiries as to how and why these treatment options are utilized (Vlieger 2007, Segar 2012, Bahceci, Bagcioglu et al. 2013), particularly for children with ADHD (Majorek, Tüchelmann et al. 2004, Sinha and Efron 2005).

The consequences for clients are that these services are not reimbursed by health insurance and are principally financed by out-of-pocket payments from users. That clients do pay for these coaching services implies that adults with ADHD have needs that are not fully addressed by public mental health and that these coaching services represent a niche that may address these needs. Little is known about these coaching practices for adults with ADHD and what the added value is according to their clientele. In light of this, our study aims to explore why adults with ADHD prefer out-of-pocket private coaching services over, or in addition to, reimbursed public mental healthcare and what are the perceived added value is of these services.

6.2 Methodology

An exploratory qualitative case-study design was chosen for this study. A strength-based coaching centre in the Netherlands was selected and semi-structured interviews were conducted with its clients.

Case selection and description

The selection criteria for a centre were twofold: firstly, the provider must provide treatment for adult ADHD outside the public mental health system; secondly, it must have scaled up its services, implying it addresses a gap in current services for adults with ADHD. We selected a coaching service based in Delft, a medium-sized city in the metropolitan area of The Hague. When founded in 2007, the centre had one facility. By 2015, it had grown to 13 facilities throughout the country. Moreover, its client base has

steadily increased over the same period of time, with 186 invoiced ADHD coaching sessions in 2007 and 1907 in 2013.

At the basis of the centre's approach is the vision that the problems of adults with ADHD, in addition to their symptoms, stem from the "collateral damage" of having ADHD; namely, the negative coping strategies that one may have developed over the years living with ADHD. It argues that addressing this collateral damage can quickly lead to improvements in wellbeing and daily functioning. Taking this perspective, coaching aims to utilize and reinforce individual strengths and competences to address collateral damage and bring about positive changes in the lives of individual clients. In practice, coaches discuss with clients their personal goals and talents, and together they decide on the content of their discussions and how to achieve those goals. This treatment trajectory, then, includes both the level of skills and abilities as well as a deeper level of emotions and self-confidence. Coaches receive internal training and examinations as well as continued education as employees of the centre.

Recruitment

Interviewees were included if they had a primary ADHD diagnosis or a diagnosis in-progress. Clients with comorbid diagnoses were also included because 60-89% of adults with ADHD are estimated to have at least one comorbid psychiatric disorder (Sobanski 2006). As adult ADHD can cause serious problems with both education and employment (Biederman, Petty et al. 2008, Adamou, Arif et al. 2013), only participants above the age of 25 years were eligible to take part, in order to highlight experiences with education and employment, and treatment.

The method for including participants was twofold. First, for convenience sampling, an e-mail was sent to the entire client base of the centre, inviting clients to contact the researcher if they were interested in participating. Second, for purposeful sampling, coaches were requested to enquire whether clients would be interested in participating, and, if so, provide a short description of the study and the contact information of the researchers for official participation. By purposefully inviting clients who held critical opinions, either or both positive, negative or both, towards the centre, a diversity of attitudes and views was ensured. For the number of clients included per recruitment strategy refer to figure 3.

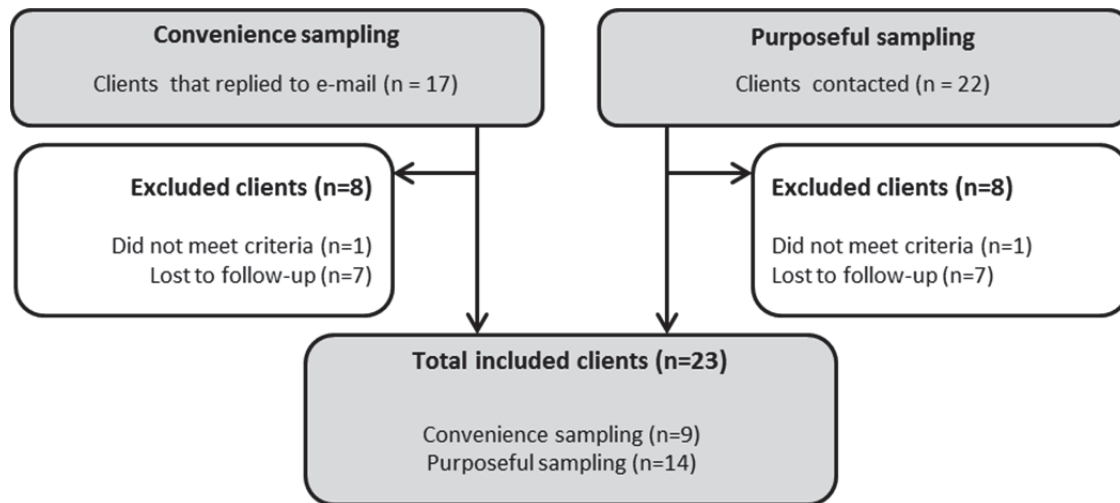


Figure 3. Number of clients contacted and included per recruitment strategy

Data collection

Semi-structured interviews were chosen for this study since this method allows study participants to further elucidate on topics that are of great importance to them while maintaining focus on topics of interest for the researchers (Britten 1995). Main themes were: experiences with the current treatment; experiences with previous treatments; favourable and unfavourable characteristics of therapists and therapies, and the extent to which these characteristics were encountered during coaching and during previous treatments.

The location of the interview was decided on by the interviewee and was required to be an environment where an open conversation was possible. The main reason for this was to ensure the interviewed clients would feel comfortable in addressing specific thoughts or feelings with regard to their therapist. The researcher explicitly mentioned affiliation with the university with no interest in positive evaluation of the received therapy. 13 of the interviewees preferred to speak in a private room at the coaching centre; four interviews were conducted at home and one at the office of the respondent. Interviews lasted 40-90 minutes.

Data analysis

Interviews were recorded and transcribed verbatim and summaries were sent to the respondents as a member check. Transcripts were read carefully and analysed using open coding in line with the content analysis of Hsieh et al (Hsieh and Shannon 2005). With this approach a preliminary coding scheme was developed. After that, a selective coding scheme was discussed and agreed upon by the research team, this scheme was then used in Atlas.ti qualitative data analysis software for selective coding.

Ethical considerations

No approval from an ethical commission was needed as the study design is non-invasive and did not involve questioning medical history or medical dossiers. Before recording, verbal informed consent was obtained for recording and publication of data under the promise of anonymity. Participants were informed of opportunity to retract from the study at any time without providing a reason and without consequence.

6.3 Results

In total, 23 clients were interviewed face-to-face and one on the phone because no suitable time and location could be found; 14 were male and the average age was 40 years. All participants but one had an official ADD or ADHD diagnosis, and, all but one participant had experiences with mental healthcare before starting coaching at the centre. Five interviewees were known to be taking stimulant medications at the time of the interview. Further demographic information is presented in table 4.

Table 4. Characteristics of the study participants

Age ^a	39,8 ± 8,0
Male	14
female	9
Education	
student	2
High school	9
Vocational education	11
University	1
Employment	
Self-employed	1
Employed	14
Unemployed	8

^a Age in MEAN±SD

From public to private mental healthcare

Most participants had longstanding treatment histories with formal mental healthcare up to 14 years. Moreover, a majority of clients was treated for other problems other than ADHD, most of which were depression and burnout complaints. Therefore, they had experiences with medications other than those

used for the treatment of ADHD, such as antidepressants or anti-anxiety medications. The experiences with formal mental healthcare were often portrayed as negative, especially when compared to coaching received at the centre. For most participants, it took a long time before ADHD was recognized as the core problem; the diagnosis and treatment of ADHD started many years after first contact with mental healthcare, which was often portrayed with a negative tone:

I wasn't initially treated for ADHD. Before that [the diagnosis of ADHD], I think I had every psychiatric diagnosis possible: depression, dysthymia, that is why it took me so long, up to 12 or maybe 13 years. Until, finally, someone had the clarity of mind to say, "well, maybe this [ADHD] is your problem". (P6, male)

During the interview, the interviewer asked the participants to elaborate on reasons for searching for alternative service providers for ADHD therapy and why they chose this particular centre. Most participants indicated that they found it 'by chance' on the internet or via friends or family and became interested by the vision and method of the centre after an introductory session or after further research:

Their approach appealed to me. You know, the combination of methods they use. The way they work fits me better than that pragmatic work [previous therapy] where they just ask you: well, what do *you* need? (P11, female)

The atmosphere felt right also in terms of their approach, which is really positive (...) looking at the possibilities instead of the deficits, and that is exactly what I am too. With me the glass always is half-full. (P14, male)

Appraisal of optimistic approach

A majority of clients perceived the centre as being solution-focused in that coaches try to draw the attention away from life problems and towards the things that go well and towards solutions to the problems. In contrast, previous mental health providers often framed their problems as chronic; for example, one interviewee explained that her psychiatrist told that mental illness is "just the same as diabetes, you'll never get rid of it" and that she would never overcome it. Contrastingly, most interviewees explained that it is a better strategy to shift the focus away from problems people can experience:

At the moment you dig yourself into your garbage bag [mental health problems], you get down, and you see the dark side of everything, and you're unable to see the positive side of things. The advantage [of this centre] is that they stop you from digging yourself into that garbage bag, and that garbage bag is good for no one. (P5, male)

Coaches point their clients to competences and talents which can be exploited. Interviewees felt that this approach fosters a more positive outlook on daily life, an important step in moving away from a focus on the deficits imposed by ADHD, towards the hope of a better life.

And they [coaches] really looked at the possibilities. People can achieve so much, but sometimes one doesn't know how to anymore. So all of a sudden, the negativity and causes of my problems were not in the picture anymore so to say. And then I thought, well if other people can overcome their problems, I too can get better. (P4, female)

According to a minority of the participants, however, there are limits to the abovementioned approach. For example, one participant explained that she had the feeling the coaches somehow neglected the existence of ADHD, while, for her, the ADHD diagnosis had been reassuring; she wanted to reframe her life in accordance with ADHD as it explained a long history of problems in her life. Another participant doubted the sincerity of the positive approach and felt that it represented an avoidance of taking responsibility to support the client in certain situations. In this example, the client had to see a doctor hired by the state to evaluate the repercussions of his diagnosis and treatment as they related to his employment and wanted his coach, for credibility and support, to come to this appointment:

She [the coach] would never honestly say she herself can't come to the company doctor; instead, she would make it a pep-talk pushing me to do it myself which will only make me stronger. That's all fine but, in this way, she makes everything the responsibility of the client. (P15, male)

It was stressed that, the positive approach should not overlook or dismiss the self-perceived needs of clients, and coaches should be sensitive as to when a more supportive role is necessary. When this was not done, the clients felt that their needs were not met or started to doubt the sincerity of the approach.

Being accepted as a unique person

In line with this positive and strength-based approach, clients felt accepted as a unique person with unique strengths, competences, needs and desires. This was frequently opposed with other experiences where clients felt equated with their disorders or where they were treated as “a number”. Formal mental healthcare was often described as impersonal:

It was shocking to see how easily diagnoses were distributed in that institute [outpatient clinic], (...) like a factory where everyone enters, gets diagnosed, gets medicated. (...) It is so massive and not attuned to the individual. (P7, male)

In contrast, interviewees communicated that the coaching process as a joint venture of both the coach and the client in which personal goals and coaching strategies were mutually agreed upon and aligned with the preferences of the client:

I really feel that she [the coach] takes me seriously and that she looks at what I need. You know, sometimes I give my ideas and she gives hers, and then we discuss. And for me, that is being taken seriously. (P3, male)

Personal relationship with the coach

An important aspect of the coach-client relationship is, according to a majority of the participants, a “personal connection” or a “click” with their coaches which makes clients feel a mutual respect from both parties. This connection, already touched upon in the previous paragraph, was considered to be the result of the open, accepting attitude of the coaches.

It feels safe. I never have the feeling that she [coach] judges me. Everything is just fine and everything is good (...) and in that way she makes better connection with the client. (P22, male)

On the other hand, with respect to experiences with formal mental healthcare, some participants felt that their therapists were unapproachable and not open to discussing treatments and goals prescribed by the therapist:

When I told them the medications did not work well they told me I shouldn't be so stubborn and do what they told me to do, you know, (...) the standard approach works best so don't be difficult. (P4, female)

Additionally, some participants valued their coaches as being “capable by experience” which, in turn, reinforced the “click” they experienced. Many coaches have endured struggles with adult ADHD and/or other mental disorders. This additional experiential knowledge gave some of the clients the feeling that their coach could better connect with them. Self-disclosure, according to some participants, was reassuring in times when clients felt they could never overcome their problems. Nevertheless, according to one client, the use of personal stories should be limited:

Sometimes personal stories [of the coach] can really work to clarify things or show how certain things work. But, you know, only in some situations, you should not continuously tell your personal stories to the client. (P23, female)

Experienced outcomes of coaching

While discussing the outcomes of coaching, participants were often not able to clearly describe what changed and how these changes were brought about. Clients generally explained that it “worked better than previous therapies.” When the interviewer asked why this was the case, participants replied that it was “more substantial,” “more thorough” or that it “simply just worked better.” In taking this conversation further, two outcomes stood out; namely, insight into how and why a person approaches daily life and feeling being better equipped when future problems arise.

By far the most frequently expressed outcome of coaching was insight. Participants mentioned that therapy enabled them to understand themselves, what they are doing and how and why they are doing it. Clients contended that coaching at the centre:

Lets you discover who you are, and what you are allowed to be... how your internal communication works, how you treat other people. They [coaches] teach you how to enjoy life, something very simple actually. (P6, male)

Some clients explained that receiving coaching made it easier for them to proactively search for solutions and options when confronted with problems rather than becoming caught in the problem again. In this way, problems become less pervasive, but more importantly, some of the participants felt they had gained more control over problems by knowing what works for them. For one person this was relaxing exercises, while for another person it was taking a step back:

Well, when I encounter problems in my life again I know I have to take a step back and think of what it is I need. And if I listen to what I need, I feel a lot better a lot faster than I used to. (P3, female)

6.4 Discussion

This study aimed to explore why adults with ADHD utilize out-of-pocket private coaching services that they have to over reimbursed public mental healthcare and what for them is the perceived added value of these services. All but one of the participants started to look for complementary services after longstanding experiences with public mental healthcare. Experiences with the coaching centre were often described in contrast to this history, often as a series of negative experiences. Which, of course, does not imply that treatment received in public mental healthcare is bad per se, but that for this group of people it did not align with their idea of 'good care'.

Psychosocial interventions for ADHD in formal mental healthcare focus on psycho-education about ADHD and the impact it has on one's life, coping strategies to deal with living a life affected by ADHD and the acquisition of skills necessary to function in daily life (Murphy 2005, Ramsay 2009, Knouse and Safren 2013). These interventions, with the exception of CBT, try to compensate for the deficits that adults with ADHD generally have, such as problems with bookkeeping and planning. Coaching at the studied centre, according to the study participants, deviates from this approach in three ways: first, it concentrates on problems and goals the clients want to address rather than focusing on predefined topics that are categorically assumed to be problematic for adults with ADHD in traditional conceptualizations of adult ADHD. Second, it aims to reinforce personal strengths and competences that can be used to address problems and reach the clients' goals. Third, self-disclosure of the life experiences of coaches is deliberately used. These were the differences that were valued by the interviewees of this study. Moreover, clients felt that coaching had a positive and substantial impact on their lives and wellbeing.

Participants especially valued the optimistic and strength-based approach, which they felt fostered hope for a better life. Clients felt they were trained to use personal strengths and competences to overcome the deficits posed by ADHD. Furthermore, coaching was perceived as person-centred as clients felt accepted as a unique person and the coaching process was described as a joint venture. Fostering hope and healing in individuals by reinforcing personal strengths and competences (Jacobson and Greenley

2001, Slade 2010), person-centeredness and the belief that everyone is capable of overcome mental illness in order to live a meaningful life (Farkas, Gagne et al. 2005, Farkas 2006, Slade, Amering et al. 2014), have been described as essential in building a meaningful life with schizophrenia. The importance of therapists' empathy towards patients has been discussed in relation to treatment for depression (Davidsen and Fosgerau 2014). To our best knowledge, this is the first article to show the added value of private strength-based approaches in the treatment and management of adult ADHD.

This study has limitations. Firstly, it is possible that the interviewed clients do not resemble the total client base of the centre due to selection bias. We did, however, try to minimize bias by using two recruitment strategies (convenience and purposeful sampling). Secondly, it is not possible to generalize our findings to the greater population of adults with ADHD, due to the small exploratory design. Moreover, the participants in this study belong to a specific group: people with longstanding, often negative, contacts with formal mental healthcare where they have frequently been treated for other disorders than adult ADHD. Although we cannot elaborate on the characteristics or magnitude of this group in the general population, we did show the existence of a group of service users who feel that their needs are inadequately addressed by contemporary public mental healthcare in the Netherlands. These people seem to benefit from complementary strength-based coaching services.

In light of our results and given the limitations of this study, two directions for future research can be identified. On the one hand, more research is needed to pinpoint the size and characteristics of the group adults with ADHD who can benefit from strength-based coaching services and who feel that their needs and preferences are overlooked and insufficiently addressed by contemporary ADHD treatments. On the other hand, more robust evidence is needed to support the use of strength-based coaching techniques in the treatment of adult ADHD.

6.5 Conclusion

Adult ADHD and its treatment are being increasingly studied and reported in contemporary literature. These investigations mainly limit themselves to evidence-based therapies, whereas other forms of therapy are on the rise yet remain unreported. Our findings suggest that strength-based coaching might prove beneficial for the treatment of adult ADHD, possibly in combination with treatments that are provided in the public sector.

The results of this exploratory study highlight two important findings. Firstly, there is a group of adults with ADHD who feel inadequately addressed by public mental healthcare; secondly, these adults seem to benefit from strength-based coaching. Future research should focus on quantifying the prevalence of adults with ADHD who have unmet needs in the public healthcare system.

Chapter 7: Adult ADHD care in the context of scientific and public debate: Perspectives of mental health professionals in the Netherlands

Abstract

Background: Public debate on Attention Deficit/Hyperactivity Disorder (ADHD) has intensified in the Netherlands over the years. Drivers for this debate are the ever-growing number of people diagnosed with ADHD, increasing use of stimulants, especially amongst adults and scientific dissonance on the causes of ADHD. The uncertain aetiology of ADHD complicates diagnosis and treatment of adult ADHD, while patient demands not always coincide with clinical guidelines.

Aim: To explore how health professionals diagnose and treat adult ADHD against the backdrop of public debate and uncertain aetiology of ADHD.

Method: 23 semi-structured interviews were conducted with health professionals with multi-disciplinary backgrounds involved in diagnosis and treatment of adult ADHD in The Netherlands.

Results: Health professionals stressed that adult ADHD is a 'real', biologically underpinned disorder but acknowledged that societal changes may amplify ADHD problems. Stimulants, taken either regularly or when needed, are considered the most effective treatment. However, not everyone in need of help has 'real' ADHD and needs stimulant medications. In order to diagnose 'real' ADHD, health professionals have to disentangle the complexes of problems their patients present. This leads to diversity in clinical practice with respect to both diagnosis and treatment.

Conclusion: Health professionals are concerned about the negative portrayal of ADHD and political pressure to decrease costs by diagnosing and treating less, while encountering real suffering of patients and not having a solid evidence base for diagnosis and treatment. This tension infringes the space in which health professionals work, running the risk of decreasing quality of care.

7.1 Introduction

Public debate surrounding Attention Deficit/Hyperactivity Disorder (ADHD) has intensified in the Netherlands over the years. Reasons for this debate are numerous: the ever-growing number of people diagnosed with ADHD in the West (Garfield, Dorsey et al. 2012, Kjeldsen, Jensen et al. 2012, McCarthy, Wilton et al. 2012), increasing use of stimulants in the Netherlands, a fourfold increase of prescriptions to adults between 2005 and 2011 (Stichting Farmaceutische Kerngetallen 2012, Stichting Farmaceutische Kerngetallen 2014), and scientific dissonance on the causes of ADHD. Whereas biomedical scientists contend that ADHD is caused by genetic and neurological factors (Swanson, Flodman et al. 2000, Tripp and Wickens 2009), social scientists explain ADHD mainly as a normative construct that designates certain behaviours as undesired which thereby become medicalized (Conrad and Potter 2000, Bowden 2013, Bowden 2013, Conrad and Bergey 2014). The debate intensified in the advent of the newly developed Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-V), in which the diagnostic criteria for ADHD are expanded which increases the number of people eligible for a ADHD diagnosis (Batstra and Frances 2012, Matte, Anselmi et al. 2015), and a possible conflict of interest between board members and the pharmaceutical industry that produces drugs for disorders (Cosgrove and Krinsky 2012).

For several decades social scientists have emphasized that the demarcation of disorders is not rigid and can change over time: the boundaries between those who are 'disordered' and those who are 'normal' is fluid with respect to historical, societal, economic, geographic and cultural aspects. Vast increases in medication consumptions for ADHD, but also for psychiatry in general, beg the question whether this could really be attributed to a natural occurring biological dysfunctioning or whether other forces, e.g. social, cultural and economic, are at work (Conrad and Leiter 2004, Conrad 2005). People become increasingly aware of the increasing demands of our society on children, students and employees which can create a need for a medical explanation of failure by those who experience it as well as a market for industries to fulfil that need (Conrad and Potter 2000, Dehue 2014). Combined with biomedical research that enables to reframe these societal problems towards biological deficits which merit medical intervention, industry driven medicalization can flourish. Especially in the case of ADHD this is problematic as there are also conceptual issues with regard to the construct: there is substantial symptomatic overlap with other DSM disorders, comorbidity is seen in up to 70 percent of patients, most symptoms are framed in terms of functional impairment which makes the criterion for 'clinically significant level of impairment' seem self-fulfilling. Moreover, stimulants used to treat ADHD seem to

have beneficial effects on people without an official diagnosis which touches upon the sensitive topic of human enhancement. In sum, the aetiology of ADHD is uncertain and there are dangers that the construct is used by the industry to generate revenue and it is difficult to discriminate between “disorder” and “human enhancement”.

The discussion surrounding ADHD is also portrayed by the public media, where ‘proponents’ and ‘opponents’ of the ADHD diagnosis openly attack each other over the existence of ADHD and the necessity and safety of pharmacological treatment. In addition, the Dutch Minister of Health, being concerned by the rising costs of ADHD care, openly urged professional organizations to decrease the number of people diagnosed with and pharmacologically treated for ADHD, suggesting health professionals are over diagnosing ADHD (Schippers 2012). It can reasonably be assumed that this polemic influences day-to-day clinical practice.

In this article we focus on adult ADHD. Historically, ADHD has been defined as a disease of childhood. Only since the turn of the millennium has it been increasingly acknowledged that symptoms and resulting impairment persist into adulthood (Wender, Wolf et al. 2001). Adult ADHD has not been studied as a separate phenomenon but rather as an expansion of an already existing category. There are indications that the adaptations of the ADHD criteria in the DSM-IV do not give a true reflection of adult ADHD (McGough and Barkley 2004). For instance, Kooij et al. (2010) have previously described that some symptoms may be less applicable to adults or that symptoms could be expressed differently or in a more subtle way. For example: where children may be excessively physically active, visibly running around or climbing, in adults this can be expressed by constant feelings of inner restlessness. Moreover, adults frequently present comorbid disorders; it has been estimated that on average 70% of adults with ADHD also have disorders such as anxiety or mood disorders (Sobanski 2006, Biederman, Petty et al. 2008, Kooij, Bejerot et al. 2010). This means that health professionals can be confronted with individuals with a complex of serious problems that are not specific to ADHD or are, at first glance, unrelated to the disorder. Therefore the diagnostic process of adult ADHD in clinical practice may be much more complex than suggested by the various versions of the DSM and other diagnostic instruments, such as the Diagnostic Interview for Adults with ADHD (DIVA). Even for children, Rafalovich (2005) described how health professionals perceive uncertainty regarding the validity of the diagnosis, express ambivalence concerning unwanted side effects of medications and make autonomous decisions in interpreting diagnostic and treatment guidelines.

To the best of our knowledge, no studies have been published that explore the perspectives and experiences of health professionals on the use and applicability of versions of the DSM in diagnosing adult ADHD in practice nor how they come to decisions concerning treatment. Therefore, in this article we explore the perspectives of health professionals on the diagnostic process and the treatment of adult ADHD. In addition we analyse how health professionals relate to the debate surrounding (adult) ADHD.

7.2 Methods

Design

A qualitative, interpretative approach was employed since this allows the study of how participants interpret, perceive and ascribe meaning to phenomena in the real world (Smith 1996, Biggerstaff and Thompson 2008), and gives researchers a deep understanding of these processes from the perspective of the participants (Green and Thorogood 2009). Semi-structured interviews were considered suitable for this approach as they provide structure to address topics of interest of the researcher as well as leaving room for individual respondents to elaborate on topics that they deem important (Britten 1995, Biggerstaff and Thompson 2008). The interviews covered three themes: (1) the definition and conceptualization of adult ADHD; (2) the diagnostic process of adult ADHD; and (3) the treatment of adult ADHD. The interview protocol, in line with the themes mentioned above, was reviewed critically by all researchers and slightly adapted after several interviews to ensure that in-depth understanding was obtained.

Recruitment and data collection

In order to explore the variety in perspectives, purposeful sampling was used. In the Netherlands, mental healthcare is provided both in (individual) private practices and in outpatient mental health clinics. Health professionals in private practices were directly contacted through the information provided on the website of their practice either by phone or by e-mail. Important was that adult ADHD was listed as one of their target areas. Participants from outpatient clinics were indirectly recruited through contact with the assistant of the institute who passed on an e-mail drafted by the researchers or who planned a telephone appointment with a professional. In total 23 interviews were held: 19 face-to-face interviews; 2 interviews via Skype and one via telephone. Since the focus was on diagnosis and treatment of adult ADHD, emphasis was placed on interviewing psychiatrists (n=14) who are responsible for both. However, since ADHD is treated in multidisciplinary teams, psychologists (n=4), mental health

nurses (n=4) and a coach were also interviewed. Interviewing continued until data saturation was reached (no new topics emerged).

Data analysis

In line with Biggerstaff and Thompson’s (2008) guidelines for the analysis in interpretative approaches, verbatim transcripts were read and reread by two researchers to obtain familiarity with the data. Data analysis then followed the thematic coding with respect to three themes mentioned before. Within each cluster Conventional Content Analysis approach of Hsieh (2005) was applied. Two researchers separately analysed three transcripts using open coding to each establish an initial coding scheme. After comparing the two coding schemes, a final coding scheme was discussed in the research group and, after consensus was reached, used to analyse all transcripts for which MaxQDA v. 11 analysis software was used.

Ethical considerations

Verbal informed consent was obtained before the start of each interview for audio-taping, transcribing and analysing the interviews under the promise of anonymity. Medical ethical approval was not deemed necessary since it involved the perspectives of health professionals and not the medical dossiers or histories of patients. Interviewees were informed that they could terminate the interview and retract from the study at any point in time without providing a reason.

Table 5. Characteristics of the interviewed health professionals

	# participants (n=23)
Male	17
Female	6
Organization	
Outpatient mental health clinic ^a	13
Independently established Practice	10
Profession	
Psychiatrist	14
mental health nurse	4
Psychologist	4
ADHD coach	1

^a Outpatient mental health clinics provide psychiatric care in the form of multidisciplinary teams

7.3 Results

Twenty-three interviews were conducted with health professionals. Six interviewees were female. Respondents had a minimum of six years and a maximum of 36 years of experiences with adult ADHD with the average being 16 years (for further information see table 5). Even though respondents stemmed from different disciplines, no meaningful differences were observed that could be attributed to discipline. In this section, we first describe the professionals' conceptualizations of adult ADHD, secondly considerations concerning the diagnostic process will be addressed, and thirdly we discuss how health professionals balance pharmacotherapy, psychosocial treatment and patient preferences. As we will show the societal controversy is present in all three sections.

Professionals' conceptualization of ADHD: a 'real disorder'

When discussing what ADHD is, most respondents spontaneously and strongly emphasized that adult ADHD is *real* and that it can cause substantial problems in the lives of the people living with it. They corroborated this opinion referring to the criteria in the DSM-IV; a majority, but not all, of the participants also stressed the neurobiological and genetic underpinnings of the disorder. Referring to the negative media coverage of ADHD wherein ADHD is criticized for being a 'non'-existent disorder, a western invention, medicalization of normal behaviour or that it is the result of bad parenting, many interviewees felt that these critiques disregard the real and sometimes extreme suffering of their patients:

I have one group [of patients] whom are really disabled people, they get car accidents, are chaotic, can love someone dearly but are unable to maintain a marriage, (...) can no longer see their children because they were too late at court [for divorce negotiations] (...) they are pathetic people that can create huge problems for themselves (...) and it makes me angry when people say it's a Western problem of luxury. (R8)

However, this psychiatrist also acknowledged that the critics have a point, by explaining that "the problem [of ADHD] is that it is gradational", and that it is "not a dual problem, one either has it or not." ADHD can better be seen as a disorder that exists in mild and in severe forms (and anything in between). Also, it cannot be simply reduced to one biological cause, but it can be protected or amplified by other factors, such as parenting and societal change. For the very severe cases the biological dysfunction is unquestionable, however for the milder cases, it was argued, context could be an important amplifying factor. Besides people with mild ADHD who get into trouble, there is a group of people who don't have

ADHD but try to get the diagnosis in order to resolve tensions imposed by societal demands. According to one participant there are: “numerous examples of students that wouldn’t graduate without treatment, because then your function a lot better” suggesting that increasingly students try to function above their capabilities. This is something different from the “real” ADHD people can suffer from:

With the differential diagnosis it is important to look whether it is an aptitude, you know, problems with neuropsychological functioning, or whether it is an issue of motivation for example. People can put high demands on themselves and find that they have to endure tasks for which they have no motivation. Then ADHD turns into an alibi, you know, an explanation for why things don’t work and then ask me to fix it, so that things do work. (...) real ADHD is more biological than social or psychological. (R20)

In relation to society, some interviewees thought that, compared to the past, people start to experience problems earlier in life and more severely. As Western ‘capitalist societies’ focus increasingly on efficiency and become faster and more complex, they impose increasing demands on people to perform to their highest standard. Faced with these demands for efficiency and performance, people drop out. In the process, societal changes do not *create* ADHD - the ADHD symptoms probably already existed in people – but they amplify the problems people experience, as explained by this psychiatrist:

In terms of a dynamic model, you can say that psychiatric problems are a disturbance of the balance between capacity and load. If the load increases because of increasing complexity of society, the same unit of capacity won’t suffice causing a series of complaints that result in a diagnosis. (R18)

The interrelation between the biological susceptibility and contextual (societal) factors was especially apparent when some interviewees elaborated on ADHD and upbringing. They explained that people with a low biological susceptibility for ADHD may develop it growing up under the wrong circumstances whereas people with a high biological susceptibility growing up under the right circumstances may not develop ADHD.

For ADHD this is very concrete: if you have parents that help you with planning (...) and if you get angry and you have problems with controlling your impulses and you have parents that sit down with you to process your emotions (...) then you will learn better coping strategies which decreases the chance that you need to take medications later in life. (R23)

In sum, the general consensus was that ADHD is 'real', also according to those participants who did not reflect on the biological aspects of the disorder, and may result in real suffering regardless of societal demands. Furthermore, most interviewees contended that societal change and parenting are amplifying factors, but they are not considered as *the* cause of ADHD. If these contextual factors *are* the cause, it is not ADHD. Therefore, the question is: how do health professionals distinguish between societal factors and real ADHD?

The diagnostic process: a complicated endeavour

Many participants described the diagnostic process of adult ADHD to be an inherently complicated endeavour that demands critical and thorough reflection. ADHD is especially considered problematic since the symptoms of ADHD and the social problems associated with them have a reciprocal causality. For example, being forgetful and chaotic can cause marital problems, but having marital problems can also cause someone to become forgetful and chaotic. The former situation reflects those who have ADHD whereas the latter situation reflects people with other problems. Moreover, both can mutually amplify each other; that is, mild ADHD problems can further complicate a difficult marriage and marital problems can amplify otherwise mild ADHD symptoms. In sum, in order to diagnose ADHD, the interviewed health professionals explained they have to establish whether it is the *real biological* ADHD. This already complex endeavour is further troubled by: (1) many of the symptoms are not specific for ADHD, (2) the contextual nature of dysfunction; and (3) the secondary gains of an ADHD diagnosis. Below we will elaborate these three complicating factors, and then describe what strategies respondents use to come to a diagnosis.

How to differentiate between normal behaviour, ADHD and other disorders – The first problem identified by many interviewees is the overlap with symptoms from other disorders, especially with depression, bipolar disorder and borderline personality disorder (BPD). For example, impulsivity is both a problem for people with ADHD as for people with BPD, which makes it difficult for health professionals to determine which disorder explains best the behaviour of their patients. Secondly, besides overlap, comorbidity, which occurs in 80% of adults with ADHD (Kooij, Bejerot et al. 2010), complicates the diagnostic process:

Those clusters of symptoms overlap a lot, so in many cases it's unclear how it all fits together and what people *really* have. (R7)

Next to symptomatic overlap and comorbidity, several health professionals explained that similar behaviours, such as distractedness or impulsivity, may have causes that are not psychiatric in nature but caused by contextual or situational factors: being in the middle of a divorce, conflicts at work, stress etc. Moreover, some of the behavioural symptoms of ADHD, such as being easily distracted, are normal in any human being to a certain extent.

You know, if you study hard and long, you'll get tired and be less concentrated, you have that, I have that, everyone has that, and that's not ADHD. (R3)

Therefore, careful judgement of the severity and resulting dysfunction is imperative in order to establish real ADHD. A few health professionals explained that the diagnostic criteria provide little guidance as to how to make this distinction. That is, the diagnostic criteria *state* what is needed for a diagnosis but do not *guide* health professionals how to decide whether a criterion is met or not. For example, some health professionals mentioned that for patients who are just below the symptom threshold but with significant impairment a diagnosis may be justified.

How to disentangle and weigh symptoms in their individual and situational context – As described above, ADHD can cause problems in various spheres of daily life, this means that ADHD can stay hidden for a long time. For example, some participants illustrated this with descriptions of intelligent patients who compensate for ADHD for a long time but start experiencing problems when life gets more complex, especially when they have children.

They often seek help when they [patients] get kids or when they leave the house to live on their own. Then, suddenly, everything seems to go wrong. (R21)

A second issue, mentioned by some respondents, is that impairment that results from ADHD symptoms depends on the context of the patient. Some individuals clearly show ADHD symptoms, but live within a context where the impairment stays limited. Others, however, may find themselves in a context where the symptoms clearly lead to impairment:

Attention problems are less problematic for a plumber than for an office assistant of the same intelligence, so the context creates the disorder (...) For example, I have weak knees, that is not a problem now, but if I want to go skiing weak knees are troublesome and can result in injuries. (...) so you can't really say that the problem exists independently of the context. (R23)

In the example above, the psychiatrist explains that the impairment disorders cause, whether mental or physical, are intertwined with the context of the individual. There is a balance between symptom intensity and impairment in relation to a patient's context that needs to be discussed between health professionals and patients, and inherently brings uncertainty and subjectivity in the process.

How to distinguish real ADHD as a means to an end – Some respondents mentioned they encounter people of whom they suspect to pursue an ADHD diagnosis in order to obtain secondary gains. The diagnostic label provides access to care and stimulants, a route to unemployment benefits, administrative support, etc. These respondents especially referred to students, who are said to want medications to maintain concentration longer, to get extra time at exams or extra funding for study.

As well as benefits for individuals, a few respondents pointed out that institutions can also benefit from the ADHD 'label'. The current Dutch reimbursement system demands health professionals work along the lines of predefined diagnosis and treatment protocols: without a label there is no money and no treatment. Moreover, a growing number of private ADHD clinics have a strong financial interest, especially since more and more people seek out the diagnosis and treatment. A psychologist shows how also here institutional interests slip into the diagnostic process:

I saw a student who, in my opinion, didn't function that bad at all, but she studies at a private school and then I think that some schools have an interest in high success rates. Then this whole ADHD trajectory will be started, because then students have more time for their exams. (...) I think it is problematic to couple services to a diagnosis because it possibly facilitates over diagnosis. (R19)

What strategies do health professionals use to come to a 'valid' diagnosis – For the diagnosis of adult ADHD, two essential considerations were consistently elaborated in the interviews with health professionals. During the diagnostic interview, they aim to establish that the core symptoms of adult ADHD, such as distraction and impulsivity, are central to the problems the patient experienced throughout their lifespan. As one psychiatrist explained:

If you develop burnouts when you're 30 and before that you could concentrate perfectly, learn easily and had a perfect impulse control, then (...) that doesn't fit the concept we have of ADHD. Often people with undiscovered ADHD develop comorbidities, such as burnout, anxiety or depression, (...) and then, like a detective,

you have to scrutinize the history of a patient to determine if the ADHD, and the concentration problems, are on the basis of those problems. (R23)

Secondly, when it is clear that the symptoms are a thread running throughout the life of a patient, they evaluate the level of suffering that the symptoms cause for the patient. Most respondents put forward that the symptoms should be regarded within the individual context of a patient to discern whether it is the ADHD that causes the dysfunction and suffering.

So you have to look whether the severity of the ADHD has such an influence that it is impossible to function on a normal level, on multiple areas, because normally people with ADHD make one big mess of their lives. (R6)

As there are no laboratory tests, such as scans or blood test, to diagnose ADHD, all respondents stressed the authority of the diagnostic criteria in the DSM and related diagnostic tools (such as the DIVA and the CAARS). However, in order to be able to use these tools, they stressed that clinical experience is essential: for example in deciding whether a certain criterion is met and in weighing the level of impairment and suffering. A psychiatric nurse, trained to perform diagnostics in concert with a psychiatrist, explained:

ADHD appears to be a very simple disorder if you look at the criteria; however [...] you need to develop a sense to really see ADHD. (R16)

This 'sense' or 'feel' for the real ADHD emerged in many stories, a psychiatrist explained:

Restlessness in ADHD has a different 'colour' from restlessness in bipolar disorder. You can say that people with ADHD are more rational than people with bipolar disorder; with bipolar people there is this temper you can feel in the interaction with them that ADHD doesn't have. (R8)

Treatment for adult ADHD: diverging perspectives

The interviewees not only indicated that the diagnostic process is complicated and surrounded by uncertainties, also treatment decisions can be complex. However, in this respect there was less consensus among the respondents, particularly with respect to whether medications should be used over the long term (continuously) or in response to particular situations, and whether psychosocial care can be a stand-alone treatment or should only be offered to supplement pharmacotherapy.

Pharmacotherapy: chronic or situational use – All respondents indicated that pharmacotherapy (specifically stimulants) effectively reduces the symptoms of ADHD, and the large majority considered pharmacotherapy essential to adult ADHD care. However, opinions differed as to the role of these pharmaceuticals and how they should be used. Because of the biological underpinnings of the disorder, some respondents contended that medication use should be taken for longer periods of time, if not permanently, also including the weekends and holidays.

I hear from a lot of patients that when they stop taking medications all symptoms come back, you know, hyperactivity, irritations all that. (...) However, sometimes they [patients] only realize how bad they need it [medication] after they stopped taking it for some time, and after that I advise against a drug holiday actually. (R22)

Contrastingly, not all participants agreed on the continued use of stimulants and some thought that medications can be used in a flexible manner. Several health professionals said that they invited their patients to stop taking medications during the weekends and holidays or when less attention was needed.

Especially with Methylphenidate you can decide when to take it, before an important exam for example, so that you can concentrate. Whereas in the weekends or on holiday you could decide to not take it and let things go for a bit. So yeah, people become their own doctors regarding that you could say. (R23)

Two reasons were mentioned for encouraging or allowing situational use of medications. Some respondents explained that stopping with medications could show patients whether new skills, such as those acquired through psychosocial therapy for example, could be maintained without pharmacological help. Other respondents argued that adults in particular are able to estimate which situations demand more attention than others and are, therefore, able to take medications when needed. This view was, however, criticized by one respondent, who stated that ADHD caused substantial problems on an ongoing basis, and not only in very specific situations:

Well, you get people who say they just want to take it [Ritalin] before an exam and I don't think that's of any use, you either have ADHD or not (...). If you only take a pill once a week then there is no real suffering, ADHD should cause problems in two aspects of life, the criteria [in the DSM] are very clear on that, so then it's not ADHD. (R14)

Psychosocial therapy: core or supportive – Some psychiatrists prefer not to prescribe medication if psychosocial therapy is sufficient to manage the problems of their patients. They contended that medications do not cure ADHD in the sense that they do not bring about structural change in behaviour, which can only be achieved by behavioural therapies. According to them, only severe cases of ADHD warrant immediate treatment with medications:

In the very serious cases you need medications to make patients function at the basal level; however if you can do it without medications and just behavioural change, that will always have my preference. (R3)

The majority of respondents, including those who expressed a strong preference for pharmacotherapy, acknowledged that pharmacotherapy alone may not be sufficient in addressing the problems adults with ADHD face. They contend that pharmacotherapy is essential to address the core symptoms of ADHD whereas psychosocial therapy helps patients to manage their lives better and suffer less from negative thoughts and emotions. These health professionals perceive pharmacotherapy to be the core of treatment and psychosocial approaches as complementary:

Medications, I think, take up 80% of the treatment (...) and next to that we offer these groups for patients where they learn about communication, intimate relations, parenting, you know, all those things that are difficult for adults with ADHD. (R8)

Working with patient preferences and public debate – In finding the right treatment combination for their patients, the preferences of patients were usually considered as decisive. Most respondents respected patients' choices not to take medication and offer psychosocial therapies instead. Others said they actively encouraged their patients to start a trial on medications since they, contrary to their patients, believed that pharmacotherapy is the most preferable treatment for that patient. A few of these respondents explained that they discontinue treatment if a patient both refuses to take medication, and shows little or no results with other forms of therapy.

If we see insufficient improvement, I'll try to motivate him [patient] one more time by explaining that his learning capabilities are impaired by the ADHD and that you can't get that under control without the meds. (R4)

A pressing problem, according to some respondents, is the obtrusion of the public debate and societal concerns into the clinical process. Negative media coverage on stimulants (as mentioned in the

introduction) convince patients that medications are unnecessary, undesirable or even dangerous. These respondents complain that, while they believe pharmacotherapy is the best treatment for their patients, some patients refuse medicines because they think it is dangerous.

Besides patient preferences, they have to work within a political context, including the minister urging them to diagnose and treat ADHD less frequently in order to stop the ADHD epidemic. Moreover, recent healthcare reforms aim to decrease the number of people treated in secondary care and treat them at the primary care level. Some respondents expressed the fear that this might reduce access of adults with ADHD to care services and jeopardize quality of care. For example, this cutting down of expenses risks under diagnosis for people who need it, but also over diagnosis for those who don't, as one psychiatrist explained:

When new budget cuts are made, it will become more difficult for those with serious problems to get care while people with money get more opportunities. If care is no longer reimbursed, providers will offer services for which you have to pay and, those providers want profit, they will give everyone a diagnosis. (R23)

Some respondents also referred to their work in general; they argued that the uncertainty, subjectivity and complexity they talked about is not specific to ADHD, but is applicable for psychiatry in general. This does not mean, that their care is not valid and of poor quality.

I must say that the negative tone in the media and that people really overlook the enormous suffering of people (...) and how we everyday see how people can live up after decent diagnosis and treatment, it really makes me sad and angry. (R13)

7.4 Discussion

This study set out to explore how health professionals diagnose and treat persons with adult ADHD against the backdrop of scientific uncertainty and the public debate surrounding ADHD. In response, health professionals feel the need to defend the construct of ADHD as a 'real disorder, with a specific diagnosis and effective treatment, and their work as a capable doctor. They refer to contemporary scientific conceptions of adult ADHD such as: the genetic and neurobiological underpinnings of the disorder (Tripp and Wickens 2009, Cortese 2012, Cortese, Kelly et al. 2012) and the authority of the DSM-IV and clinical guidelines such as the NICE guidelines for ADHD and the European Consensus

Statement (APA 2000, NICE 2008, Kooij, Bejerot et al. 2010). In particular, the importance of stimulant medications, especially in combination with psychosocial approaches such as psycho-education and coaching, was agreed upon by the vast majority of participants in this study (Biederman, Spencer et al. 2004, Kooij, Bejerot et al. 2010). At first glance the perspectives of professionals align with the conceptualization, definition, diagnosis and treatment of adult ADHD as presented in official guidelines and scientific literature.

Looking more closely, however, reveals that it is challenging to apply scientific categories, such as adult ADHD, to the complex and erratic nature of the lives of patients in their individual contexts. Health professionals reported conceptual issues regarding ADHD, such as the limited specificity of its symptoms in discriminating between ADHD, normal behaviour and other disorders. Additionally, the diagnostic criteria do not acknowledge the reciprocal causality of symptoms and impairments in life. In this regard, health professionals feel that guidelines and protocols provide limited guidance. In the translation of formal guidelines to daily practice all respondents deemed clinical experience essential in order to make sound clinical decisions. This finding aligns with Rafalovich (Rafalovich 2005) who showed how health professionals make individual decisions in applying the diagnostic criteria of childhood ADHD resulting in ambivalence and uncertainty in diagnostic and treatment decisions. Moreover, Bhugra, Easter et al. (2011) also showed that psychiatrist strongly lean on clinical experience in making diagnostic decisions and showed substantial variation between psychiatric practices.

This ambivalence is fuelled by two tensions in the landscape wherein health professionals have to provide mental health services. Firstly, there a tension between political pressure to reduce the number of people diagnosed with ADHD and treated (Schippers 2012) and health professionals having their own code of conduct and are expected to base their decisions on research evidence (Dehue 2014). Evidence that essentially indicates the opposite, namely an under-diagnosis of ADHD urging health professionals to be more alert for the disorder (Kessler, Adler et al. 2006, de Graaf, Kessler et al. 2008, Dehue 2014). Secondly, there is a tension between Evidence-Based Medicine and person-centred care. Dutch health professionals have to work according to 'Diagnosis Treatment Combinations' (DBC's) – an equivalent of the 'Diagnosis Related Groups' in the USA. A diagnosis is needed for a treatment, which is already outlined in evidence-based guidelines and protocols, that can then be reimbursed by insurance companies. This system stimulates diagnostic processes where the diagnosed disorder, rather than the individual, becomes the centre of treatment (Sambeek, Tonkens et al. 2011). At the same time, health professionals are urged to provide person-centred care that takes into account patients' individual life

issues, preferences and contexts (Mead and Bower 2000, Pulvirenti, McMillan et al. 2014). In the delivery of person-centred care, tacit knowledge is needed to interpret and apply guidelines and to deviate from guidelines if they do not match the preferences and contexts of individual patients or are not in line with their experiences in clinical practice.

In line with Rafalovich (2005) and Bhugra, Easter et al. (2011), we showed that health professionals do not operate in a vacuum, but feel influenced by external factors. We showed how societal demands, political interference, insurance companies and public debate which results in seemingly paradoxical forces to which health professionals have to align their practice. In the past, social scientists rightfully questioned the dominance of medicine and the authority of doctors in order to protect to rights of patients (Helman 2007). However, it seems that health professionals lose more and more autonomy to make decisions which, according to the respondents, is not always in the best interest of patients since health professionals need space to come to sound clinical decisions that do justice to the complex and erratic nature of ADHD and everyday life of their patients.

Future research should validate and further explain how, exactly, health professionals diagnose ADHD and what the observed variance means for quality of care. Qualitative inquiry of clinical practice and tacit knowledge of professionals, its explication and critical appraisal, is important not only to understand how research evidence informs clinical practice, but also to transform this knowledge into new evidence (Upshur, VanDenKerkhof et al. 2001, Upshur 2002, Rycroft-Malone, Seers et al. 2004). Future guidelines need to acknowledge complexity and uncertainty of diagnosis and treatment of adult ADHD and make tacit knowledge of health professionals (and patients) explicit in order to supplement or amend existing clinical guidelines.

Limitations and strengths

As no observational methods were employed, one of the weaknesses of this study is that we have no data to corroborate or contradict the explanations provided by health professionals during interviews. Also, no data were gathered that could quantify the uncertainty and variance in ADHD diagnoses and treatment. Additionally, because of the qualitative nature of the study, it is not possible to generalize our findings to the full population of health professionals. Since this study was conducted in the Netherlands, it is difficult to generalize these findings to other countries since different countries use different diagnostic systems. However, since our findings align with those of Rafalovich (2005) and Bhugra, Easter et al. (2011), it can be hypothesized that our findings may provide relevant insights to

other countries. Nevertheless, future research should investigate how these findings manifest themselves in the Netherlands and other countries.

Our results show how relevant the experiential tacit knowledge of health professionals is; their stories shed a different light on scientific categorizations and protocols and show misalignment with the complexity and uncertainty that surrounds real world problems, in this case diagnosis and treatment of adult ADHD.

Chapter 8: Comparing patients' perspectives of 'good care' in Dutch outpatient psychiatric services with academic perspectives of patient-centred care

Abstract

Background: Over the past six decades, the concept of patient-centred care (PCC) has been discussed in health research, policy and practice. However, research on PCC from a patients' perspective is sparse and particularly absent in outpatient psychiatric services.

Aim: To gain insight into what patients with bipolar disorder and ADHD consider 'good care' and what this implies for the conceptualization of PCC.

Method: A literature review on the different conceptualizations of PCC was combined with qualitative explorative research on the experiences and needs of adults with ADHD and with bipolar disorder with mental healthcare in the Netherlands using focus group discussions and interviews.

Results: The elements addressed in literature are clustered into four dimensions: 'patient', 'health professional', 'patient-professional interaction', and 'healthcare organization'. What is considered 'good care' by patients coincided with the four dimensions of PCC found in literature and provided refinement of, and preferred emphasis within, the dimensions of PCC.

Conclusions: The study shows the value of including patients' perspectives in the conceptualization of PCC, adding elements, such as 'professionals listen without judgment', 'professionals (re)act on the fluctuating course of the disorder and changing needs of patients', and 'patients are seen as persons with positive sides and strengths'.

8.1 Introduction

The concept of patient-centred care (PCC) has been applied to healthcare policy and healthcare delivery for more than 60 years (Hudon, Fortin, Haggerty, Lambert, & Poitras 2011). In 2001, the US Institute of Medicine added PCC to its objectives in recognition of the role of PCC in improving quality of care (Institute of Medicine 2001). Since then, PCC has become the focus of recent healthcare reform in many Western healthcare systems (J. H. Robinson, Callister, Berry, & Dearing 2008; Scambler & Asimakopoulou, 2014). Reasons for the popularity of PCC are twofold. First, it is grounded in the moral and ethical belief that it is the right thing to do regardless of its influence on health outcomes (Duggan, Geller, Cooper, & Beach, 2006). According to medical ethics, the autonomy of patients should be respected and they should be treated with respect and dignity (Epstein, Fiscella, Lesser, & Stange 2010). Second, the delivery of PCC is associated with improved health outcomes, satisfaction with care and reduced healthcare costs (see e.g. Epstein, 2000; Greene, Tuzzio, & Cherkin, 2012; Hudon et al. 2011; Mills, Frost, Cooper, Moles, & Kay 2014; J. H. Robinson et al. 2008; Storm & Edwards 2013).

Since its inception in the 1950s, various efforts have been made to define and conceptualize PCC. Initially, PCC was referred to as “individualized care based on patient-specific information” (Hobbs 2009 p53) because each patient “has to be understood as a unique human-being” (Balint 1969, quoted in Saha, Beach, & Cooper, 2008 p1). A definition of PCC that is commonly used is the one formulated by the US National Academy of Medicine (formerly the Institute of Medicine, IOM) “a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patient's wants, needs and preferences and that patients have the education and support they need to make decisions and participate in their own care” in every stage of healthcare from entry to discharge (Institute of Medicine 2001, p7). Other more instrumental conceptualizations recognize PCC as a measure of the quality of healthcare provided by healthcare organizations (J. H. Robinson et al. 2008). Although PCC has a long history of political and academic attention, it is still being criticized for its unclear conceptualization. According to Stewart (2001, p444), “PCC is better understood for what it is not” and definitions are “often oversimplified” and “fail to capture the indivisible whole of a healing relationship.”

In this article we are particularly interested in PCC in the context of mental health. In this context, PCC is mostly described within specific subfields, for example dementia (e.g. Clissett, Porock, Harwood, & Gladman 2013; Stokes 2005), forensic psychiatry (e.g. Encinares & Golea 2005; Livingston, Nijdam-Jones,

& Brink 2012) or psychiatric education (e.g. McGinty, Larson, Hodas, Musick, & Metz 2012; L. Robinson, Bamford, Briel, Spencer, & Whitty 2010). Most literature concerns inpatient psychiatry which poses a distinct set of problems, such as hospitalization, isolation and coercion, as compared to outpatient services (e.g. Gabrielsson, Savenstedt, & Zingmark 2014; Geller 2012; Storm & Edwards 2013). As the majority of the Dutch patients is treated in an outpatient clinic (Trimbos Instituut 2015), it is important to understand the conceptualization and implications for practice of PCC in this area as well.

However, research that takes a patient's perspective on PCC is sparse. This is striking as the core idea of PCC is that the patient should be placed at the centre of healthcare provision (J. H. Robinson et al. 2008). To the best of our knowledge only two qualitative articles have been published about the perspectives of mental health patients on PCC, in which the need was expressed to be viewed as valuable human beings by service providers and by society (Corring & Cook 1999; Williams et al. 1999). Although articles have been published on perspectives of mental health patients on good care, this is not yet linked to PCC (e.g. Johansson & Eklund 2003). Additionally, no articles have been published that explore PCC from the perspective of patients treated in outpatient psychiatric services. We argue that patients' stories are needed to give meaning to the concept of PCC discussed in the literature and to see if this conceptualization matches the perspectives and experiences of psychiatric patients. Thus, the aim of this study is to gain insight into what patients with bipolar disorder and ADHD consider 'good care' and what this implies for the conceptualization of PCC.

8.2 Methods

A three-step approach was used. First, a literature review was conducted to synthesize a model that integrates recent conceptualizations of PCC. Second, qualitative explorative research was conducted on the experiences and needs of adults with ADHD and adults with bipolar disorder with respect to mental healthcare in the Netherlands. Finally, the finding of the literature and the patient perspectives were compared.

Literature review

Search strategy – Empirical research on PCC and its implementation in specific healthcare settings is extensive. However, relatively few articles focus on theoretical or conceptual underpinnings of the concept. As the latter were the focus of our interest, we chose to only include review articles and

theoretical articles that used literature as their prime data source. Two researchers (EM and BR) separately performed searches and search strings and results were discussed by the entire research team in order to develop the final search string. The search for relevant literature was performed in four databases: PubMed, CINAHL, PsycInfo and Web of Science. The keywords used were patient/person/user/client centred/oriented/focused care OR patient/person/user/client centeredness, in the title, in both US and UK spelling, AND dimension OR concept OR principle in the abstract, AND literature OR review, in the abstract.

Conflicting ideas on what to include or exclude were resolved through discussion by the research team. Articles were included if they were (1) about the theoretical conceptualization of PCC, and (2) were literature reviews. Articles were excluded when (1) they were not written in English, (2) they were about PCC in a specific context (e.g. specific disease), or (3) no full-text was available. Search results from the four databases were imported in endnote and the duplicates were removed resulting in 83 original articles. 56 articles were excluded after screening for eligibility on basis of title and abstract. 18 articles were excluded after reading the full text, resulting in the inclusion of 8 articles. Additionally, 2 more articles were included after reference tracking of the included articles. Figure 4 shows a flow chart of the systematic search.

Analysis – All elements of PCC derived from literature were studied and discussed by two authors; conflicting ideas were resolved through discussion within the research team. Subsequently, the elements were clustered into core dimensions.

Empirical data

Qualitative explorative research was conducted on the experiences and needs of people with adult ADHD and bipolar disorder with healthcare, using focus group discussions (FGDs) and semi-structured interviews.

Participants and data collection – With respect to adult ADHD, participants discussed their experiences with and needs for adult ADHD care in the Netherlands in four FGDs (n=30). Participants were included when they (1) had a primary ADHD diagnosis and (2) were 21 years or older.

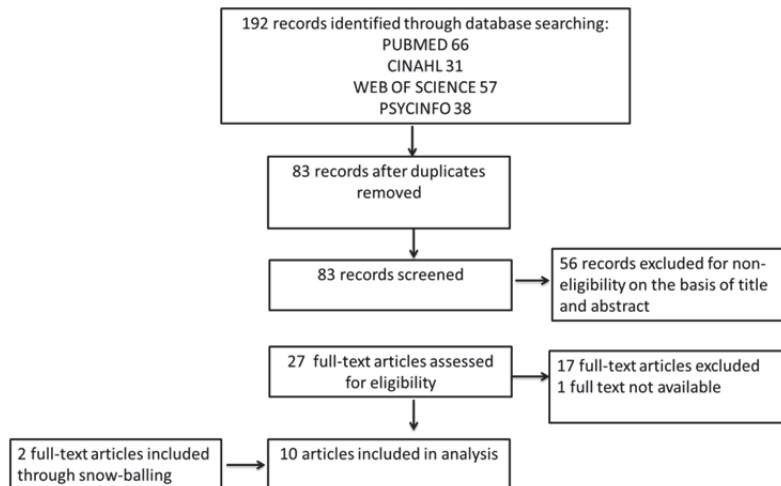


Figure 4. Flowchart of article retrieval and inclusion

People with bipolar disorder participated in six focus groups (n=35) or were interviewed (n=9) about experiences with and needs for mental healthcare. Inclusion criteria were (1) people who were diagnosed with bipolar disorder, (2) were above the age of 18 years old and (3) were stable at the time of the interview or focus group.

Since comorbidity is common in people with ADHD and bipolar disorder, in both studies participants with comorbidities were included in the study. FGDs took two hours and used a design that guided the discussions to reflect on all stages of care received: accessibility, diagnostic process and treatment. The interview guide had the same structure as the FGDs. FGDs and interviews were recorded and transcribed verbatim; summaries were sent to participants for member check.

Data analysis – Data were analysed thematically using a coding sheet based on the integrated PCC model derived from the systematic review. Additionally, open coding was done, in order to be able to include elements that were not mentioned in the literature but considered important aspects of good care by patients. Use was made of the qualitative analysis software program MAXQDA.

Ethical considerations – According to Dutch regulations, no ethical approval from the Medical Ethical Committee was needed for this study. All participants gave verbal or written informed consent for audiotaping, analysis and publication. Participation was on a voluntary basis and participants could withdraw from the study at any point in time, without giving reasons and without consequence. Anonymity of all participants was ensured in every phase of the research.

Table 6. Overview and summary of the included articles

Author(s) 'Title' Journal	Year	Type of review	Core dimensions of PCC described
Hobbs <i>'A dimensional analysis of patient-centred care'</i> Nursing research	2009	Dimensional analysis (n=69)	Describes 5 dimensions of PCC. <i>Perspective:</i> alleviating vulnerabilities <i>Context:</i> fragmentation of service provision; patient acuity; staffing; centralized and decentralized decision making; efficiency; effectiveness <i>Condition:</i> heterogeneous response to illness; needs exceed capacity; suffering; disease condition; approach of health professional to patient; caring presence of health professional; characteristics of health professional; role orientation of health professional <i>Process:</i> therapeutic engagement <i>Consequences:</i> lessen suffering; needs of patient met; effective care; minimize erosion of individual identity; address complexity by health professional; broadening explanatory perspective of illness by health professional
Kitson et al. <i>'What are core elements of patient-centred care? A narrative review and synthesis of the literature form health policy, medicine and nursing'</i> Journal of advanced nursing	2012	Narrative review (n=60)	Describes 3 themes. <i>Patient participation and involvement:</i> patient participating as a respected and autonomous individual; the care plan is based on the patient's individual needs and the care addresses the patient's physical and emotional needs <i>Relationship between the patient and health professional:</i> a genuine health professional-patient relationship; open communication of knowledge, personal expertise and clinical expertise between the patient and the professional; health professional having appropriate skills and knowledge; having a cohesive and co-operative team of professionals <i>The context where care is delivered:</i> access to care; policy practice continuum/language used; barriers to PCC; supportive organizational system; therapeutic environment
Leplege et al. <i>'Person-centeredness: conceptual and historical'</i>	2007	Conceptual and historical analysis (n=10)	Describes 4 concepts. PCC means: Person as expert: participation and empowerment; Respect the person behind impairment or disease;

<i>perspectives'</i> Disability and rehabilitation			Addressing the person's difficulties in life; Addressing the person's specific and holistic properties
Lusk & Fater 'A concept analysis of patient-centred care' Nursing forum	2013	Concept analysis (n=24)	Describes attributes, antecedents and consequences of PCC. <i>Attributes:</i> encouraging patient autonomy; caring attitude of health professional; individualizing patient care by the health professional <i>Antecedents:</i> the need for healthcare intervention, the ability of the patient or significant other to participate in his/her own care <i>Consequences:</i> experience of power; shared decision-making; caring; self-care ability; patient satisfaction
Mead & Bower 'Patient-centeredness: a conceptual framework and review of the empirical literature' Social science & Medicine	2000	Narrative review (n=41)	Describes 5 dimensions. Biopsychosocial perspective; patient-as-person; sharing power and responsibility; therapeutic alliance; doctor-as-person
McCormack et al. 'Exploring person-centeredness: a qualitative meta-synthesis of four studies' Scandinavian Journal of Caring Science	2010	Qualitative meta-synthesis (n=4)	Describes PCC on the basis of prerequisites, care environment, care processes and outcome. <i>Prerequisites:</i> professionally competent; developed interpersonal skills; commitment to the job; clarity of beliefs and values; knowing 'self' <i>The care environment:</i> appropriate skills mix; shared decision making systems; effective relationships; supportive organizational systems; power sharing; potential for innovation and risk taking <i>Care processes:</i> working with patient's beliefs and values; engagement; sharing decision making; having sympathetic presence; providing for physical needs <i>Outcome:</i> satisfaction with care; involvement with care; feeling of well-being; creating a therapeutic culture
Morgan 'A concept analysis of person-centred care'	2011	Concept analysis (n=50)	Describes PCC on the basis of attributes, antecedents and consequences. <i>Attributes:</i> holistic; individualized; respectful; empowering <i>Antecedents:</i> vision and commitment; organizational attitudes and behavior; shared governance

Journal of holistic nursing			<i>Consequences:</i> improves quality of care; increased satisfaction with healthcare; improved health outcomes
Pelzang <i>'Time to learn: understanding patient-centred care'</i> British Journal of nursing	2010	Narrative review (n=17)	Describes two models; a systems model introduced by Flarey (1995) and a process model, consisting of 7 dimensions introduced by Gerteis et al., 1993. <i>Process model:</i> respect of patients' values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; transition and continuity of care <i>Systems model:</i> Organizational self-care: development; retention/recruitment; image Masters of change: planning; research; adaptation Partners in care: collaboration; coordination; communication Patient-centred environment: values; empowerment; advocacy
Scholl et al. <i>'An integrative model of patient-centeredness- A systematic review and concept analysis'</i> PLOS ONE	2014	Systematic review (n=417)	Describes 15 dimensions. Essential characteristics of health professional; health professional-patient relationship; patient as unique person; biopsychosocial perspective; health professional-patient communication; integration of medical and non-medical care; teamwork and teambuilding; access to care; coordination and continuity of care; patient information; patient involvement in care; involvement of family and friends; patient empowerment; physical support; emotional support
Sidani& Fox <i>'Patient-centred care: clarification of its specific elements to facilitate interprofessional care'</i> Journal of Interprofessional Care	2014	Integrative literature review (n=178)	Describes 3 components and 1 non-specific element of PCC. Components: <i>Holistic care:</i> attend to all patient's needs at the time of particular healthcare encounter or experienced over time; target the totality of patients' condition; all patients' needs i.e. physical care, comfort, emotional care; education; development and enactment of a care plan that incorporates health promotion, illness prevention and behavioural change strategies <i>Collaborative care:</i> patients' involvement in decision making; encouraging independence and self-directed care; developing an effective partnership; offering and respecting patients' choices; finding common ground on what

			<p>the problem is; collaborating on problem solving by understanding patients' problem; negotiating treatment goals; sharing information in complete, accurate and timely way; educating patient; sharing power and responsibility</p> <p><i>Responsive care:</i> maintaining consistency between intervention and patients' needs, values and preferences; individualizing care; acknowledging the patient as an individual by concentrating on patient's circumstances rather than the disease; understanding and respecting patients' perspectives, feeling and needs; right for autonomy; providing flexible, personalized care</p> <p><i>Non-specific element:</i></p> <p><i>The therapeutic relationship:</i> patients respect professionals' expertise; healthcare professionals are personable, open to and respectful of patients' knowledge and experiences; health professionals have competent communications skills; health professionals listen; health professionals share information; health professionals communicate effectively; health professional provides technical and emotional support</p>
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8.2 Results

In current literature, PCC is conceptualized in a variety of ways. All reviews included in this study integrated the conceptualization of a variety of studies into a new conceptualization, albeit at different levels of analysis and with a different scope. Some reviews strictly speak about the theoretical dimensions (or components or themes) of the concept of PCC, while others include a discussion of required skills, factors contributing and barriers to PCC as part of the conceptualization. Corresponding to our aim, we have excluded the latter and demarcated our analysis to the theoretical dimensions of what PCC entails. An overview of the included articles is provided in table 6.

The elements addressed in literature were clustered into four dimensions (figure 5): 'patient', 'health professional', 'patient-professional interaction', and 'healthcare organization. All articles describe the focus of health professionals on the unique preferences, needs and values of each individual patient as an important element of PCC. The 'patient' is conceptualised as a human being and has the right to be heard and receive tailor-made care and treatment (see figure 5, A). The implications of this view for the interaction between health professionals and patients is also discussed by all articles, calling for a new style of communication and shared responsibility (see figure 5, B). Furthermore, many articles argue that not only the person behind the patient but also the person behind the health professional, and his/her role and attitude, is essential for PCC (see figure 5, C). Although a conceptualization including patients, health professionals and their interaction is widely recognized and used, some scholars have argued that a greater focus needs to be placed on the organizational level of PCC, and not solely on its constituent parts (see figure 5, D). The dimensions of PCC are closely intertwined. For analytical purposes we will discuss each dimension separately, juxtaposing what was found in literature with our empirical data, in order to understand how patients' perspectives of good care align with these conceptualizations of PCC.

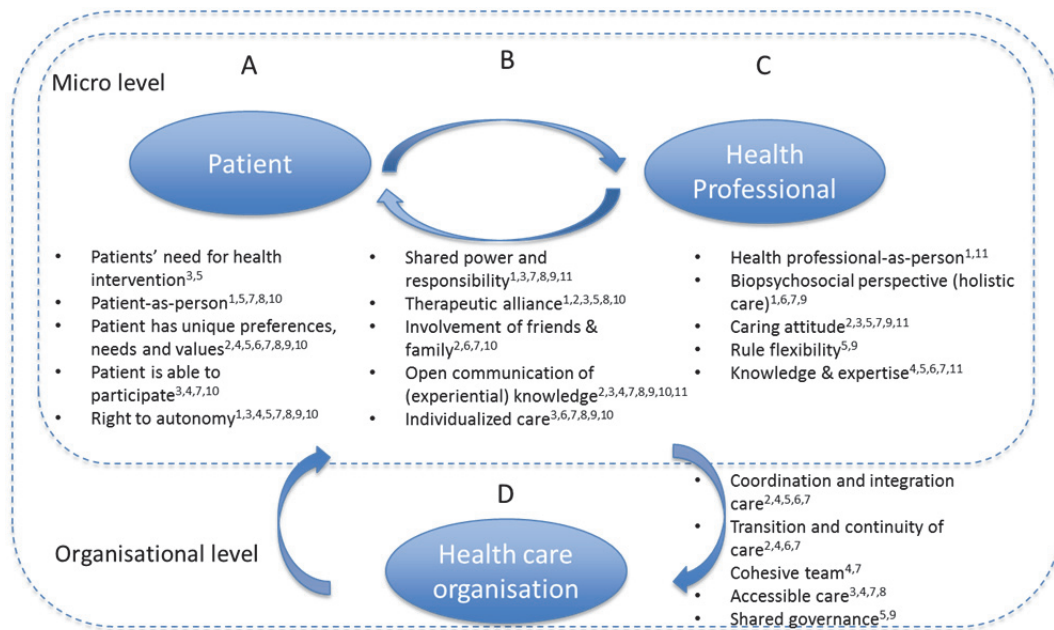


Figure 5. The integrative model of PCC. 1. Mead and Bower 2. Gerteis (in Pelzang, 2010) 3.Lusk & Fater 4.Kitson et al. 5. Hobbs 6.Pelzang 7.Scholl et al. 8.Sidani & Fox 9.Morgan 10.Leplege et al 11.McCormack et al.

Patient

In PCC the patient is first and foremost seen as a *unique person* – as “an experiencing individual” (Mead & Bower 2000, p.1089), with his or her “own way of perceiving and experiencing” (Pelzang, 2010, p.913). As a consequence, patients have “a heterogeneous response to illness” (Hobbs 2009, p.55). Thus, as opposed to the commonly held belief that all patients with the same diagnosis should receive the same treatment, in the PCC discourse it is emphasized that patients have *unique preferences, needs and values* in relation to their illness (Kitson, Marshall, Bassett, & Zeitz, 2013; Mead & Bower, 2000; Morgan & Yoder 2012; Pelzang 2010; Scholl, Zill, Harter, & Dirmaier 2014; Sidani & Fox 2014). Moreover, fully respecting the unique preferences of patients also implies that patients decide whether they even need or want care (Lusk & Faber, 2013; Hobbs, 2009). In addition to being unique, in PCC a patient is seen as *able to participate* in his/her own care, and has the *right to autonomy* (Lusk & Fater 2013).

In the stories of people with ADHD and bipolar disorders many examples of ‘being unique’ and the desire to be treated accordingly appear. Prominent in these stories is the conviction that a person is more than his or her diagnosis:

[The therapist] should treat me as a person. That's the most important: treat me as a human being and not as a problem. (Female, 51, bipolar disorder)

Really look at who you are as a person, and place the ADHD next to that person, because everyone has different problems with which he struggles or another history that troubles him. (Female, 33, ADHD)

A diagnosis, whether bipolar disorder or ADHD, is just one aspect of human life and coincides with other aspects such as family life, professional life and the person's place as an individual human being in society. In addition to support for each of the elements of PCC regarding the patient that were found in literature, our data provides more in-depth insights into some of the elements.

First, an important aspect of considering 'patients-as-persons', not explicitly discussed in the studied literature, is that many patients stressed that they have a variety of *strengths and competences*, in addition to merely deficits associated with mental disorder, which can be used in the treatment trajectory. According to these patients their strengths are hardly addressed in current healthcare practice:

It's always like oh you are diagnosed with ADHD so you can't study and you can't concentrate (...). Turn that around and approach it more positively: you're more creative, you're more intelligent, you hear and see more, you're better suited for a think-tank. (Female, 50, ADHD)

Sometimes they only speak about bipolar, and you think, I am more than just bipolar. I am a great reader, or speak my languages fluently, etcetera. (Female, 69, bipolar disorder)

These patients not just ask for recognition of these strengths, but also awareness that these strengths could form a source for personalized treatment.

Second, many stories shared by patients support the idea that the way in which the diagnosed disorder works out for individual patients and their context is unique. There are differences between individuals in both their personal characteristics (I am a different person than you) and their experiences of illness (my ADHD is different from your ADHD). The symptoms, the severity of the symptoms and the problems that these symptoms cause vary from one individual to another, and can have a very different impact on the daily lives of persons living with it. In addition to the current conceptualization, patients stress that

preferences, needs and values are not just individually determined but are, to a certain extent, situational and can change over time. For the delivery of PCC, this means that personal desires and contexts help to fine-tune treatment to maximize effectiveness and satisfaction *within* that context:

When I am in nature I am in a flow. A lot is context dependent; at a different place on earth I am fine without medication. (Male, 57, bipolar disorder).

Third, patients appreciate the ability to share experiential knowledge between themselves, as other patient can have valuable tips on how to deal with problems related to the disorder.

With peers, I found out that they have tricks how to circumvent certain problems or how to ignore them. (Female, 21, ADHD)

Thus, according to patients, 'good care' implies acknowledging, and being sensitive, to different forms of uniqueness. Patients generally desire to be treated with dignity and respect, attuned to their personal needs, preferences and values, with a focus on their individual strengths, and value the exchange of experiences with peers. Patients' unique desires are not stable per se; they can be situational and may change over time.

Health professional

PCC demands a new conceptualization of the health professional as person, just as the 'patient' was re-conceptualized as a unique person, implying an additional set of characteristics. According to Steward (cited by Mead & Bower 2000, p1088), a patient-centred health professional adopts a biopsychosocial perspective on illness and is "willing to become involved in the full range of difficulties patients bring to their doctors and not just their biomedical model". In addition to knowledge and professional expertise essential to medical practice (Hobbs 2009; McCormack, 2004; Pelzang 2010; Scholl et al. 2014), the health professional has a caring attitude which is understood as being respectful, empathic, honest and, above all, being present (Hobbs 2009; Lusk & Fater 2013; McCormack 2004; Scholl et al. 2014). This requires careful listening in order to understand the patient's lived experience (Lusk & Fater 2013; Sidani & Fox 2014). Furthermore, health professionals should be aware of and reflective to their own emotional responses (McCormack 2004; Mead & Bower 2000; Scholl et al. 2014). Rule flexibility is needed to determine "when and how to deviate from established norms and standards when the patient situation dictates" (Hobbs 2009, p55). This means that the health professional needs to be

assertive, rather than dominant or compliant, in relation to both the patient and their healthcare organization.

Almost all patients acknowledged that their health professionals should – of course – be knowledgeable and competent as this is essential for a valid diagnosis and obtaining the right treatment, but they also emphasized the importance of a caring attitude, including being empathic and listening carefully. Many patients value a healthcare professional who finds a balance between active and open listening and, based on their role as a professional with knowledge and expertise, being directive when necessary.

He should also dare to confront you, so say something like: ‘hey, you say you have no problems with planning, but you were late for our last three appointments’. (Female, 27, ADHD)

He should also just ask the right questions, because he is still the therapist; it is important that the therapist gives a certain direction, but if he pushes me too much I am gone. Honey attracts more bees than vinegar. This is also true for healthcare. (Male, 25, bipolar disorder)

Patients often expressed that they want professionals to appreciate their input and listen to them nonjudgmentally.

[An ideal health professional is] someone who doesn't judge, who gives you the feeling he doesn't have preconceived ideas. (...) Someone who doesn't put pressure on you so that you, yourself, can put ideas forward and doesn't tell you what to do and how to do it, but is still able to steer you. (Male, unknown, ADHD)

Regularly stories were told which showed this is often not the case yet:

Once I was given the wrong pills and became very manic. When I said that I thought something was wrong, they said: ‘Nah, just keep on going, let’s finish this first’. (Female, 34, bipolar disorder)

Furthermore, several patients mentioned that health professionals seemed to have a preference for pharmacotherapy over non-pharmacological treatment, while they rather preferred a broader perspective, including attention to lifestyle change, sports and nutrition.

A consultation with the psychiatrist is short. I would say, just try once to spend only half of the time on the pharmaceutical aspects, make it 50/50. (Male, 68, bipolar disorder)

Thus, according to patients, it is important that a healthcare professional takes a holistic approach, balances being directive and being supportive, and integrate their own expertise with that of the patient.

Interaction between patients and health professional

As PCC demands a reconceptualization of 'patients' and 'health professionals', this inherently implies a different relationship between them. The patriarchal doctor-patient relationship has to be transformed into a more personal relationship between the patient and the health professional in order to enact therapeutic change in patients (Mead & Bower 2000). According to Hobbs (2009, p57), this therapeutic alliance develops through a "cyclical process based on the development of trust" and "involves availability and responsiveness of health professional and patient to one another". Both the health professional and the patient are acknowledged as knowledgeable actors. The former should provide accurate and tailored information concerning the disease and treatment and the latter should be stimulated to share personal knowledge about his or her health condition and illness experience (McCormack 2004; Mead & Bower 2000; Pelzang 2010; Scholl et al. 2014; Sidani & Fox 2014). In other words, PCC demands "mutual participation" wherein power and responsibility are shared, there is an open exchange of knowledge and where both the doctor and the patient reflect on their affects and how they mutually influence each-other (Mead & Bower 2000). Together these aspects should result in an individualized care plan for each patient.

Many people with ADHD and bipolar disorder stressed the importance of a good relationship between the health professional and the patient. Especially a connection with the health professional was often mentioned to be of major importance for reaching a conducive therapeutic environment and therapeutic alliance. In our study, several patients described this connection as feeling comfortable with and having trust in the healthcare professional, not only in his or her knowledge and skills but also in the willingness to listen without judgments.

You only tell someone like that your deepest secrets if [you trust them] (...) there should be the right sort of feeling, it's to do with your relationship, otherwise you wouldn't do that easily. (Male, 25, bipolar disorder)

Interpersonal skills, such as empathy or allowing time for self-disclosure or small talk were also seen as important attributes for a personal connection and therapeutic alliance by some patients:

At a certain moment, I reached the point with the psychiatrist that he was talking about his vacation and his sailboat (...) and the atmosphere was so relaxed that I told him things I probably didn't even want to tell him, but because the relationship was so good I talked a lot about myself. (Male, 25, bipolar disorder)

For other patients, an important attribute to reach this connection was the ability to share decision-making power and responsibility, including diagnostics. These participants felt they were mostly on the receiving end of the process where professionals distributed labels. Rather, they would like to see the diagnostic process to be a joint venture:

I am one of those people who for 10 years had to convince people I have ADHD but to them I was a hyperactive woman with returning depressions because of my hyperactivity ... only later the diagnosis [ADHD] was given. (Female, 47, ADHD)

Despite the fact that certain behaviours or skills can help to create a personal relation; this connection, may also be based on personal preferences, some sort of 'click':

There is also something as having a 'click' with a doctor, and I think I have been really lucky for having that with my psychiatrist. (Female, 34, ADHD)

Thus, according to patients, a good relationship can be influenced by the behaviors and skills of health professionals, but also depends on personal preferences and a click.

Healthcare organization

The organizational structure and culture sets boundaries to the interaction, treatment options, and overall *patient-centeredness*. As Saha et al. (2008, p2) argue: "there is a great deal more to fix in the healthcare system than the interaction style of its practitioners". They argue that the healthcare organization needs: (1) to have a committed and engaged board, (2) to empower health professionals to respond to patients' needs, and (3) to facilitate health professionals to 'bend' the rules, if necessary, to deliver tailor-made care (Hobbs 2009; Morgan & Yoder 2012; Pelzang 2010). Patient-centred healthcare organization should deliver coordinated and integrated care, continuous care and accessible care (Kitson et al. 2013; Lusk & Fater 2013; Pelzang 2010; Scholl et al. 2014). Coordination and integration, refers to

the collaboration within teams and between specialisms or different types of services, so that care for patients flows smoothly and is not fragmented (Hobbs 2009; Pelzang 2010; Scholl et al., 2014). Fragmentation of care creates discontinuity and prevents healthcare professionals from gaining full understanding of the patient's illness or following his or her progress (Morgan & Yoder 2012; Pelzang 2010). According to Scholl et al. (2014), integrated care also entails the integration of medical and non-medical care, such as alternative care or spiritual care and support services.

When reflecting on the organizational level of mental healthcare, patients mainly addressed the importance of a well-coordinated healthcare where different aspects of care are integrated to reach an individualized treatment plan. First, many patients put forward that a healthcare organization needs to be equipped to deal with the fluctuating course of mental disorders. For example, several participants with ADHD explained that sometimes they were off treatment for a period of time. When they started to experience impairment again, or changes occurred that affected their functioning, they desired supervision by a therapist. However, most institutes have long waiting lists and, after some time, treat returning patients as new patients for financial reasons. This means the whole treatment process has to start all over again.

Say I stopped with my medications and I want to come back, I have to reapply, I have to wait for a couple of weeks and I get a whole new therapist (...) isn't that weird? I find it hardly accessible and that I find a real pity. (Female, 50, ADHD)

The fluctuating course of bipolar disorder requires healthcare that is accessible at any time, as illustrated in the following quote:

Yeah, the accessibility is very problematic, especially outside of office hours, you know, the disease also doesn't keep to a nine to five schedule. But the system is not designed for that. (Female, 34, bipolar disorder)

Second, most patients stressed that good collaboration within and between disciplines is important. In particular, many participants pointed at the beneficial aspects of alternative therapies. Even though these therapies may not have been proven effective as treatment for their disorder, these participants themselves experienced the positive effects of these therapies. They desired the integration of alternative therapies, or certain parts thereof, in their own treatment plan:

Listen, if the therapies aren't compatible I can understand [that it's difficult], but I don't see why an alternative therapist can't call a normal therapist so that they can talk about it. (Female, 34, bipolar disorder)

A third element that was regularly mentioned by patients is the continuity of care between various sectors in the healthcare system. For example, the time between a referral by a GP and the first meeting with a psychiatrist in specialist care should be short and referral between professionals from different disciplines, for example from a psychologist to a psychiatrist, should be smooth. However, many participants report that the time between seeking help and getting adequate care can be substantial, often referred to as 'a long quest', which may lead to dangerous situations.

But the GPs also don't have a guideline how to treat someone with bipolar disorder, they rather refer you to someone else. But then you end up on a waiting list for a couple of months before you can have your first conversation with a psychiatrist. (Female, 51, bipolar disorder)

Some participants criticized that their professionals for financial reasons did not refer them to a specialist better equipped to address (parts of) their problems:

They should not be focused on running their own business, you know, I find it terrible when a psychologist or a psychiatrist treats you they just want to keep you, because you are a golden goose and they are not prepared to refer you to someone who is better for you. (Female, 33, ADHD)

In short, according to patients, a healthcare organization should provide the possibility for cooperation with therapist/coaches within and outside the system, to act and react to the fluctuating needs of patients. This entails better accessibility outside office-hours and ensures continuity of care, even after having left the system for while.

8.4 Discussion and conclusion

Based on a literature review, all elements of PCC as described were integrated in one model of PCC. In addition, the perspectives of people with ADHD and people with bipolar disorder on what constitutes 'good care' were investigated. Next we analysed to what extent their stories on 'good care' align to

current conceptualizations of PCC. The core elements most elaborated upon in the reviews relate to the interaction between patients and health professionals, and the role of the health professional and the skills the health professional needs to deliver PCC, which primarily entails treating patients as unique individuals with their own experiences. Other scholars extend this discourse and argue that organizations play an important role as well, by either hampering or facilitating PCC.

Listening to the stories of patients provided no new core dimensions, but they helped in (1) understanding what the dimensions entail for people with ADHD and bipolar disorder, and (2) to verify and refine these dimensions. First, where in literature listening is described as an important aspect of a caring attitude of a health professional, our results add the importance of listening *without judgment*. Sometimes patients feel ashamed of their own behaviour, more often they have experiences of not being accepted because of it. A second refinement, is the acknowledgement of a *personal connection* with the health professional, in addition to the conceptualization of the patient-professional relationship as described in literature. This is of great importance as personal and sensitive experiences and feelings are topics of conversation. A third refinement, in relation to the organization, is that the need for flexibility is stressed, to be able *to act and react on the fluctuating course of the disorders* and the *changing needs of patients*. Patients ask for improvements in the accessibility of services, by extending office hours and easier re-admission into mental health clinic facilities when necessary. Fourth, the current conceptualization refers to 'patient-as-person': patients stress the importance of seeing the patient as a person with *positive sides and strengths*, and not merely as a person with deficits. Finally, patients indicate that, next to the health professional's expertise, they highly value the *experiential knowledge* of other patients. After all, patients gain knowledge about their disorder, and even though each person's trajectory is unique, patients feel that these individual stories on how to cope with the disorder are helpful.

Comparison of the perspectives of people with ADHD and people with bipolar disorder with other studies on patients' perspectives on care, shows many similarities. The wish to be listened to non-judgmentally and attention for situational support needs is also described in a study of Billsborough et al. (2014) on support needs during periods of mania and depression for people with bipolar disorder. The desire of adults with ADHD for more accessible and continuous care, which includes treatments not typically offered for ADHD, have also been described in the UK in a study on patients' experiences of impairment, service provision and clinical management (Matheson et al., 2013). The importance, as well as the potential problems, of a health professional acting professionally and demonstrating empathy as

a person is also described by Eliacin, Salyers, Kukla, and Matthias (2015) on the patients' understanding of shared decision making in mental health setting and Williams et al. (1999) on the user perspectives on person-centeredness in social psychiatry.

Addressing the patient as 'knowledgeable' or as an expert is mentioned by some scholars in the context of PCC (e.g. Corring & Cook 1999; Eliacin et al. 2015; Kitson et al. 2013; Leplege et al. 2007; Lusk & Fater 2013), but is more extensively and explicitly evident in the area of patient participation in healthcare and health research (Caron-Flinterman, Broerse, & Bunders 2005; Entwistle, Renfrew, Yearley, Forrester, & Lamont 1998; Epstein et al. 2010). Acknowledging these other discourses on patients' experiential knowledge within the PCC discourse could strengthen the epistemic position of patients in medical practice and challenge the dominant biomedical approach.

Few studies pay attention to the system in which healthcare professionals have to act. To move beyond the incidental patient-centred interaction between health professional and patient, we suggest that 'patient-centeredness' be perceived as a characteristic of a health system, which is responsive and adaptive to the needs of patients – a health system in which (organizational) structures and cultures are conducive to patient-centred practices. Such a health system “adapt(s) to the often unexpected and context-dependent requirements” (Epstein et al. 2010, p. 1492). This requires a move from the intentions of (groups of) individuals to structural change around patient-centred care. Combining the present PCC discourse with a multilevel perspective (e.g. Essink 2012; Shields 2013) and that of complex adaptive systems (e.g. Minas 2014) could enrich endeavours to understand and scale-up patient-centred care. Such a process would add attention to system-wide cultures and structures to the current narrow focus on patient-centred practices (encompassing primarily patients and health professionals in their interaction).

Strengths and limitations

This study has several strengths. First, it increases our understanding of the conceptualization of PCC from a patient's perspective in the field of mental health (outpatient psychiatric services) and contributes to reducing the gap in literature about this topic. Second, a systematic review was conducted using recent literature about the conceptualization of PCC – providing the most current and relevant insights into the topic. A third strength is that we included perspectives of people with ADHD and people with bipolar disorder on healthcare.

A limitation of our study is that we focused on the conceptualization of PCC in mental health, using two psychiatric disorders as exemplary. However, although there were many similarities in the accounts of both patient groups on what constitutes 'good care' further research into the extent to which the identified refinements are applicable to other psychiatric disorders and somatic diseases is warranted. Furthermore, our analysis could be enriched by including and integrating theories and approaches of closely related developments in mental health, like recovery-oriented care, collaborative care, and service-user participation.

In sum, this innovative study shows that what is considered 'good care' by patients with ADHD and bipolar disorder resonates with key dimensions of PCC as found in literature. Furthermore, the study demonstrates the value of patients' perspectives in the refinement of, and preferred emphasis in, the conceptualization of PCC.

Chapter 9: Discussion and conclusion

The research presented in this thesis is conducted in a field of substantial debate and controversy. As outlined in the introduction, adult ADHD is a complex problem that reflects scientific and societal changes and is increasingly the subject of public scepticism. Over the past 50 years, the biomedical perspective on ADHD has been increasingly dominant while a limited number of social scientists have focused on the history of ADHD and how it has become one of the most common psychiatric disorders in modern society. The social sciences, but also some psychiatrists have taken an increasingly critical perspective on ADHD and its treatment. In the meantime, the voices of adults living with ADHD and health professionals working with ADHD patients have been relatively silent. The aim of this thesis is therefore:

To provide insights into the perspectives of patients and health professionals on adult ADHD and ADHD care in order to contribute to continuous efforts to increase the quality of care and the well-being of people with ADHD.

In this chapter, I first provide an overview of the perspectives of patients and health professionals, identifying differences and similarities. Second, I discuss how these perspectives relate to the current debate surrounding ADHD. I then elaborate on the key lessons of this study for clinical practice and person-centred care. After having discussed the strengths and weaknesses of this study, I close by outlining future paths of research.

9.1 Perspectives of adults with ADHD and health professionals

The first two research questions of this thesis address the perspectives and needs of adults on daily life with ADHD and adult ADHD care, and the perspectives of health professionals who work with adult ADHD patients. In this section, I summarize and discuss the findings in relation to these two research questions. In addition, I discuss the similarities and differences in the stories of patients and health professionals.

Perspectives of adults with ADHD

In the focus group discussions, a number of topics emerged that are important to adults with ADHD in relation to daily life (chapter 4). First of all, many participants experience the characteristic inattentive and hyperactive-impulsive symptoms of ADHD as problematic. They explained that they feel powerless in controlling their thoughts and emotions resulting in a range of individual problems: the inability to perform simple every-day tasks, finish what they started or maintain attention on tedious tasks. For some participants, this was combined with the seemingly contradictory ability to perform highly complex tasks that demand sustained attention. These life problems that stem from the core ADHD symptoms are well documented (Young, Bramham et al. 2008, Brod, Pohlman et al. 2012, Matheson, Asherson et al. 2013); the seeming contradiction between the inability to perform 'easy tasks' and being very successful in others was also a strong theme in the narratives explored by Fleischmann and Fleischmann (2012). A second pronounced theme in the focus groups was the suffering that results from the interaction of ADHD-related problems with the social world. The majority of participants experienced a lack of understanding from the people around them, including employers, colleagues, friends and family, which resulted in feelings of rejection and alienation. These social consequences of the symptoms are also well documented by other studies (Young, Bramham et al. 2008, Fleischmann and Fleischmann 2012, Fleischmann and Miller 2013). However, our results progress this understanding by describing the mutually amplifying effect between the ADHD symptoms and feelings of being rejected by society, feeling alienated from society and feelings of low self-worth. In line with Fleischmann and Fleischmann (2012) many study participants stressed that their ADHD also made them unique individuals with unique problems, deficits and especially competences, the latter, to their frustration, hardly receiving attention. To the best of our knowledge, our results are the first to report on the future needs and desires of adults with ADHD. In the future, they would like to see more general acceptance of ADHD and its accompanying problems, both by their direct social environment and by society in general. Some explained that the way forward is to acquire self-knowledge and match individual strengths, competences and deficits with the right environment. Adults with ADHD in our focus groups want to be accepted and appreciated as valuable individuals with personal competences and strengths, despite the presence of deficits associated with ADHD.

The perspectives of adults with ADHD on healthcare, described in chapter 5, started with the problems with the diagnostic process. For many, obtaining an ADHD diagnosis was a frustrating, long process. Many had previously received care for burnout and depression complaints which had delayed the diagnosis and treatment of ADHD for years; for some it meant they had to push health professionals to

seriously consider an ADHD diagnosis. Some of our participants experienced misdiagnosis and often related this to a lack of attention for individual circumstances, contexts and the inherently individual nature of ADHD. Also in literature, problems in early detection of ADHD are commonly described, especially the interaction of adults with ADHD with their GPs is described as problematic in countries where the GP is the gatekeeper of care (Matheson, Asherson et al. 2013, Hannås 2015, Hansson Hallerod, Anckarsater et al. 2015).

Regarding care, all participants recognized the positive effects of ADHD care on increasing their functioning and well-being; but many also mentioned the limitations of stimulants and the importance of psychosocial therapy. This is in line with studies of (Young, Bramham et al. 2008, Matheson, Asherson et al. 2013, Hansson Hallerod, Anckarsater et al. 2015). However, the results of our study provide a further understanding of their healthcare experiences and needs on the following topics. Oftentimes, participants stated that care aimed to directly address the symptoms of ADHD, such as strict planning to provide structure in daily life instead of the problems they experience. Some participants criticized the lack of positive approaches to exploit personal strengths to cope with ADHD while others contended that the effects of ADHD on daily life are individual and contextual and, therefore, care should take that explicitly into account. In other words, many patients complained that care is too disease-centred and desired more individual healthcare provision. This is also the case for pharmacotherapy with some participants experiencing it as very positive while others preferred to try other treatments first, such as psychosocial therapies.

Clients of a private coaching centre appreciated exactly this, namely the centre's person-centred and strength-based approach (chapter 6). In contrast to public mental healthcare where ADHD is typically treated, the coaching centre has no contracts with health insurance companies so the clients have to finance treatment themselves. Participants explained that their coach formed a personal relationship with them and tried to find personal strengths and resources to address or circumvent their problems. Moreover, clients felt they could discuss topics that were of prime importance to *them* rather than a predefined set of topics.

In conclusion, the problems of adults with ADHD go beyond symptoms alone. Participants repeatedly stressed that an individual is more than just a collection of ADHD symptoms and has, instead, unique combinations of competences and problems with their own personal situation. Care, therefore, should not only address the symptoms of ADHD but also have regard for the individual within his or her situation. A wider application of strength-based approaches might be an important resource to help

adults with ADHD increase their level of functioning within society because such an approach treats every individual as unique with a unique combination of strengths, competences and weaknesses. From the stories of patients, it can be concluded that adult ADHD care could be more person-centred, taking the individual, contextual nature of adult ADHD more into account with a stronger focus on positive, strength-based interventions.

Perspectives of health professionals

As described in chapter 7, the interviewed health professionals generally stressed that adult ADHD is a 'real' disorder that can cause substantial problems in the lives of adults. Many pointed to the clear neurobiological and genetic underpinnings of the disorder to corroborate this position. In response to criticisms challenging the validity of adult ADHD and its treatment, they explained that ADHD is a valid diagnosis, that there is adequate treatment, and that early diagnosis and treatment is important to relieve the suffering of their patients.

All respondents emphasized that the diagnostic process for adult ADHD is a complex endeavour that demands critical reflection as ADHD can be obscured by various factors. First, the diagnostic criteria show overlap with other disorders, such as bipolar disorder or borderline personality disorder. Second, adults with ADHD generally have comorbid disorders, including bipolar disorder and borderline personality disorder. The combination of symptomatic overlap and high comorbidity makes it hard to separate ADHD from other disorders classified in the DSM. Furthermore, the symptoms of ADHD can be overshadowed by social problems, such as marital issues or stress at work, repeated depressions and burnout complaints. Even more problematic, societal changes, which place increasing demands on individuals to perform successfully, can also cause some people to start experiencing problems that might appear to resemble ADHD. Therefore, health professionals are wary of people who might desire the diagnosis of ADHD to pursue secondary gains, such as access to stimulants. In order to diagnose ADHD, health professionals have to disentangle the complex problems presented by their patients to establish retrospectively whether ADHD is the underlying cause of their problems. To tackle this problem, individual judgment and clinical experience were explained to be essential, giving a 'feel' of what ADHD looks like in practice.

Most clinical participants contended that pharmacotherapy is the most important strategy to address the symptoms of ADHD but there are different opinions on how medications should be used and on the use of psychosocial therapies. While some health professionals favoured the situational use of

medications to support patients during certain times and activities, others contended that patients should take their medications consistently. Most health professionals regarded pharmacotherapy as the most effective and, therefore, first-line treatment. For them, psychosocial therapy was an addition to address problems that pharmacotherapy cannot address. For some, behavioural change through psychosocial therapies was the prime goal, even though they acknowledged that pharmacotherapy can be of substantial support to achieve that.

For both diagnosis and treatment, the current clinical tools were generally found to be of limited help for clinical practice. For the diagnosis, the criteria were considered 'vague'. For example, most symptoms contain the word *often* ('often loses things', 'often forgets things') but what that means in practice is not specified. Clinical tools are also of limited help to establish whether ADHD is *the* cause of the problems which has substantial impact on the treatment choice. For treatment, the guidelines do not provide support on how to make treatment appropriate to the lives of patients. This places an extra emphasis on the importance of clinical experience. The ambiguity experienced by health professionals has been reported for children by Rafalovich (2005); to the best of our knowledge, the study presented in chapter 7 is currently the only one to explore the perspectives of health professionals for adults with ADHD.

Comparing the perspectives of adults with ADHD and health professionals

The perspectives of patients and health professionals show many similarities. Patients and health professionals generally stressed that ADHD is a valid disorder that can cause substantial suffering. They also acknowledged that it is highly intertwined with the personal situation and that impairment can change after certain life events, such as having children. Even though opinions of patients and health professionals varied on how to use stimulants, both acknowledged their effectiveness in addressing the symptoms of ADHD. There were also some differences between the perspectives of patients and health professionals. Patients mainly focused on the role the disorder plays in their daily lives and how it interacts with their social environment. They discussed how difficult it had been to obtain the diagnosis and how, for some, it had been a shock which resulted in a period of grief and a need to re-assess their past life. For most patients, ADHD is more than a set of symptoms; it is part of their personality and is inextricably interlinked with all domains of life, such as friends, family, parenting, work and societal judgment. Care, however, focuses mainly on the symptoms of ADHD with the ideology that symptom reduction results in better health outcomes and social functioning. For patients, however, this is not enough; they would like care to take a more holistic perspective.

Most health professionals considered that the care they provide is usually aligned with the needs and wishes of their patients, but explained that they do not always agree with the desires of their patients. Also, health professionals stressed the importance of disentangling the complex problems of patients to establish whether ADHD can be diagnosed. In other words, they acknowledged that ADHD and the individual situation is intertwined but stressed that the diagnostic process demands them to separate ADHD from the other factors to come to a valid diagnosis. In terms of care, most health professionals emphasized the superiority of stimulants in the treatment of ADHD while patients desired a less strict focus on medications. Accordingly, patients generally preferred a stronger focus on personal strengths and competences, while health professionals gave priority to relief of negative symptoms, generally considering that psychosocial therapy should be used to address residual problems, such as low self-image and comorbidities.

From the comparison described above, the tension between health professionals' efforts to take an evidence-based approach and patients' desire for more patient-centred care is apparent. This tension is important for clinical practice and future research in the ADHD field and will, therefore, be more thoroughly addressed in section 9.5. Next, I demonstrate how the perspectives of patients and health professionals relate to the debate surrounding ADHD.

9.2 How do the perspectives of adults with ADHD and health professionals relate to the ADHD debate?

As described in chapter 2, the controversy surrounding ADHD seems to revolve around the question of whether ADHD is 'real' or not. Dominant in this controversy is the biomedical perspective which acknowledges that ADHD is a valid disorder. This is based on a naturalistic definition of ADHD as a genetic and neurobiological disorder that can be objectively distinguished from the healthy population (Spencer, Biederman et al. 2007, Tripp and Wickens 2009, Cortese 2012). Accordingly, since it is a biological disorder, the most effective treatment is pharmacotherapy which targets the biological deficit of the disorder (Kooij, Bejerot et al. 2010). This perspective is supported by biomedical and clinical scientists. The other perspective is the socio-cultural one which takes a normativist stance to ADHD and perceives it predominantly as a societal construct (Conrad and Potter 2000, Timimi and Taylor 2004, Moncrieff and Timimi 2013). Proponents of this perspective stress that ADHD, as a social problem, has arisen because of changing societal demands with respect to the social and economic functioning of

individuals (Dehue 2014), sometimes arguing that the construct is used by the pharmaceutical industry to generate revenue (Conrad 1975, Dehue 2014). From this latter perspective, pharmacological treatment is usually undesirable because the cause of the problem is the changing societal demands. This perspective is taken by some social scientists in their criticism of the dominance of the biomedical model and the increasing use of stimulants. However, these critiques have not yet contributed to solutions at either the individual or societal level. That does not mean that these critiques are invalid but, rather, they do not yet help resolve the controversy that surrounds ADHD.

The research presented in this thesis shows that this long-standing controversy is known by many patients and health professionals, and they regularly reflected on it in the focus groups and interviews. According to the interviewed health professionals, mental disorders are not solid entities that can be discovered by a simple biological test and cannot easily be disconnected from the situation of individual patients and societal changes. Accordingly, in the scientific literature it is increasingly recognized that the biological factors of disorder are only one aspect that should be placed in the larger social context (Coghill, Nigg et al. 2005, Nigg 2012). Even if the biological causes of ADHD can be solidly established, some interviewees stressed, the expression of the disorder and the suffering it causes will still be inextricably linked to the situation and experience of individual patients. The intensifying critiques of whether ADHD exists or not gave many health professionals the feeling that they have to defend the ADHD construct and the importance of their work in helping people who suffer from ADHD. They strongly underscore the 'real suffering' of patients, arguing that adequate diagnosis and treatment provide substantial relief. The relief provided to patients often remains unacknowledged by those arguing that ADHD does not exist. As some commentators argue, even if ADHD is mainly a socio-cultural construct, this does not necessarily invalidate the suffering people experience or invalidate the need for treatment and the relief it can provide. Many health professionals seemed to be worried that if the critical socio-cultural perspective becomes dominant, access to treatment will be reduced even further, either because adults with ADHD become more hesitant to seek treatment or through the implementation of policies that restrict resources available for ADHD care.

For patients, the medical perspective was often soothing as it provides an acceptance and legitimization of their problems, implicitly providing recognition that they are not to blame for their struggles and failures. However, many participants of the focus groups consider that the biological perspective is too deterministic because the need for life-long medications is inherent to the biomedical perspective. For many patients, this is not the case. In reaction to negative public image of ADHD, many desired to be

accepted more positively as valuable individuals with individual strengths, capacities and weaknesses. Accordingly, in response to the deterministic side of the biomedical perspective, participants wanted care to focus more on personal strengths and capacities and how they can be exploited for a better life. In other words, patients, in line with health professionals, encounter problems that relate to the biomedical side of the disorder, as well as the societal side.

The results of this thesis demonstrate that the ADHD controversy is based on a false dilemma in which the biomedical/naturalistic and socio-cultural/normativist perspectives are treated as mutually exclusive. In line with the conclusion of Bowden (2013), we found in our research that adults with ADHD and health professionals integrate medical and societal aspects of ADHD. Adults with ADHD often indicated that they are different from 'normal people' and that the ADHD resides in themselves. The problems they experienced are usually related to interaction with society and social functioning. Bröer and Heerings (2013) also found that adults with ADHD integrate both *social* and *biological* aspects in interpreting their disorder. In addition, many health professionals stressed that the impairment and suffering experienced by adults with ADHD are due to inter-linkages between ADHD and personal situations. Additionally, some health professionals pointed out that increasing demands of society lead more people to experience dysfunction and impairment due to ADHD behaviours, acknowledging that mental disorders such as ADHD are subject to societal changes. However, since the biomedical perspective is dominant, societal aspects are rarely integrated into research that aims to support clinical practice. This results in a gap in contemporary knowledge on ADHD: there is a lack of research on questions that are relevant to the daily lives of adults with ADHD and how to integrate this knowledge in clinical practice.

We conclude that more research is needed that integrates both biomedical and societal aspects and which aims to answer questions relevant to the daily life of adults with ADHD and day-to-day clinical practice. This begs the question of why such a research agenda is not yet in existence, especially since more and more scholars stress the importance of integrating the biological with the social (Singh 2008, Choudhury, Nagel et al. 2009). A possible explanation for the lack of such a research agenda is provided by the theory of boundary work. Boundary work, as coined by Gieryn (1983), describes the struggles of science to demarcate itself from non-science. However, as Albert, Laberge et al. (2009) propose, the same demarcation mechanisms can be described between scientific disciplines. Put simply, scientific disciplines are preoccupied with strengthening disciplinary boundaries in order to safeguard professional autonomy. ADHD currently falls under the authority of the medical discipline and makes

resources available to that profession, including research funds and reimbursements for treatment of ADHD. Interdisciplinary research would require that the biomedical field and the social sciences not only work together but work across disciplinary boundaries. This is not easy because different disciplines work within different paradigms, with different ideas on what constitutes 'good science' and what criteria should be used to evaluate scientific research. Spanning these disciplinary boundaries and opening up to the ideas of the other disciplines that may seem alien or in completion with their own, is therefore difficult. Moreover, scientists who try to engage in 'boundary spanning' by taking a more holistic, integrated perspective run the risk of being criticized by both sides for different reasons, for example using 'unscientific' qualitative methods or not exploring the subject from the right, critical perspective.

9.3 What lessons can be learned for clinical practice and person-centred care for adults with ADHD?

Adults with ADHD highlight three important aspects which should receive greater priority in their ADHD care. First, care should acknowledge the importance of the individual. Participants recognized that there are substantial differences between people with ADHD at the level of the disorder as well as in terms of the expression of impairments in their individual situation. Accordingly, they desired that the binary yes/no diagnosis of ADHD should make way for a more individual diagnosis which also explores how (aspects of) ADHD works for each individual situation and how it relates to individual personality. Treatment could then be attuned to individual diagnosis: for who, when and how is medication effective and what psychosocial therapies are relevant to develop the most effective treatment configuration for individual patients. Alternative therapies were also seen as a valuable addition to treatment in managing specific problems. For this reason, such therapies should become part of public care. Second, consistent with the perspectives discussed in section 9.2, adults with ADHD often expressed the wish for a stronger focus on personal strengths and qualities rather than treatment focused on ADHD deficits. They acknowledged that there are certain things they simply cannot do and recommend an emphasis on personal strengths and competences that can be exploited to circumvent or compensate for deficits, rather than continually trying to do things they cannot master. Finally, many patients saw a more pronounced role for peer-contact in future treatment. They stressed that ADHD patients develop a

practical knowhow over the years of living with ADHD and that they can help each other acquire skills to compensate for ADHD deficits.

These improvements to care align with the concept commonly described as patient-centred care (Mead and Bower 2000, Entwistle and Watt 2013). However, as chapter 8 shows, patient-centred care (PCC) cannot be implemented as a 'one-size-fits-all' strategy to increase the quality of care. Even though the core concepts of PCC resonate with the ideas of patients, the perspectives of patients are needed to further contextualize and enrich the patient-centred care literature. For example, in psychiatry, patients with adult ADHD as well as bipolar disorder wanted stronger acknowledgement of the situational nature of mental disorders and the need for better access to care. Moreover, the importance of the personal relationship with the therapist was stressed, including affinity with the therapist and the therapist's interpersonal skills. This finding points to the inherently social constructivist nature of the concept of PCC, and thus to the need to tailor PCC to the perspectives of a specific patient group.

Most health professionals stressed that patient-centred clinical practice is important and that they already worked 'patient centred', but that it is not possible nor desirable at all times. Implementing the concept of PCC, as interpreted by patients, is in practice constrained by health professionals' commitment to evidence-based medicine (EBM) reflected in contemporary clinical guidelines and reimbursement rules (Diagnose Behandel Combinatie, DBCs). Many health professionals pointed out that they might have to deviate from guidelines and institutional regulations if they are to be more patient centred. In our research, some health professionals said they sometimes did deviate, but most preferred to work according to the evidence-based guidelines. However, EBM cannot automatically be equated with 'good care', at least not according to patients in this study. Here, EBM is criticized for its focus on a relatively narrow set of outcome measures which, in the case of ADHD, only relate to the reduction of symptoms (Goldenberg 2006, Lambert 2006). EBM has demonstrated the superiority of pharmacotherapy in ADHD symptom reduction while psychosocial therapies have only shown limited effect and alternative therapies have either shown no effect or have not yet been researched (Weiss, Safren et al. 2008, Mészáros, Czobor et al. 2009, Knouse and Safren 2013). Adults with ADHD, however, tended to assess the effectiveness of a therapy on a broader set of outcome measures which included a range of indicators related to quality of life, such as being appreciated at work, by friends and family, being able to participate in society and feeling happy about oneself. This is consistent with the general consensus of the PCC literature that care should be aligned with the goals that matter to patients (Rathert, Williams et al. 2015, Richards, Coulter et al. 2015).

When comparing these perspectives, it seems that EBM and PCC are currently at odds with each other. EBM uses clinical epidemiological methods of generalization across populations to establish effectiveness of treatments, compared to no placebo or another available treatment, based on statistical analyses (Paley 2006). The aim of EBM is to find those treatments that are more efficacious, less harmful or less costly when compared to non-treatment (placebo) or existing treatments. According to advocates of PCC, such as Bensing (2000), EBM is inherently disease-centred because it aligns diseases with a statistical superior treatment. PCC, conversely, is centred on the conceptualization of the 'patient as a person' with a unique experience of his or her disease in a unique situation. Health professionals who aim to deliver PCC need to be sensitive to the uniqueness of each patient and of the patient's experiential knowledge. The scientific underpinnings of PCC stem from medical anthropology and the medical humanities where sickness is conceptualized by the overlapping concepts of *disease* and *illness* (Young 1982). Disease refers to the biological or physical aberrations at the basis of sickness, while illness refers to the psychological and social experience of sickness. PCC demands that illness experiences are acknowledged and taken into account by health professionals because it is the illness experience that matters most to patients. Accordingly, methods preferred by advocates of PCC are qualitative and ethnographic as they yield narrative and contextual data. However, PCC is still criticized for its lack of theoretical clarity and empirical grounding. Therefore, care that is both evidence-based and person-centred seems to be contradictory because evidence-based decisions are not person-centred and person-centred decisions are not evidence-based, at least not yet.

Based on the results of the studies presented in this thesis, however, it can be proposed that these contradictions are also based on a false dilemma. One can imagine the situation in which both perspectives on clinical practice are integrated: where research evidence forms the basis of decisions that work best for individual patients and where experiential knowledge is acknowledged and valued as essential to fine-tune treatments in order to achieve maximal benefits for individual patients. In order to achieve this, a new way of producing research evidence is necessary for which I will propose starting points in the final section.

9.4 Research strengths and weaknesses

One strength of this research is its rich data. The primary data sources of the studies, interviews and focus groups, were extensively documented. All conversations and discussions were audiotaped and

transcribed verbatim. All participants and respondents were sent summaries of the conversations and summaries of the conclusions in order to check whether the researchers grasped the messages they conveyed and whether the conclusions drawn from the data resonated with the participants. After the interviews and focus groups, there was time to discuss the process. Participants were asked to reflect on the process, whether there was enough opportunity and the right atmosphere to talk about their experiences, whether they felt understood by the researcher, and whether they were convinced by the neutrality of the researcher and the applicability of the research design.

As the main researcher I have ADHD myself which was a strength and a potential weakness. Being also a patient, I had a good eye for details, was able to quickly understand the participants and have a pre-determined sensitivity to other perspectives than my own. In the focus groups, I disclosed at some point that I also had an ADHD diagnosis. This usually helped participants feel even more at ease. Various participants indicated that they felt better understood by someone who has gone through similar experiences. Some said they found it encouraging: "Someone with ADHD can do PhD research!" In general, it had a positive effect on the atmosphere and openness of participants. The danger of bias – inherent in being a patient-researcher – was primarily addressed by involving multiple researchers throughout the project. All FGDs and interviews were conducted and analysed in tandem with another researcher (not being a patient-researcher). With regard to design, analysis and presentation of the results, there were regular reflections with a group of researchers at the Athena Institute. In addition, findings of the studies were continually compared to the relevant literature in order to analyse and understand similarities and differences.

With regard to the internal validity, it was important to ensure that the full variety of perspectives was explored and that data saturation was reached. For the health professionals, we were able to include participants from a variety of disciplines. For the focus groups, however, even though saturation was reached, some remarks with regard to the diversity have to be made. The use of an advertisement for voluntary participation might have attracted participants with a strong opinion. This might also mean that people with severe and very mild ADHD might not have been reached. We also had a substantial level of no-show in the first series of FGDs. To compensate, we included more participants per focus group in the second series; however, no-show was relatively low and in two focus groups more participants showed up than were originally included. This resulted in focus groups with up to thirteen participants which might have hindered some participants from sharing their ideas. In addition, women participants outnumbered men; this is striking because prevalence studies typically report that men

more often have ADHD. Even though saturation suggests that all perspectives had been voiced, the bias present in our study sample makes it impossible to generalize our findings to the larger population of adults with ADHD in the Netherlands. Future quantitative research is needed to establish the distribution of these perspectives within that population.

The presented studies have all been conducted in the Netherlands and cannot unequivocally be translated to other health systems. The ADHD diagnosis is based on the DSM published by the American Psychiatric Association. Some European countries use the International Classification of Diseases (ICD), 10th edition, from the World Health Organization where it is called Hyperkinetic Disorder (HKD). In the ICD-10, the presence of hyperactive symptoms is needed for an ADHD diagnosis, resulting in lower prevalence since the “attention deficit” subtype is not included (Lee, Schachar et al. 2008); this has been established for children but we are unaware of studies that explore the differences between HKD and ADHD for adults. For health systems where the use of the DSM is standard, findings may be more applicable. For example, the study of Matheson, Asherson et al. (2013) found barriers with regard to healthcare in the UK comparable to this thesis. Future research is needed to relate the findings of our studies to those in other European countries and the USA.

In comparison with other mental disorders, ADHD can be said to have a unique position, particularly due to the efficacy of stimulants in treating the disorder; the effects are relatively large compared to other psychiatric medications and the effect is immediate which is not often the case with, for example, antidepressants (Kooij, Bejerot et al. 2010). Additionally, an increasing number of studies report that students without an ADHD diagnosis benefit from taking stimulants in boosting their grades (Teter, McCabe et al. 2005, Franke, Bonertz et al. 2011, Levinson and McKinney 2013). This latter point makes the ADHD debate unique because it touches upon the sensitive and controversial topics of industry-driven medicalization and human enhancement. Nevertheless, many findings of this research are similar to those of other research on psychological disorders, such as bipolar disorder as shown in chapter 8. Similarities include problems in daily life, such as stigma and societal participation; problems with care, such as slow and difficult diagnosis; lack of knowledge in primary care; difficulties in finding an appropriate treatment; and ideas about ‘good care’. As suggested in chapter 8, these problems may be due to health system factors, leading to similar experiences by patients with differing disorders. Further research should explore these health system factors in order to understand how these experiences of people with mental disorders are related and can be accommodated for.

9.5 Further research

This thesis has shown that adults with ADHD and health professionals face many challenges with regard to the management of ADHD, adult ADHD care and the debate that surrounds ADHD. To contribute to the well-being of adults with ADHD, further research is needed to inform clinical practice and to address the controversy between the biomedical/naturalist and the socio-cultural/normativist perspective. (Garfield and Garfield 2000) stressed that health professionals may have a variety of reasons for not employing guidelines in clinical practice for example as they do not reflect the complexity of the real world. Several health professionals in our research contended that the guidelines have limited practical value in diagnosing adult ADHD; it can be hypothesized that involvement of health professionals in their development could have addressed these shortcomings and could have made the guidelines more valuable for clinical practice. To address this issue, future research is needed on what actually happens in the clinical encounter, how health professionals and patients enact the diagnosis and treatment.

In order to contribute to quality of care, future research should also establish the full variety of health outcomes that are relevant to adults with ADHD. This thesis provides a stepping stone for this research in chapters 4 and 5 and in section 9.4. Nevertheless, further research is needed to corroborate and refine our findings. This evidence can then be used to re-evaluate already existing therapies as well as to consider the potential of new therapies. Psychosocial therapies should, in particular, be re-evaluated because although they show only limited effect on symptom reduction, they are highly valued by patients because they increase their quality of life. Accordingly, future research into medication should explore how pharmacotherapy can be optimized: who benefits most from medications and how those medications can best be aligned with the lives of individual patients in specific situations. More importantly, in addition to questions of efficacy, patient-defined health outcomes can provide an invaluable starting point for evidence-informed PCC for adult ADHD.

It is important that future research takes into account the perspectives of patients and is relevant to the complexity of day-to-day clinical practice. It needs to involve a far greater diversity of patients in order to determine the effectiveness of treatments in diverse populations. Practical clinical trials, as Tunis, Stryer et al. (2003) coin them, should not focus on a strictly defined subgroups of individuals rarely encountered in clinical practice but should include participants from a variety of backgrounds, expressing a variety of symptoms and levels of impairment, and demonstrating comorbidities as this is common for adult ADHD. Moreover, using qualitative methods in design, complementary to the

traditional quantitative and epidemiological methods, can be valuable. Qualitative methods can reveal hidden, unanticipated or unintended effects, both positive and negative, of the treatment under study. In addition, patient goals with regard to treatment often vary over time as we have demonstrated. The use of qualitative methods during clinical trials may provide valuable insights into how patient goals change over time in relation to treatment. If the perspectives of multiple stakeholders are included in research, possible barriers and facilitators for the implementation of new therapies can be established. Using qualitative methods in tandem with epidemiological methods in random control trials (RCTs) may provide insights into these hidden effects but, additionally, may show how treatment goals of patients can change over the duration of treatment. This knowledge can be used in future guidelines to help support treatment decisions for individual patients. In sum, new evidence for existing and new treatments should be based on integrated research methods so that it is better able to establish efficacy for a more diverse set of outcome measures, important to daily life with ADHD and clinical practice, to deliver more evidence-informed PCC.

Research is needed that addresses the public debate surrounding ADHD. For this, it is not only important to involve direct stakeholders but also the wider public. Scientific advances over the last decades have facilitated scientists in their efforts to study the genes and the living brains of individuals and to correlate their findings with a variety of human physical, psychological and behavioural characteristics (Braun 2007). As a result, these characteristics are increasingly reframed in terms of biological processes. Singh and Rose (2009) and Dehue (2014) pointed to the possible dangers of relating ADHD to criminal behaviour which, especially combined with genetic research, could pave the way for preventive pharmacotherapy. Society has become increasingly aware of the increasing demands it puts on children, students and employees, creating a need for a medical explanation of failure by those who experience it as well as a market for industries designed to meet that need (Dehue 2014). Combined with biomedical research which reframes societal problems as biological deficits meriting medical intervention, an environment is being created in which industry-driven medicalization can flourish, fuelling public debate. Excluding the public from decision making with regard to these types of research is likely to further polarize the discussion and runs the risk of pursuing the interests of a small group of people rather than society as a whole (Dehue 2014). An *open dialogue* is needed to question the influence of private industry on scientific research, to discuss the goals and limits of modern society, and to decide what behaviour is considered dysfunctional and when medical intervention is justified. In dialogue with society, the science of ADHD and mental disorders, in general, can become more socially robust, more responsible and be more effective in understanding and managing mental disorder.

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Summary

Attention Deficit Hyperactivity Disorder (ADHD) is a common psychiatric disorder which is characterized by inappropriate levels of attention, hyperactivity and impulsivity. Prior to the year 2000, ADHD was defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a childhood disorder that fully remitted after adolescence. With the publication of DSM-IV-TR in 2000, amendments were made to make the criteria applicable to adults. As a much more recent disorder, adult ADHD not only inherited the same uncertainties and controversies of its childhood counterpart but also has some specific problems of its own. Childhood and adult ADHD are surrounded by substantial public concerns. In particular, the dramatic increase in stimulant prescriptions to treat ADHD has fuelled public scepticism. This, combined with the complications involved in diagnosing ADHD raises doubts whether the many ADHD diagnosis are 'real ADHD'. In the Netherlands, there is increased political pressure to decrease the number of ADHD diagnoses and stimulant prescriptions. Nevertheless, health professionals and ADHD advocates argue that a group of people experiences problems that can be helped by an ADHD diagnosis and treatment. In short, ADHD is a complex medical and societal problem that is surrounded by uncertainty and debate and, as such, it demands exploration from various perspectives.

To date, the field of ADHD research has been dominated by biomedical and clinical scientists. However, the perspectives of health professionals who work with ADHD on a daily basis and, in particular, the perspectives of people diagnosed with and treated for adult ADHD have rarely been explored. In addressing this knowledge gap, this thesis aims to provide insights into the perspectives of patients and health professionals on adult ADHD and ADHD care in order to contribute to continuing efforts to increase the quality of care and the wellbeing of people with ADHD. Exploring the experiential knowledge of patients and health professionals is important for three reasons: (1) it fills a long-standing knowledge gap; (2) it aligns with current health system reforms which involve patients in research and treatment decisions; and, most importantly, (3) this knowledge, in tandem with existing research evidence, can be used to improve quality of care and to question and to fine-tune clinical recommendations, guidelines and practices.

Theoretical background and study questions

In this thesis, ADHD is first described from a biomedical perspective, namely its aetiology and prevalence, diagnostic process and treatment. This is followed by a short philosophical discussion of the

nature and definition of disease and disorder that underlies the sociological accounts of ADHD. In these accounts, ADHD is typically described as a construct of modern societies, which may have biological causes, rather than a pure biological entity. When placed in the current socio-economic and political landscape, the social study of ADHD helps to understand why disorders of hyperactivity and inattention emerge and are increasingly treated with stimulants. Subsequently, the growing interest in patient-centred care is discussed which is a strong trend in health systems reform. These insights are brought together in a transdisciplinary model of evidence-based practice that includes the experiences, perspectives and needs of patients and health professionals on adult ADHD. Two research questions address the gap of knowledge in the micro-systems of the model:

1. What are the perspectives of adults with ADHD towards ADHD and adult ADHD care?
2. What are the perspectives of health professionals towards ADHD and adult ADHD care?

In order to understand the complex nature of adult ADHD in a wider context, two research questions are formulated that address the higher levels in the model:

3. How do the perspectives of patients and health professionals relate to the broader ADHD debate?
4. What lessons can be learnt in order to contribute to a more person-centred care for adult ADHD?

Methodology

This thesis mainly uses a qualitative, exploratory approach. Qualitative methods are used because they give an in-depth understanding of the experiences, and the meaning of those experiences, of individuals who encounter certain phenomena, such as getting sick and receiving treatment or being a physician who encounters and treats patients.

Addressing the first and third study question we conducted three studies on: (1) the daily life experiences of adults with ADHD; (2) the perspectives of adults with ADHD towards adult ADHD care; and (3) the experiences of adults with ADHD in relation to a strength-based coaching methodology provided by a private coaching centre in the Netherlands. In a fourth study, we addressed the second and third research question by investigating the perspectives of mental health professionals on adult ADHD, its diagnosis and treatment. Finally we addressed the fourth study question by drawing upon the data presented in the first part combined with data from a similar study that explores the perspectives

of people with bipolar disorder, and linking this to recent insights on Patient-Centred Care. Studies 1 and 2 used focus groups and studies 3 and 4 used semi-structured interviews.

Results

In the focus group discussions, a number of topics emerged that are important to adults with ADHD in relation to daily life (chapter 4). First of all, many participants experience the characteristic inattentive and hyperactive-impulsive symptoms of ADHD as problematic. They acknowledged, however, that the real suffering stems from the negative judgments of others rather than the symptoms themselves. Many participants thought they were unable to behave in the way that the social world, i.e. friends, family or work, wants from them which results in problems with their self-image. The majority of participants experienced a lack of understanding from the people around them, including employers, colleagues, friends and family, which resulted in feelings of rejection and alienation and sometimes low self-worth. Importantly, the powerlessness to change behaviour, the negative judgment of others and feelings of low self-worth were explained to be mutually reinforcing.

The perspectives of adults with ADHD on healthcare, described in chapter 5, started with the problems with the diagnostic process. For many, obtaining an ADHD diagnosis was a frustrating, long process. Many had previously received care for burnout and depression complaints which had delayed the diagnosis and treatment of ADHD for years; for some it meant they had to push health professionals to seriously consider an ADHD diagnosis. Regarding care, all participants recognized the positive effects of ADHD care on increasing their functioning and well-being; but many also mentioned the limitations of stimulants and the importance of psychosocial therapy. The strict focus of adult ADHD on stimulant treatment and skill training, i.e. the enforcement of strict planning on daily life, caused participants to perceive care as disease-centred. Many participants stressed that care can be improved by a more person-centred approach aligning care with individual strengths, weaknesses and contexts. Clients of a private coaching centre appreciated the centre's person-centred and strength-based approach (chapter 6).

The problems of adults with ADHD go beyond symptoms alone. Participants repeatedly stressed that an individual is more than just a collection of ADHD symptoms and has, instead, unique combinations of competences and problems with their own personal situation. Care, therefore, should not only address the symptoms of ADHD but also have regard for the individual within his or her situation. A wider application of strength-based approaches might be an important resource to help adults with ADHD

increase their level of functioning within society because such an approach treats every individual as unique with a unique combination of strengths, competences and weaknesses. From the stories of patients, it can be concluded that adult ADHD care could be more person-centred, taking the individual, contextual nature of adult ADHD more into account with a stronger focus on positive, strength-based interventions.

As described in chapter 7, the interviewed health professionals generally stressed that adult ADHD is a 'real' disorder that can cause substantial problems in the lives of adults. Many pointed to the clear neurobiological and genetic underpinnings of the disorder to corroborate this position. In response to criticisms challenging the validity of adult ADHD and its treatment, they explained that ADHD is a valid diagnosis, that there is adequate treatment, and that early diagnosis and treatment is important to relieve the suffering of their patients. All respondents emphasized that the diagnostic process for adult ADHD is a complex endeavour that demands critical reflection as ADHD can be obscured by various factors such as the individual context of patients and the demands posed upon by modern society. For both diagnosis and treatment, the current clinical tools were generally found to be of limited help for clinical practice especially since they do not address the complexity practitioners experience in day-to-day clinical practice.

The perspectives of patients and health professionals show many similarities, although there appears to be a tension between health professionals' efforts to take an evidence-based approach and patients' desire for more patient-centred care is apparent. This tension is important for clinical practice and future research in the ADHD field.

Discussion and conclusion

The research presented in this thesis shows that this long-standing controversy surrounding adult ADHD is known by many patients and health professionals, and they regularly reflected on it in the focus groups and interviews. According to health professionals, mental disorders are not solid entities that can be discovered by a simple biological test and cannot easily be disconnected from the situation of individual patients and societal changes. The results of this thesis demonstrate that the ADHD controversy is based on a false dilemma in which the biomedical/naturalistic and socio-cultural/normativist perspectives are treated as mutually exclusive. We found that adults with ADHD and health professionals integrate medical and societal aspects of, and explanations for, ADHD. This is important since most contemporary clinical research evidence ignores or even rejects social and societal

factors. Since patients and health professionals have to deal with both the biomedical and the societal factors of ADHD, the omission of the latter decreases its usefulness of contemporary research evidence for day-to-day clinical practice. We conclude that research is needed that integrates both biomedical and societal aspects and which aims to answer questions relevant to the daily life of adults with ADHD and day-to-day clinical practice.

Adults with ADHD highlight three important aspects which should receive greater priority in their ADHD care. First, care should acknowledge more the importance of the individual. Second, adults with ADHD often expressed the wish for a stronger focus on personal strengths and qualities rather than treatment focused on ADHD deficits. Finally, many patients saw a more pronounced role for peer-contact in future treatment. These improvements to care align with the concept commonly described as patient-centred care. Most health professionals stressed that patient-centred clinical practice is important and that they already worked 'patient centred', but that it is not possible nor desirable at all times. Implementing the concept of PCC, as interpreted by patients, is in practice constrained by health professionals' commitment to evidence-based medicine (EBM) reflected in contemporary clinical guidelines and reimbursement rules (Diagnose Behandel Combinatie, DBCs). When comparing these perspectives, it seems that EBM and PCC are currently at odds with each other. Based on the results of the studies presented in this thesis, however, it can be proposed that these contradictions are also based on a false dilemma. One can imagine the situation in which both perspectives on clinical practice are integrated: where research evidence forms the basis of decisions that work best for individual patients and where experiential knowledge is acknowledged and valued as essential to fine-tune treatments in order to achieve maximal benefits for individual patients. In order to achieve this, a new way of producing research evidence is necessary.

In terms of internal validity, a strength of this research is its rich data. The primary data sources of the studies, interviews and focus groups, were extensively documented. With regard to the internal validity, it was important to ensure that the full variety of perspectives was explored and that data saturation was reached. As the main researcher, I have ADHD myself which was a strength and a potential weakness (bias). Bias has been addressed by involving other researchers in the design, data collection and analysis, and by regularly reflecting on the findings and interpretation within a larger research team. The presented studies have all been conducted in the Netherlands and cannot unequivocally be translated to other health systems.

This thesis has shown that adults with ADHD and health professionals face many challenges with regard to the management of ADHD, adult ADHD care and the debate that surrounds ADHD. To contribute to the well-being of adults with ADHD, further research is needed to inform clinical practice and to address the controversy between the biomedical/naturalist and the socio-cultural/normativist perspective. Research is needed that addresses the public debate surrounding ADHD. For this, it is not only important to involve direct stakeholders but also the wider public.

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