Categorically Complex

How do we conceptualize and understand the psychiatric classification ADHD?

UMC Utrecht Brain Center

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Hoe conceptualiseren en begrijpen we de psychiatrische classificatie ADHD?

(met een samenvatting in het Nederlands)

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Introduction

General introduction

Psychiatric classifications are terms that refer to clusters of symptoms that are commonly observed together. They were developed with the goal of standardizing mental health care and mental health research, but their impact has come to stretch well beyond that. Classifications shape the way we understand psychological differences between people, both in mental health practice and in society as a whole. People with similar stories are grouped together through classifications. The way in which we understand and communicate about these classifications impacts the way we understand their individual stories. Mental health practice has come to lean on these classifications increasingly, and with this increase, they have also become heatedly debated. In particular developmental disorders, such as Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD), have been at the center of this polarized discussion.

The topic of psychiatric classification and the debate surrounding it is highly complex, and while researching this thesis, it has often felt as if there is a creature hidden beneath the surface, lurking in the depths. We can only sometimes observe some of the tentacles above the surface that affect the lives and development of children, adolescents and young adults. In fact, this metaphor may underestimate the complexity of psychiatric classification, as it suggests that the different tentacles are somehow separate and unrelated. It does not capture the intricacies and interplay that really exists between the 'tentacles'. But in an attempt to delineate the discussion around psychiatric classification, I have divided the major topics into five tentacles. These tentacles will be the building blocks of this introductory chapter and they will be used as a means to contextualize subsequent chapters in this dissertation. The five different tentacles roughly cover:

- Tentacle 1: Are classifications 'real'?
- Tentacle 2: How do we define and understand classifications?
- Tentacle 3: Do classifications explain the causes of problematic behaviors?
- Tentacle 4: How do classifications affect the individuals who receive them?
- Tentacle 5: Are classifications clinically useful?

Attention-Deficit/Hyperactivity Disorder (ADHD) is at the center of this dissertation, so it will also be the focus of this introduction. However, much of what I discuss below can also be applied to other developmental and psychiatric classifications and these will be used as examples where appropriate. This introductory chapter will (1) provide an overview of the terminology chosen in this dissertation, (2) give a brief overview of the history of psychiatric classification in general and ADHD in particular, (3) elaborate on the five tentacles of psychiatric classification and (4) contextualize how the subsequent chapters fit into this overall picture.

Diagnosis, classification or label?

In daily life, the terms 'label', 'classification' and 'diagnosis' are often used interchangeably. Yet, in clinical practice, these terms do not refer to the same aspect of diagnostics. Diagnosis refers to a clinician's analysis of the difficulties experienced by an individual. A diagnosis, in Dutch mental health care, often includes a paragraph or two at the end of a clinical report describing the difficulties experienced and how these may have come about. This diagnosis may meet the criteria of a (psychiatric) classification as defined by the Diagnostic and Statistical Manual (DSM-5) (American Psychiatric Association, 2013). If it does, an individual may be classified as having a particular psychiatric disorder. Such a classification is also referred to as a label in layman's terms.

This dissertation is about psychiatric classifications, not psychiatric diagnoses. Hence, I have attempted to consistently use the term 'classification'. If you do encounter the term 'diagnosis', I refer to the more elaborate analysis of experienced difficulties. You might also (infrequently) encounter the term 'label', which I generally use as a synonym for classification. Many people do not know exactly what psychiatric classifications are, but the term 'label' is widely understood. The word 'label' is therefore not intended to be derogatory in any way. It is simply a synonym of classification that I sometimes use for a general audience.

A brief history: psychiatric classification

The study of mental health and mental illness dates back as far as ancient Greece, where philosophers and scientists such as Socrates and Hippocrates used behavioral observation to develop descriptions of and theories about causality and etiology of mental health problems (Frances, 2013, 2016; Pilgrim, 2007). However, it wasn't until the late 19th century that the precursors of modern psychiatry developed, culminating in the publication of the first Diagnostic and Statistical Manual (DSM) in 1952 (Alarcón, 2009; Pilecki et al., 2011). In both the DSM-I and DSM-II biological, psychological and social factors were supposed to contribute to mental health problems (Engel, 1980; Ghaemi, 2009). The DSM-I and DSM-II took a psychodynamic approach and used descriptions of unspecified neurobiological causality (Sanders, 2011). Mental illnesses were often classified as reactions to environmental events. Treatment focused on uncovering the events that triggered mental illness and providing patients with therapeutic interventions to facilitate processing those events.

Throughout the 1960s and 1970s, much critique of psychiatry was voiced due to the inaccuracy of psychiatric classification and the limited effectiveness of psychiatric treatment (Frances, 2013; Sanders, 2011). In response, a large paradigm shift took place in psychiatry with the publication of the DSM-III in 1980 (Pilecki et al., 2011; Pilgrim, 2007; Smith, 2017). The DSM-III was much more descriptive in nature and applied the medical model: mental illness should be identified and classified based on systematic observation

and description of standardized symptom clusters (Frances, 2013; Sanders, 2011). Clearly defined diagnostic criteria had to be met before a classification could be given. Contrary to popular belief, these symptom clusters were largely based on expert consensus and not on empirical research (Sanders, 2011). This classificatory approach was further implemented in subsequent publications of the DSM-IV and DSM-5 (American Psychiatric Association, 2013). The DSM classifications we know today were therefore developed over the last 40 years, with the intention of standardizing mental health care, improving communication about experienced difficulties and providing guidelines for research on mental health (Frances, 2016).

A brief history: Attention-Deficit / Hyperactivity Disorder

Similar to the evolution of psychiatric classifications as a whole, the classification Attention-Deficit / Hyperactivity Disorder (ADHD) has been through different iterations. Descriptions matching that of current-day ADHD have been found in ancient Greek accounts (Victor et al., 2018), as well as texts generated in the 18th and 19th century. They present accounts of individuals with mental restlessness and the inability to focus (Efron, 2015; London & Landes, 2021; Taylor, 2011). In the 1920s, these descriptions were first categorized under the classification Minimal Brain Damage (MBD). Symptoms were thought to be a result of the Spanish Influenza Pandemic (Efron, 2015; Taylor, 2011). The term MBD persisted until the 1960s, when the classification was called into question due to a lack of evidence for brain damage or brain injury causing the disorder. The term was therefore changed to 'minimal brain dysfunction', suggesting a disturbance in rather than damage to the brain. In 1968, DSM-II included a classification similar to that of ADHD, Hyperkinetic Reaction of Childhood, which aligned with the psychodynamic perspectives of the time. The psychiatric perspective then radically shifted with the publication of the DSM-III in the 1980s (Efron, 2015; Smith, 2017; Taylor, 2011). This is the first iteration of the DSM that included the classification Attention Deficit Disorder (with or without hyperactivity). The inclusion of the classification sparked a focus on the neurobiological and neuropsychological underpinnings of ADHD. In the fourth and fifth editions of the DSM, numerous smaller changes were made to the criteria for ADHD.

To give an ADHD classification, DSM-5 prescribes that five or more symptoms of inattention or five or more symptoms of hyperactivity and impulsivity must persist for a minimum of 6 months. These symptoms need to be inconsistent with the developmental stage of the individual and impact a variety of contexts and activities. Symptoms need to have been present in two or more settings before the age of 12 years and should significantly impact functioning in each of these settings. Moreover, the classification cannot coincide with schizophrenia or other psychotic disorders, and symptoms should not be better explained by other psychiatric or mental disorders (American Psychiatric Association, 2013). The DSM-5 newly includes symptoms descriptions and wording for adult classification.

Moreover, the DSM-5 states that ADHD and ASD can now be classified together and that comorbidities are common with an ADHD classification. ADHD is now also included in the neurodevelopmental disorders chapter, as opposed to the Disruptive Behavior Disorders chapter, as in DSM-IV (Efron, 2015).

The 5 tentacles of psychiatric classification

The next sections will include an outline of the five tentacles of psychiatric classification. Tentacles one, two and three provide an overview of the debate on how we understand classifications in psychiatry and in society. Tentacles four and five take a slightly different approach and focus on the impact and implications of classifications on the individual and on clinical practice.

Tentacle 1: Are classifications real?

The realness of our psychiatric classifications is much debated in psychiatry, and hinges on our understanding of when something is 'real'. At the core of this debate is the question of whether classifications are natural or social kinds (Beebee & Sabbarton-Leary, 2010; Cooper, 2004; Hacking, 2007; Maj, 2018; Zachar, 2000). The natural kind perspective suggests that classifications are representations of naturally existing categories which cut 'nature at its seams' (Beebee & Sabbarton-Leary, 2010; Cooper, 2004; Hacking, 2007; Maj, 2018; Zachar, 2000). This presupposes that distinct (biological) mechanisms underly classifications: classifications are fixed, lie within the individual and researchers simply need to do a better job of discovering what underlies them. The social kind perspective assumes that classifications are societal constructs that we have created and embraced (Boyd, 1991; Kendler et al., 2011). It suggests that we can decide if and when to classify experienced difficulties. Taking a social kind approach allows for more leeway to critically assess the current diagnostic system, but for many people it feels like a denial of the very real problems children and their caregivers face.

Despite these reservations, this thesis operates largely from a social kinds perspective. This perspective aligns best with our current understanding of psychiatric classifications: they are descriptive in nature (further explained in tentacle 2) and we have found little evidence for distinct underlying biological mechanisms (further explained in tentacle 3). It is important to note however that the social kinds approach does not call into question the realness of classifications. If we agree on what classifications mean, then we can also agree to acknowledge that difficulties experienced by bearers of classifications are real and deserve recognition and support.

Despite the social kinds perspective fitting our current understanding of psychiatric classification best, the language that we use to describe classifications largely promotes a natural kinds approach. A logical fallacy has crept into how we communicate about classifications. Classifications are names for clusters of behavior. Yet, in the way we talk

about them, the classification is often said to cause those same behaviors. We use circular reasoning to explain difficulties experienced. Classifications become a 'tangible entity' (a natural kind) causing psychiatric difficulties (Erlandsson et al., 2016; Pérez-Álvarez, 2017). For example, when a child is hyperactive, we classify this behavior as ADHD. ADHD is a name for the symptoms experienced. But we subsequently say that ADHD is the cause of that same hyperactivity. This is an incorrect inference comparable to saying that heat waves cause hot weather. We have made the societal agreement to call five consecutive days of hot weather a heat wave, but it is a complex interplay of weather patterns that causes the increase in temperature, not the heat wave itself.

This circular reasoning has been referred to as reification (Dehue, 2008; Mirowsky & Ross, 1989; Nieweg, 2005). Reification literally means turning a definition into 'a thing' (res = thing, in Latin). Reification therefore refers to our tendency to talk about diagnostic classifications as if they are concrete and tangible causes of problematic behavior. This might seem like an innocent linguistic mistake, but it reinforces the rationale that psychiatric disorders refer to biological mechanisms that cause problematic behaviors. One example of this is Shift Work Sleep Disorder, described by Trudy Dehue, a leading Dutch philosopher who brought increased attention to reification in Dutch psychiatry. Shift Work Sleep Disorder (SWSD), as the name suggests, is a 'disorder' that is common among people who work night shifts. Symptoms may include insomnia, excessive sleepiness, irritability, headaches, lack of energy and difficulty concentrating (Schwartz & Roth, 2006). People who experience these symptoms after working night shifts may be classified as having SWSD. However, concluding that the described symptoms are caused by SWSD (an inference often made after a classification is given), reifies SWSD. People with a classification of SWSD are not tired or sleepy because they have SWSD, they are tired and sleepy because they work through the night.

Signaling circular reasoning and reification in psychiatry challenges the natural kinds approach and the (often implicit) assumption that a single causal mechanism underlies all symptoms associated with a classification. However, it does not challenge the reality of the difficulties experienced by the individual with a classification. Hot temperatures are a reality we experience, even though they are not caused by heat waves. Insomnia, irritability or excessive sleepiness are frustrating but real consequences of working night shifts, even though they are not caused by SWSD. Similarly, hyperactivity is a reality that a child may experience, even though it is not caused by ADHD. Exactly how natural and social kinds approaches to psychiatry affect the broader societal understanding of psychiatric classification, and ADHD specifically, requires further exploration and study.

Tentacle 2: How do we define and understand classifications?

We have established that many gradual (and occasionally radical) adaptations have been made to our definitions of psychiatric classifications. This changing nature of classifications

leads to continued questions about (1) what do our classifications (and specifically ADHD) mean? (2) why do we decide to group certain behaviors together and define them as psychiatric disorders (3) is it justifiable that we are recognizing and classifying more children who are experiencing difficulties? Or (4) are we problematizing normal (childhood) behaviors and therefore classifying too many children, adolescents and adults? There are no straightforward answers to these questions. They are open to debate and should be discussed with the interests of all stakeholders in mind, and preferably all stakeholders involved in the debate. In this section, we will explore some of our current knowledge on how to define and understand classifications.

First, we need to establish that psychiatric classifications are, by definition, purely descriptive. They are names that we give to clusters of behaviors or symptoms commonly observed together (American Psychiatric Association, 2013; World Health Organization, 2004). We are the ones who make the decisions about how to categorize symptoms and define our classifications. For example, if a child shows inattentive, impulsive or hyperactive behavior and experiences significant impairment, we have decided that the classification ADHD can be applied. Similarly, if a child shows social and communicative impairment combined with rigid and inflexible behaviours, we have decided that the classification ASD can be applied. The preface of the DSM-5 includes the following statement, explicating that classifications do not inform us on etiology, pathology or causality of classifications: the DSM is descriptive and a-theoretical (Tsou, 2015).

> *'Since a complete description of the underlying pathological processes is not possible for most mental disorders, it is important to emphasize that the current diagnostic criteria are the best available description of how mental disorders are expressed and can be recognized by trained clinicians.' (DSM-5 preface - American Psychiatric Association, 2013).*

As decisions on how to define psychiatric classifications are made by 'us', there has been much room for debate about and criticism of these chosen definitions. This criticism is often fed by the increase in occurrence of psychiatric classifications since they first came into use (Frances, 2013). For example, a large-scale Dutch study showed a notable increase in self-reported psychiatric disorders from 17% between 2007 and 2009 to 26% between 2019 and 2022 in 18 to 64 year-olds (ten Have et al., 2023). Similarly, ADHD classifications are also said to have increased. These findings have been supported by studies on different samples from for example the United States (Anderson, 2018; Centers for Disease Control and Prevention, 2022; London & Landes, 2021), the UK (McCarthy et al., 2012), Canada (Brault & Lacourse, 2012) Israel (Davidovitch et al., 2017), as well as in the Netherlands (Gezondheidsraad, 2014). Although criticism has been voiced about the various methodologies used in these prevalence studies and we can debate the exact definition of 'prevalence' in ADHD, there seems to be a consensus that 'rates of diagnosis'

have gone up (Polanczyk et al., 2014)

The increased use of psychiatric classification has often been attributed to the adaptations made in their definitions. These adaptations are occurring in both their 'official' DSM descriptions, and in our informal societal understanding of them. Formally, DSM-5 made numerous (highly disputed) adaptations to the criteria. Some examples are adaptations to Major Depressive Disorder, ASD and ADHD: (1) The criteria for Major Depressive Disorder have come to exclude the bereavement criterium. Therefore, individuals who are grieving a loss, may now be classified with major depressive disorder (Pies, 2014). (2) The criteria for Autism Spectrum Disorder (ASD) were also adapted. Individuals who were previously categorized as having Asperger Syndrome are now classified as having ASD (Rosen et al., 2021) (3) Finally, the criteria for age-of-onset in ADHD were also changed. We can now classify ADHD with symptom onset of up to 12 years of age, instead of up to 7 years (Epstein & Loren, 2013). These changes mean that different - and often more - people can be included in these widening psychiatric categories.

The changing nature of classifications is also reflected in our 'informal' understanding of their definitions. A first example is the phenomenon of 'hidden developmental disorders' in women. This phenomenon has been described in both ADHD and ASD classifications (Green et al., 2019; Lai et al., 2017; Quinn & Madhoo, 2014; Waite, 2010). The underlying rationale is that ADHD and ASD may "express themselves differently" in women than in men and are therefore less frequently recognized in women. This phenomenon implies that women may 'have' such disorders without them being detected, and in some cases without causing impairment (because of compensation or camouflaging) (Green et al., 2019; Lai et al., 2017). First of all, it is noteworthy that the statement 'ADHD or autism may express themselves' is problematic in itself, as it reifies these disorders (tentacle 1) and implies a shared etiology (tentacle 3). Furthermore, statements such as these forego the inherently descriptive nature of diagnostic classifications. Since classifications are mere descriptions of behaviors, the conclusion cannot be that disorders express themselves differently. The conclusion should be that we are making a decision to include an increasingly broad set of symptoms into their descriptions. For example, we are now not only classifying hyperactive boys as having ADHD, but are also deciding to categorize 'dreamy girls' the same way (Quinn & Madhoo, 2014; Waite, 2010). Similarly, the ASD-classification is now not just applied to individuals with significant social and communicative impairments, but also to individuals who are socially and communicatively strong, but report increased nervousness, fear of or diminished energy due to social interactions (Green et al., 2019; Lai et al., 2017).

A second example of such unofficial changes is the ongoing discussion around the attribution of positive characteristics to psychiatric classifications. In our informal understanding of ADHD, a commonly described, and even researched, characteristic

is 'creativity' (Hoogman et al., 2020; Ten et al., 2020). This is often considered a positive characteristic associated with ADHD. However, this rationale is complicated. On the one hand, it is commendable and important to stress that individuals with psychiatric classifications have a variety of characteristics, including ones that are positive and advantageous. On the other hand, we can question if it is conducive to both the identity development of individuals, as well as our broader understanding of psychiatry, to include positive characteristics in our (informal or even formal) definitions of psychiatric disorders. Should we really be attributing creativity to ADHD, or should we be underlining that every individual has positive characteristics that exist independently of, or even despite, struggles in other areas of life?

This tentacle has highlighted that our psychiatric classifications are defined by us. How we decide to categorize behaviors and adapt classifications over time impacts how we understand the difficulties experienced by individuals. It is of paramount importance to keep in mind that these changes in definitions do not change anything in the difficulties or challenges experienced by an individual. Moreover, we need to continue to question what behaviors we want define as problematic and classify as psychiatric disorders. Getting the perspectives of different stakeholders on how these definitions are understood is an important next step in better understanding how we can and should conceptualize ADHD in our society.

Tentacle 3: Do classifications explain the causes of problematic behaviors?

As described in the previous section, the DSM makes no claims about etiology or underlying pathological processes. Classifications are descriptive and atheoretical. Yet much of the research in psychiatry, clinical psychology and clinical neuroscience has centered on finding the causal mechanisms underlying psychiatric classifications (Efron, 2015; Frances, 2013, 2016; Salekin et al., 2022). This research can very roughly be subdivided into the biomedical and psychosocial approach. The biomedical approach considers ADHD to have a biological cause, and understands it as a heritable, persistent neurodevelopmental disorder (Anckarsäter, 2010; Frances, 2016; Pilecki et al., 2011; Wilson, 1993). The psychosocial approach understands ADHD as a dynamic outcome of how an individual responds to his or her surroundings (Batstra et al., 2020; Singh, 2002). The pendulum of psychiatric research has swung in both directions since the development of the first DSM, but, in the last two to three decades, has largely been positioned on the side of the biomedical model.

An extensive overview of research on biomedical causes of ADHD is well beyond the scope of this Introduction, as entire dissertations have been devoted to just tiny pieces of this complicated puzzle. Overall, researchers continue to debate whether biological mechanisms underlying psychiatric classifications even exist (Batstra et al., 2014; Meerman et al., 2017; Singh, 2002; Timimi, 2017). An example of one such discussion

is that the neurobiology of children with and without an ADHD classification differs slightly in a number of brain areas, and is therefore taken to hint at a neurobiological origin of the classification (Hoogman, Bralten, et al., 2017; Sowell et al., 2003). However, these differences are found only at the group level and have small effect sizes (Batstra et al., 2017; Dehue et al., 2017; Hoogman, Buitelaar, et al., 2017). The likelihood of finding detectable neurobiological differences at the individual level is therefore near negligible. We cannot say with any certainty that an individual child with a classification of ADHD is neurobiologically different from an individual child without it. Allen Frances (Frances, 2016), chair of the task force overseeing the development of the DSM-IV, summarizes:

> *"Biological findings, however exciting, have never been robust enough to become testworthy, because the within-group variability always drowns out the between-group differences. It appears certain that we will be stuck with descriptive psychiatry far into the distant future".*

Frances' conclusion is further emphasized by the lack of biomarkers to test for any of the psychiatric classifications described in the DSM (Timimi, 2014).

Even though much of the criticism of psychiatry in recent years has been aimed at the biomedical approach, it should be noted that psychosocial approaches have been no more successful in delineating specific and clear causes for ADHD (Azeredo et al., 2018; Kim et al., 2020; Thapar et al., 2012, 2013). One likely explanation is that the causes of the behaviors classified as ADHD are complex and multivariate, and different for every individual. Moreover, with ongoing changes to our definitions of classifications, they are moving targets (Hacking, 2007) and therefore difficult to study reliably. As noted by Frances, the differences between individuals with an ADHD classification tend to drown out any differences that may set apart children with ADHD from those without it. This argument applies to both potential underlying causes, but equally to the symptoms ascribed to classifications. The lack of findings on causality has led to major critiques of the ADHD classification, as it raises the question of why we are grouping these children together within a single diagnostic category. If research continuously points to the conclusion that there are no common causal factors leading to the variety of behaviors within a category, what is the worth of grouping them into such an overarching classification?

This question can in part be answered by taking a different approach. Rather than looking at what classifications mean in a group context, we can also look at the value of classifications at the individual level. Tentacle 4 will further elaborate on this approach, but a relevant consideration to the question above is provided by Werkhoven et al. (2022) in their evaluation of psychiatric classifications.

> *"In society as we know it today, a label conveys a clear message that some characteristics must be accepted as part of who that person is, periodically or permanently" (Werkhoven et al., 2022)*

Werkhoven and colleagues (2022) note that the critique of causality may be fitting in a scientific context, but it tends to overlook the value of classifications for stakeholders in other contexts. Specifically, in an individual's experience, a classification may well serve as an explanation for experienced problems and difficulties, even if classifications do not provide any deeper explanation of scientific causality. Providing insight into clusters of difficulties that commonly occur together in groups of people, can feel like an adequate cause of difficulties for the individual. Classifications have been shown to provide relief in that sense. They lead to more acceptance of experienced difficulties and tend to take blame away from the individuals who do not fit well with society's standards (Klasen, 2000; Thachuk, 2011).

Tentacle 4: How do classifications affect the individuals who receive them?

The exact effect of a classification on the individual is something we know very little about. There have been studies exploring the direct impact of classifications (for example looking at stigma associated with mental health problems), but an overarching evaluation of the impact of classification on the development of the life-span of individuals is complicated. There are few ways to ethically (experimentally) study how having or not having a classification does or does not affect someone in the long run. Much of the data that does exist is based on observation or report, or in the case of stigma, on experimental vignette studies. This tentacle aims to explore some of the impact of classifications that we do know about.

On the one hand, classifications may have numerous positive effects for and on the individual. A classification may lead to better understanding and normalization of problematic behaviors. A possible pathway that has been described in the literature is that classifications stress the absence of personal blame. It may lead to increased understanding for and acceptance of experienced difficulties, which will in turn encourage helpful behavior from others (Angermeyer & Matschinger, 2003). Other studies have shown that individuals with an ADHD classification report feeling more understood and recognized because of it. It reduces the blameworthiness of difficulties (Klasen, 2000; Thachuk, 2011). Moreover, as mentioned previously, classifications have been shown to provide relief and lead to more acceptance by individuals of the difficulties they experience and their perceived inability to adhere to society's standards (Werkhoven et al., 2022).

On the other hand, numerous disadvantages have also been described. Classifications may decontextualize the difficulties experienced. A classification is applied to the individual: it is the child who has ADHD, not the environment, school, or family system. This implies that problems lie with or within the child and may leave little space for exploring the context in which problematic behavior occurs (Freedman, 2016; Meerman et al., 2017; Singh, 2002; Timimi, 2017; van Hulst et al., 2021). This decontextualization is exemplified by the relative birth-month effect (Cuffe, 2020; Holland & Sayal, 2019; Krabbe et al., 2014;

Whitely et al., 2019): younger children, with their birthday later in the school year, are diagnosed with ADHD more often, and receive ADHD medication more frequently, than their older classmates. This effect has been reported in countries all over the world and is independent of the month in which the school year starts. Most researchers in the field hypothesize that we tend to overlook the relative age of children when they are in the same class (Cuffe, 2020; Holland & Sayal, 2019; Whitely et al., 2019). Younger children exhibit younger behavior, but instead of recognizing it as such, we classify it as ADHD. Such differences in relative age, and the younger behavior associated with it, may indeed cause difficulties for children in class and the teacher alike. But whether the relative age of a child should determine whether they receive a psychiatric classification is something we should seriously debate.

Classifications may also carry stigma, and as such may be taken to reflect negatively on a classified individual (Corrigan & Watson, 2002; Hinshaw, 2005). Stigma can take on numerous forms, but the literature most commonly describes public stigma and self-stigma (Corrigan & Watson, 2002; Kaushik et al., 2016). Public stigma is stigma directed from the public towards an individual with a psychiatric classification. Self-stigma refers to the internalization of such public stigma. Stigma consists of three components: (1) stereotypes, social knowledge structures learned and shared by members of a group; (2) prejudice, the endorsement of and emotional reaction to negative stereotypes; and (3) discrimination, the behavioral reaction to prejudice (Corrigan & Watson, 2002; Kaushik et al., 2016). For example, the perception that an individual with a psychiatric classification is dangerous (stereotype), can lead to fearfulness (prejudice), which in turn can cause avoidance and social distancing (discrimination) (Angermeyer & Matschinger, 2003; Corrigan & Watson, 2002; Martin et al., 2007).

The presence or absence of stigma may impact individuals carrying a classification in decisions on whether or not to share their classification with others (Fowler & O'Connor, 2021; Huws & Jones, 2008). If the environment endorses largely negative perceptions of classifications, sharing may lead to negative impact on how they are perceived and how others behave towards them. However, if perceptions are more positive, sharing may have the opposite effect. Yet, studies on the impact of classifications on stigma show mixed results (Benson et al., 2015; dosReis et al., 2010; Kinnear et al., 2016; Lebowitz, 2016; Selman et al., 2018). Some studies suggest that classifications place individuals and behaviors in increased negative light, and hence lead to more stigmatization (Angermeyer & Matschinger, 2003; Klasen, 2000; Lebowitz, 2016; Martin et al., 2007; Ohan et al., 2011). Other studies show that it is not the classification that is stigmatized, but the underlying behaviors (Dolphin & Hennessy, 2017; Kaushik et al., 2016; Law et al., 2007; Swaim & Morgan, 2001). These studies suggest that labels may in fact counteract stigmatization by redirecting blame away from the individual (Chambres et al., 2008; Klasen, 2000).

It is clear from the above that classification can have differing effects on individuals. On the one hand, classifications have been described to have many positive effects. On the other, they may lead to the decontextualization of experienced difficulties. Moreover, the conflicting results on stigma mean that it is complicated to provide general advice to classified individuals on whether and how to communicate their classification. It seems likely that classifications can have both benefits and drawbacks, depending on the context, and quite possibly simultaneously.

Tentacle 5: Are classifications clinically useful?

The ultimate goal of mental health care is to provide support, help and appropriate treatment options for people with mental health problems. Classifications were intended to inform clinical practice about what an individual may need or require in terms of help or treatment. These categories were therefore originally developed to be analogous to other medical categories: they were expected to be able to point to specific treatments related to underlying causal mechanisms (Maj, 2018). However, over time expectations have been dialed down to two main avenues of clinical utility: (1) helping to formulate a management plan and (2) providing information about possible outcomes (Jablensky, 2016; Maj, 2018). Moreover, by providing consistent and specific descriptions of experienced problems, classifications have guided and stimulated research practices and research funding (Frances, 2013). They help to standardize communication and make it easier for all involved to discuss problems and treatment options (Frances, 2016). Individually, classifications can validate the difficulties experienced and therefore encourage patients to seek necessary help and support. Classifications can help guide individuals with a classification and their caregivers in searching for information, help, institutions, schools and support networks (Werkhoven et al., 2022).

However, the usefulness of psychiatric classification in clinical practice has also been criticized due to the heterogeneity of symptoms and the low predictive validity of classifications (Maj, 2018; Timimi, 2014, 2015). Common nonspecific factors have often been found to be more predictive of treatment efficacy than factors specific to treatment or to classification. In therapeutic interventions, the therapeutic alliance has been shown to be the best predictor of treatment efficacy, across the board. The bond formed between therapist and patient is a much better predictor of outcome than the type of intervention or content thereof (Baier et al., 2020; Flückiger et al., 2018; Goldsmith et al., 2015; Karver et al., 2018; Timimi, 2014; van Benthem et al., 2020). Similar conclusions have been drawn for many psychopharmacological treatments in psychiatry. The effects of medication can in part be attributed to getting people into the right 'psychological state' as a basis for improvement. Pharmacological substances have effect independent of assigned classification and often do not target those specific biochemical imbalances associated with psychiatric classifications they have often been claimed to target (Moncrieff, 2009; Timimi, 2014, 2015).

Although classifications are limited in providing specific information about what an individual requires in terms of support or help, some suggestions for practical measures do perhaps follow from the criteria for a classification. For example, someone who is inattentive will probably fare better in environments with fewer distracting stimuli. Someone who struggles with implicit social communication, might do better if social cues are communicated explicitly and directly. Classifications can improve awareness of such symptoms and in turn guide practical adaptations (Werkhoven et al., 2022).

In these five tentacles I have attempted to delineate and summarize the debate that is ongoing about psychiatric classifications. Questions revolve around (1) what our classifications entail and if they are 'real', (2) how we choose to define them, (3) if any specific causal mechanisms underlie them, (4) what their impact is on the individual and (5) if they adequately inform clinical practice. Some of these questions have in part been answered by the literature, but many questions remain. Specifically, gaps in knowledge exist about how classifications are communicated about and understood 'in the wild' by all the different stakeholders that utilize them. Moreover, the ambivalence in opinions and findings about the individual consequences and clinical utility of classifications makes it difficult to draw definitive conclusions about how we can better manage our classificatory system. Subsequent chapters of this thesis will therefore aim to provide further answers to these questions.

Outline of the dissertation

The subsequent chapters of this dissertation will focus on the tentacles described above with the aim of better understanding the debate about psychiatric classifications and to answer some of the questions that arise from this debate. Specifically, Chapters 2 and 3 focus on how ADHD is understood by ADHD stakeholders and in psychoeducational materials and how classifications are navigated in these two contexts. Chapter 4 focuses mainly on tentacle 4 and explores how psychiatric classifications affect how a young adult is perceived by the public. And finally, Chapter five fits with tentacle 5 and addresses the clinical utility of reward sensitivity, a trait commonly associated with ADHD, for predicting treatment outcome. The chapters are further summarized below:

Chapter 2

The aim of Chapter 2 is to explore how ADHD stakeholders navigate and make sense of the complexity surrounding an ADHD classification. We analaze stakeholder perspectives from seven focus groups: adults classified with ADHD, adolescents classified with ADHD, parents of children classified with ADHD, clinicians, researchers, teachers, and policy makers. We collect verbatim data of the seven discussions on ADHD and analyze the responses prompted by our questions using thematic analysis.

Chapter 3

The aim of Chapter 3 is to better understand how the classification ADHD is explained and given meaning in psychoeducation. Psychoeducation is an important source of information for shaping parents' and children's understanding of ADHD. Furthermore, it may affect the therapeutic alliance and how we understand psychological differences in society. We analyze 41 written psychoeducational materials from four different countries: the USA, the UK, the Netherlands and Hungary. We use discourse analysis to identify patterns in how the materials construct the discourse on ADHD.

Chapter 4

The aim of Chapter 4 is to study the impact and stigma associated with classifications. We investigate whether knowing about her psychiatric classifications affects people's perception of a personal story told by a young adult woman. Participants watch a brief film of her talking about her social interactions, with or without prior knowledge of her classifications. Participants then answer a series of questions about how they feel about, think about and expect to behave towards her.

Chapter 5

The aim of Chapter 5 is to assess the clinical utility and predictive value of traits associated with ADHD on treatment outcome. In this chapter, we assess whether individual differences in reward sensitivity can be used to predict which children with ADHD will benefit most from a behavioral intervention that includes reinforcement. A 12-week behavioral intervention is offered to 21 children with ADHD and their parents. Reward sensitivity is assessed prior to the intervention using a combination of psychological and physiological measures. ADHD symptoms are assessed pre- and post-treatment, to determine the efficacy of the behavioral intervention.

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Chapter 2

Hidden in plain sight

How individual ADHD stakeholders have conflicting ideas about ADHD but do not address their own ambivalence

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Abstract

Introduction. Psychiatric classifications refer to clusters of behavioral symptoms. We know much about how psychiatric classifications are intended to be used in theory. Yet the scientific study of the practice of classification to date is limited. We aimed to explore how individuals navigate and make sense of the complexity surrounding an ADHD classification. *Methods.* We used thematic analysis to analyse stakeholder perspectives from seven focus groups: adults classified with ADHD, adolescents classified with ADHD, parents of children classified with ADHD, clinicians, researchers, teachers, and policy makers. *Results.* We found seven themes in how stakeholders navigate the classification ADHD. Yet, what stood out was an overarching discursive pattern: individual stakeholders expressed highly ambivalent ideas about ADHD but did not address their own ambivalence. *Conclusion*. We suggest that promoting a social kinds perspective on ADHD may help us navigate the complexity and ambivalence associated with ADHD more competently.

Introduction

Psychiatric classifications, such as ADHD, are names that refer to clusters of behavioral symptoms (American Psychiatric Association, 2013; World Health Organization, 2004). These names matter. A classification is often taken by a person to represent how their story is understood by a therapist. This in turn impacts the therapeutic alliance, a robust mediator of treatment outcome (Baier et al., 2020; Flückiger et al., 2018; Goldsmith et al., 2015; Karver et al., 2018; van Benthem et al., 2020). Moreover, the impact of classifications has come to stretch well beyond the realm of mental healthcare (Corrigan & Watson, 2002; First et al., 2019; Hacking, 2007). Psychiatric classifications indirectly shape the way we understand psychological differences in society.

We know much about how psychiatric classifications are intended to be used in theory. Yet the scientific study of the practice of classification is limited. From a theoretical perspective, we know that classifications were developed to increase reliability, validity and communication in diagnostic practice and research (Angermeyer & Matschinger, 2003; Frances, 2016; Pilecki et al., 2011; Sanders, 2011). In addition, classification aims to provide an indication of prognosis and guide decisions regarding care and treatment allocated to affected individuals, including children with ADHD (Anckarsäter, 2010; Angermeyer & Matschinger, 2003; Frances, 2016; Pilecki et al., 2011; Sanders, 2011). On the other hand, the increase in the prevalence of ADHD-classifications has raised questions on the reliability and validity. This increase has been argued to represent a social and cultural shift in the perception and acceptance of diversity among young people (Frances, 2013; te Meerman et al., 2017; Timimi, 2014; Verhoeff, 2015). Moreover, the word 'disorder' can be taken to suggest that the term ADHD represents a stable and causal 'core deficit' in the functioning of the child, promoting fatalism and inappropriate interventions (te Meerman et al., 2020; Thachuk, 2011; Timimi, 2014; van Hulst et al., 2021).

Empirical studies of the effect of diagnostic classifications show that individuals with an ADHD classification report feeling more understood and recognized because of it. These studies find that classification can reduce the blameworthiness of difficulties (Klasen, 2000; Thachuk, 2011). On the other hand, the negative stigma that is often associated with the classification ADHD (Lebowitz, 2016) influences the development of children in ways that are not yet understood. Concerns are also increasingly being raised about the failure of biomedical research to uncover definitive causes of and cures for DSM-categories (Anckarsäter, 2010; Frances, 2013, 2016).

Despite the extensive theoretical and empirical literature, we know little about how individuals navigate and make sense of the complexity surrounding an ADHD classification. Our previous work shows different conflicts in how ADHD is explained by experts in psychoeducational materials (van Langen et al., 2022), but does not provide information on how this is integrated and understood by ADHD stakeholders in practice.

This integration of information can be linked to the concept of tinkering: the attempt to understand, integrate and negotiate the complexity of available knowledge and technologies to accomplish 'good care' (Mol et al., 2010).

In this study, we aimed to explore the practice of classification, by investigating how a broad set of stakeholders navigated the classification ADHD. The results may be useful in advising stakeholders how to better navigate a classificatory term such as ADHD 'in the wild'. We analysed perspectives on ADHD classification from seven stakeholder groups: adults classified with ADHD, adolescents classified with ADHD, parents of children classified with ADHD, clinicians, researchers, teachers, and policy makers. We collected verbatim data from seven focus group discussions on this topic and analysed the discussion prompted by our questions using thematic analysis. We hypothesized that perspectives on ADHD classification would vary both between stakeholder groups and between participants within a stakeholder group. However, we had no a-priori hypotheses on the nature of these perspectives and aimed to explore a broad range of different perspectives on ADHD classification.

Method

Procedure

In this qualitative study, we assessed how the classification ADHD is used and understood in daily practice. Over the course of 18 months, we organized seven focus groups with the following stakeholders: adults with ADHD, adolescents with ADHD, parents of children with ADHD, clinicians, researchers, teachers, and policy makers. We prompted discussion on the classification ADHD with a standardized set of questions (see Data Collection and Supplementary Material 1). The Medical Ethical Committee of the University Medical Centre Utrecht judged that the overall research project did not require evaluation based on the Medical Research Involving Human Subject Act (WMO) and that it complied with the Netherlands Code of Conduct for Research Integrity. Reporting of the study methods and results was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ; 32).

Participants

We identified seven stakeholder groups, each involved in, or subject to the process of diagnostic labelling. Individuals who self-identified as a member of any of the seven groups were eligible to participate. Four to eight participants were recruited for each group, as recommended in the literature (Kitzinger, 1995; McLafferty, 2004; Rabiee, 2004). Several clinicians unexpectedly brought colleagues to this focus group, so we included a higher number of participants in this group (10). We used a variety of different recruitment methods: we invited stakeholders using online advertising and social media posts (purposive sampling), we invited individuals through our own network (convenience

Table 1: Participant demographics per focus group

	Participants	Number	Female/Male	Average Age	Age Min/Max
1	Adults with ADHD	5	4/1	39,8	23/52
2	Parents	4	4/0	50,0	44/60
3	Clinicians	10	7/3	46,5	28/65
4	Teachers	6	4/2	44,1	27/64
5	Researchers	6	4/2	31,7	26/34
6	Policy Makers	4	3/1	50,5	43/57
7	Adolescents with ADHD	4	2/2	14,5	12/17

sampling) and asked interested participants to recruit within their own networks (snowball sampling). A general description of participants in each group is provided in Table 1.

Data Collection

The first three focus groups (adults with ADHD, parents of children with ADHD and clinicians) were organized in conference rooms of the University Medical Centre Utrecht. Due to COVID-19 restrictions, we held the subsequent focus groups using the video-conference platform WebEx. As recommended in the literature (Kitzinger, 1995), focus groups lasted approximately two hours. They included a 5-10 minute introduction and a 15 minute break. Audio recordings were made of each focus group meeting.

We designed a preliminary list of topics with questions for the focus groups. We discussed this list with colleagues from our broader research project on diagnostic labels. Based on their feedback, we refined the topic list and designed the focus group manual provided in Supplementary Material 1. This manual was used for all focus groups and served as a general guide for discussion.

Two researchers (BvH and MvL) moderated the focus groups. At the start of each session, we introduced the research project and urged participants to ask any lingering questions. All participants then signed for informed consent. We then started the recording and initiated the introduction round. Subsequently we introduced the questions, as stated in the manual. During the focus groups we encouraged stakeholders to talk freely and openly with one another. Participants were specifically instructed to discuss topics they found most relevant and ask each other questions to elucidate their answers. At the end of the session, a short debriefing took place, during which participants had the opportunity to ask questions and reflect on the focus group.

Analysis

A detailed overview of our analysis plan is provided in Supplementary Material 2. We transcribed all focus group recordings verbatim. We imported the transcriptions into NVivo 12 Pro and carried out a thematic analysis. We identified the most important

themes in each of the groups using a bottom-up approach without preconceived ideas or structures of what the data should represent. MvL carried out the first two steps of the coding process, open coding and axial coding for each of the focus groups separately. She visualized the coding schemes in powerpoint presentations and wrote memos on the content of the data. The preliminary thematic structure of the data was discussed and explored during in-depth discussions.

In preparation of the third step of selective coding, MvL relistened and reread each individual focus group and studied all coding schemes, memos, and notes. Subsequently, MvL and BvH integrated data and patterns across focus groups. An overarching coding scheme was constructed, and the themes were further defined, named and described in Nvivo to support analyses and find relevant text excerpts.

Results

We found a total of seven different themes in our focus group discussions. Four themes were present in most or all focus groups and three themes were specific to a (subset of) focus group(s). In addition, we found one discursive pattern that we will describe first, as it was present across the first four themes.

Discursive pattern

Dormant ambivalence

We hypothesized that perspectives on ADHD classification would vary both between stakeholder groups and between participants in a particular stakeholder group. Unexpectedly, we identified a different pattern. We found that participants would endorse differing perspectives, even if these perspectives conflicted. So rather than choosing a 'side' in a particular debate, participants would agree with all 'sides' within a debate at different points during the conversation. Consequently, a single stakeholder would make conflicting statements in the course of a focus group. Interestingly, participants seemed to be largely unaware of this conflict. We call this phenomenon 'dormant ambivalence'. Participants appeared to agree with opposing perspectives but did not actively address the opposition or ambivalence during the conversation. The data are lacking in statements such as 'on the one hand (….), but on the other hand (….). Instead, multiple realities appeared to exist simultaneously for participants, without participants discussing the extant contradictions.

Themes present in all or most focus groups

ADHD says both nothing and a lot about a person

We started each of the focus groups with the following question: "What does having ADHD say about a person?". A straightforward answer would have been to strictly follow the DSM-criteria and name the associated symptoms of hyperactivity, inattention and

impulsivity. Yet, this was not the response we got. One of the first responses we received across all groups was a variation on the statement: "Having ADHD says nothing about a person". Noticeably, this answer did not correspond with the data from the rest of the conversations. After participants noted that having ADHD meant nothing, they would often list a multitude of things having ADHD does say about a person. Occasionally, DSM-criteria were mentioned, but other responses included: (1) having ADHD suggests that someone experiences difficulties or problems, (2) having ADHD suggests that a person deviates from the norm, (3) having ADHD suggests that a person needs additional help and support, (4) having ADHD means that someone has visited a clinician and received psychological assessment, and (5) having ADHD indicates that someone has altered brain structure or functioning.

Table 2. ADHD says both nothing and a lot about a person

Quote Focus group 1: Adults with ADHD
While introducing herself, one participant mentioned how important her ADHD diagnosis was to her, that a lot had fallen into place when she was classified and that it had given her a much better understanding of herself. When asked what having ADHD said about a person, she said 'nothing' and questioned what having ADHD said about her.

Participant 1.2	"A *lot fell into place for me and I thought, ah, now I understand a lot of things*"
	(…)
Moderator	"*What does having ADHD say about a person?*"
	(…)
Participant 1.2	"*Well, my first inkling is [to say] nothing. It actually says nothing. If I look at our society, and that is something I struggle with personally, we always need [to get] a classification first, [ascribe] a label or a box, before someone can get the right help. Because then I wonder, but what does it actually say about me?"*

Quote Focus group 3: Clinicians
One participant first stated that she could not say what ADHD says about a person, because it does not say anything. Yet subsequently, she noted that we diagnose ADHD when people get stuck and that the classification ADHD informs us on brain-functioning, citing the ADHD-brain.

Participant 3.0	"*So yes, what does it say about a person? I cannot answer that question at all, [it] says absolutely nothing.*"
	(…)
Participant 3.0	"*But we have agreed to diagnose ADHD if someone gets stuck in multiple areas [of life], but you can still have an ADHD-brain. At least that is what I would call it, having an ADHD brain.*"

Quote Focus group 2: Parents of children with ADHD
Similarly, one participant in this group said, within a single sentence, that ADHD means nothing and yet it also means that someone has certain characteristics.

Participant 2.2	*"Well technically [ADHD means] nothing, no. Certain characteristics, that a label has been attached to."*

The impact of the classification ADHD is both positive and negative

Throughout the focus groups, participants extensively discussed the advantages and disadvantages of having an ADHD classification. Positive aspects mentioned included: (1) it takes away blame from an individual child and stimulates the acceptance of diversity, (2) it provides clarity, (3) it explains why children behave the way they do and (4) it opens doors to support and treatment. In the same vein, participants discussed negative aspects of having an ADHD classification. Many of the disadvantages mentioned were direct contradictions to the advantages mentioned. These included: (1) having a classification might lead to stigma and stimulate focus on negative characteristics of a child. As such, it may lead to less acceptance of individual variation and lays blame with that individual. (2) The classification does not indicate what an individual needs and might be taken to suggest that all individuals with the classification require the same approach and treatment. (3) The diagnosis (participants usually referred to ADHD as a diagnosis rather than a classification) is vague, unclear, and unspecific. Every individual with a classification is different and knowing his or her classification does not help to understand an individual child.

Table 3: The impact of the classification ADHD is both positive and negative

Quote Focus group 1: Adults with ADHD

This participant resented the classification ADHD, because of the number of value-judgements she felt are attached to it. She felt the classification does not do her justice. Yet in a subsequent remark, she stated that if only she had known about having ADHD sooner, her life would have been a lot easier.

Participant 1.3	"*I think the term ADHD is horrible. I feel like it [the term ADHD] is totally wrong, because there are so many value judgements attached to it: [in a disparaging voice] 'you are a little hyperactive today…' All of that. While I think, can we please do something that does me justice! [disparaging voice:] 'Oh, and I'm a bit ADHD too'*
Participant 1.5	*[disparaging voice] "I am a little bit depressed too"*
Participant 1.3	*"Yes everybody [goes] 'I am a little bit hyperactive too', I think it's terrible, and then you get these discussions about getting rid of our stickers [labels], and I think, my goodness, if only I had known, my life would have been so much easier. So, that's it really, I think [the term] ADHD is becoming increasingly empty."*

Quote Focus group 2: Parents of children with ADHD

The quote below shows a similar contradiction, where one participant first said the classification ADHD leads to more help, money, and support from schools. Yet in a subsequent statement, the same participant remarked that the classification leads to people only looking for what is wrong with her child rather than for what he needs.

Participant 2.1	"*For me [the classification ADHD] only means that the school and other organizations are willing to help you with that particular bit [of the problem]. Without the label, they won't. The label [only] means money, it does not change a thing about my child".*
	(…)
Participant 2.1	"*Yes, [they] only look at what is wrong with him, instead of what he needs"*

Quote Focus group 4: Teachers
One teacher mentioned that having an ADHD classification might lead to more understanding and acceptance of ADHD-related behavior. Then the same teacher stated that ADHD leads to a continued negative association with or negative evaluation of a child and their behavior.

Participant 4.5	*"For some people [it [ADHD] leads to] understanding, for some children it provides [more] understanding of their situation".*
Moderator	"*[understanding] from themselves, from their parents, from their teachers?*"
Participant 4.5	"*Well, from everyone I think"*
Moderator	"*And how does this understanding work? Strange question perhaps, but how…*"
Participant 4.5	"*Well, they know, or they can better place, where their behavior is coming from, or what causes it. That leads to a better understanding of the situation, so [understanding] of that some things don't go well. And some do. And that you maybe feel you are extra special, so yeah, in that way you can gain understanding of your own behavior, as a child."*
	(…)
Participant 4.5	"*But if you are that 'ADHD-child' who is always messing around in class, and if you are constantly referred to that way, then you can develop a very negative association [with ADHD] and a very negative self-image."*

Considering ADHD to be a category is both helpful and harmful

Across all groups, participants mentioned that the classification ADHD can function as a convenient shorthand to understand what an individual needs quickly. It indicates the need for a certain treatment or approach and helps parents, teachers, and clinicians to make an initial quick assessment of treatment options. Yet simultaneously, in all groups participants mentioned that the classification does not actually provide any information about an individual. They discussed that care should always be provided based on individual needs rather than based on a classification. In several groups, participants would criticize and even ridicule parents, clinicians and teachers who did, in fact, use the classification as a shorthand. In other words, participants stated that the classification can and should be used as a shorthand and at the same time criticized individuals around them who did so. Both perspectives are not necessarily mutually exclusive, but it was noticeable that participants did not attempt to actively integrate these perspectives.

Table 4: Considering ADHD to be a category is both helpful and harmful

Quote Focus group 1: Adults with ADHD
One participant argued that we should steer clear from labeling everyone, and that people should be allowed to simply be, without bringing in classifications or names. When the moderator tried to verify that we can tell people's story without classifications, she described how she defines everyone in her family by their classification.

Participant 1.3	"*But [if] you want a name [label], you could also just say 'I am human'.*"
Participant 1.1	"*Yes, well, I would like that, but we are not at all ready for that as a society. There is already much, much more room for all the different colors and shapes [than there was]. But we are also taking that too far, in that everyone has to have a color or shape, while at a certain point we'll get to.. we'll just let things be.*"
Moderator	"*That [problems] can exist without a label?*"
Participant 1.1	"*Without a label.*"
Moderator	"*So, what your [Participant 1.3] question was, you say you are 'human', and someone asks 'what kind of human are you?', and then one day, you will be able to tell your whole story, but you won't need that label [ADHD] anymore? Is that possible?*"
Participant 1.1	"*Yes, in our house, my son has autism, I have ADHD, there is nothing wrong with my daughter, but we say 'you have has eczema, and dad is colorblind'. You know, so that we how we..*"

Quote Focus group 6: Policy Makers
In this quote, one of the policy makers described how an ADHD classification should serve as a road map to better determine how to handle and support someone. Yet, subsequently she stated that teachers should not use previous experiences or outdated stereotypes to handle or support children in their classrooms but should rather consider an individual child's needs.

Participant 6.4	"*It [the classification] is a point of departure, and, actually, you should be given a map. The person who gives the diagnosis should give other people a roadmap. That way, we don't just answer the question of whether it is ADHD or not, but it serves as a point of departure, of 'okay we are doing this and this, and it means this for you, this for your teachers and this for your friends'. It can serve as a roadmap.*"
	(…)
Participant 6.4	""*Yes, and often I think that teachers have had experiences in the past, with another student who had a similar label, and that time specific things worked. So, then it is tempting and easy to think that it will be the same now, especially if it [the experience] was like five years ago, when we treated it [ADHD] in a more stereotypical way. Then you might have missed a few steps of what we are referring to; we are trying to stimulate development, and focus more on an individual [child].*"

ADHD is rooted in the brain and in society, both as a cause and a consequence

We noted that discussions surrounding causality and consequences of ADHD were complex, confusing, and often difficult to follow. This was because ADHD was described both as a cause of problematic behaviors, and a consequence of these same behaviors.

Simultaneously, ADHD was described as both a neurobiological and a societal problem. Participants noted that society leaves little room for children to develop freely. Children who deviate from the norm are quickly labeled. Society leaves little space for developmental variability and children are expected to excel and perform at a high level from a young age. Yet in most focus groups, participants also described ADHD as a disorder of the brain. The neurobiology of individuals with a classification was said to be different from the neurobiology of individuals without a classification. Participants referred to this phenomenon as an 'ADHD brain'. It was difficult to pin down participants' point of view in these discussions, as participants seemed to jump from one perspective to another, without acknowledging or interpreting the differences and similarities between perspectives.

Table 5: ADHD is rooted in the brain and in society, both as a cause and as a consequence

Quote Focus group 3: Clinicians
The conversation below gives an example of one such conversation. Participants agreed that children do not get enough time and space to fully develop. Yet they did not believe that this is a cause of ADHD. They then reiterated that children do not get the opportunity to mature and underline that society imposes certain expectations and norms on children, and that this may lead to children developing an impairment. Then cause and consequence were reversed and ADHD was discussed as the cause of impairment. Subsequently, in response to the question of whether ADHD is a cause or a description, one participant brought up the ADHD brain.

Participant 3.9	"*There is nobody here who disagrees with you that we should be attuning [our society] to the needs of those children.*"
Participant 3.5	**"***No, but those children don't get that time and space anymore.*"
Participant 3.9	"*Well, that is the question, so you, you are more or less assuming that children develop ADHD from people not engaging with them properly.*"
Participant 3.7	"*No, that is not true*"
Participant 3.5	"*No, you don't get ADHD from [how people engage with you]*"
Participant 3.7	"*Children don't get the time to grow up*"
Participant 3.0	"*No, which improvements are needed with regard to the term ADHD? Nothing wrong with the term ADHD, I think, that's roughly what we have said here. But we have to realize that in this society, in this moment, the demands we put on children, that..*"
Participant 3.3	"*They lead to them dysfunctioning more quickly, to getting stuck….*"
Participant 3.7	"*But that does not always need to be caused by ADHD*"
Participant 3.6	"*No, but that is the tendency, [to ascribe it to ADHD]"*
Moderator	"*Is ADHD a cause or a description?*"
Participant 3.9	"*Yes, exactly*"
Participant 3.0	"*Well, in my eyes, but we already talked about this at the beginning, I call that an ADHD-brain.*"

Quote Focus group 1: Adults with ADHD
This participant explained that individuals with ADHD often only struggle because their environment is not properly attuned to their needs. Yet he then went on to describe how ADHD is an engagement disorder that appears to be inherent to the individual and related to his/her ability to connect and disconnect their attention.

Participant 1.5	"*Because you struggle more with things… But people with ADHD don't have to struggle more, it only works out that way because they are not in the right environment.*"
	(…)
Participant 1.5	"*I have a sort of personal hypothesis, that I can't test, because I am no longer a researcher, [that] ADHD is much more of an engagement disorder. So it literally is the connecting and disconnecting of attention, and I see [it] in many cases. If you look at hyperfocus, a bomb could literally explode behind you, but you stay focused, because you are engaged and your brain doesn't disconnect anymore, it gets stuck. And sometimes it [isn't] stuck and it will connect to anything because it doesn't know, well, the reward-seeking part of the brain has something to do with it. I don't know, I am no longer a researcher. But that is kind of how I explain it, it is an engagement disorder and it is just difficult to control what you attend to.*"

Quote Focus group 2: Parents of children with ADHD.
This participant first explained that medication helps her son focus on his tests at school. Yet subsequently, she made a point of stating that it is 'bizarre' that we give children medication to change who they are and what they can and cannot do.

Participant 2.3	"*Yes, Ritalin, that is the solution. Oh ADD, well, then you're given Ritalin, then everything is okay*"
Participant 2.1	*"Well, but that's not a.."*
Participant 2.3	"*Maybe it does help him, I don't know*"
Participant 2.1	"*Yes, it does help my son, a lot, to only focus on his tests, while [he's] taking the test. Instead of [thinking about] video games and those sorts of things*"
	(…)
Participant 2.1	"*But with children, we say, okay, so now we know that you are not a blue flower, you are a pink flower. So we give you pills, so that you can have blue flowers anyway. Well, that is bizarre, right? I think that is completely insane. [Why can't we] just embrace that this child has pink flowers. It's great right? It changes things up.*"

Themes specific to (a set of) stakeholder groups

Adults and Adolescents with ADHD
In the two stakeholder groups of adults and adolescents classified with ADHD, there was a specific focus on medication. This theme was extensively discussed in both groups and medication use was experienced differently by various participants. Participants were interested in each other's experiences and clearly wanted to discuss the topic of medication. Noticeably, there was no in-depth discussion of the impact and implications

of medication use in any of the other groups.

Parents and Teachers

In the two stakeholder groups with parents and teachers, there was much focus on the quality of teaching and schooling. Parents extensively discussed their children's and their own experiences with the schooling system and with teachers and noted many flaws in the system. Specifically, they discussed a lack of funding for appropriate support, a lack of expertise from teachers regarding the specific needs of their child and a tendency to overlook individual children's needs. Notably, the stakeholder group with teachers discussed similar topics. Teachers in this focus group were critical of the expertise of their fellow teachers and were highly critical of the lack of funding and flexibility in the schooling system to support children with special needs. Similar topics were occasionally mentioned in other focus groups, but to a much lesser extent.

ADHD researchers

The stakeholder group with ADHD researchers was the only group where a clear meta-discussion of the utility and meaning of psychiatric classifications developed. The other groups mostly worked from the assumption that ADHD is a valid category and that we need to work out how to apply this category properly, whereas this was elaborately discussed (and disputed) in the group of ADHD researchers. Other groups elaborated on the direct implications of an ADHD classification, its advantages and disadvantages and when to use it. The researchers also discussed the utility of a classification for children and what these classifications mean, including concepts of reification and circular reasoning in psychiatry.

Discussion

We carried out an exploratory thematic analysis of the perspectives of participants in seven focus groups of stakeholders on the classification ADHD. We aimed to explore the practice of classification, as opposed to the theory of classification. We found seven different themes in how stakeholders navigate the classification ADHD. Four themes were common to all or most stakeholder groups, while three themes were unique to a (subset of) focus group(s). In addition, what stood out was an overarching discursive pattern: participants expressed highly ambivalent ideas on ADHD but made little to no reference to their ambivalence.

We hypothesized that perspectives on ADHD classification would vary both between stakeholder groups and between participants within a stakeholder group. However, we were left confused by contradictory accounts from stakeholders, where they agreed with different sides of a debate sequentially. Conflicting accounts on ADHD were not debated between participants, rather, they were endorsed by the same individuals, with participants switching between perspectives as the discussion evolved. Ambivalence is a

common phenomenon, defined as a state in which both positive and negative feelings are simultaneously associated with an object (Thompson & Zanna, 1995; van Harreveld et al., 2015). However, the experience of conflict and ensuing negative affect determines whether objective ambivalence becomes subjective ambivalence (conflict is experienced) or remains dormant (conflict is not experienced) (Armitage & Arden, 2007; Priester & Petty, 2001; van Harreveld et al., 2015). In our stakeholder groups, participants did not put the conflict between (their own) different perspectives into words. As such, we hypothesize that their ambivalence was dormant, in that participants were not aware of the conflicting aspects of their accounts.

This is relevant, as unacknowledged ambivalence may hinder the development of care practices for individuals with an ADHD classification. Mol, Moser and Pols note that "good care requires persistent tinkering in a world full of complex ambivalence and shifting tensions". Managing ambivalence is therefore of paramount importance to 'good care' and requires adaptability and 'attuned attentiveness' (Heerings et al., 2022; Mol et al., 2010). In our focus groups, we noted that participants do indeed tinker with their accounts of ADHD, as they attempted to combine and utilize different perspectives to navigate good care for ADHD. However, participants remained unaware of the conflicts that ensued. This aligns with findings from an earlier project, in which we found similar conflicts in how ADHD is explained by experts in psychoeducational materials (van Langen et al., 2022). As such, we speculate that more competence in expressing and navigating ambivalence in our understanding of ADHD, will result in better care practices.

In navigating the complexity of psychiatric classifications, a social kinds approach might allow for more leeway than a natural kinds approach. The natural kinds approach suggests that classifications are representations of naturally existing categories which cut 'nature at its seams' (Beebee & Sabbarton-Leary, 2010; Cooper, 2004; Hacking, 2007; Zachar, 2000). This approach leads to the (implicit and explicit) hypothesis that distinct biological mechanisms underly classifications, which are therefore fixed and lie within the individual. In contrast, a social kinds approach assumes that classifications are societal constructs that we have created and embraced (Boyd, 1991; Kendler et al., 2011). This allows for a more critical assessment of the current diagnostic system and suggests that we can decide if and when to classify experienced difficulties. Specifically, we surmised that participants in our focus groups (implicitly) operated largely from a natural kinds approach, where they believed classifications capture 'true biological entities' that cause problematic behaviours. Yet participants do attempt to integrate ideas from the social kinds approach into their rationale, and this leads to (undetected) conflict. Promoting a social kinds perspective, where the descriptive and a-theoretical nature of psychiatric classifications is stressed (Tsou, 2015), may provide a framework for developing more awareness and competency in navigating the complexity of psychiatric classification.

We found three themes that did align with our hypothesis that perspectives on ADHD would vary between stakeholder groups. In the first of these, we found that youth and adults with ADHD often shared individual experiences with medication use. There was a lack of discussion about medication in the other focus groups, most noticeably in the focus groups of professionals. This may point to an underestimation of how, for individuals living with an ADHD classification, thoughts about ADHD classification and thoughts about medication are connected. In the second theme, we found that parents and teachers extensively discussed teaching and schooling, and their experiences with what they perceived to be a flawed system. This discussion highlights the importance of the schooling system in dealing with ADHD, and specifically to listening to those who are at the forefront of the diagnostic process. In both themes, the contributions of stakeholders with a lived experience underline important themes that may otherwise be missed. The third focus group-specific theme was found among ADHD researchers and revolved around a conceptual discussion of the ADHD classification (Batstra et al., 2014; Nieweg, 2005; te Meerman et al., 2017). This theme addressed the ongoing scientific discussion on the validity and utility of diagnostic classifications (Batstra et al., 2014; Frances, 2013, 2016; Nieweg, 2005; te Meerman et al., 2017). This discussion has been ongoing among Dutch researchers for numerous years, yet our results suggest that this debate has not yet spread beyond the academic environment.

Overall, we found conflicts in the way stakeholders understand ADHD that stakeholders themselves seemed unaware of. If we can encourage more awareness and competence in expressing and navigating the ambivalence associated with an ADHD classification, this may ultimately lead to better care practices.

Limitations

We cannot judge to what extent our participants were representative of all stakeholders in ADHD. Although we attempted to invite stakeholders with different backgrounds and perspectives, it is possible that some selection bias was introduced by (of necessity) including only individuals willing to participate. However, we were able to probe a variety of different perspectives and in this sense our sample was informative for this exploratory analysis. A second limitation is that we did not discuss our results with participants. This could be highly relevant to a follow-up study, as it may well be interesting and informative to ask participants to reflect on their dormant ambivalence.

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Supplementary Material 1: Script for focus groups

1. Introduction focus group (+/- 10 minutes)

    * Short introduction of the research project. (We want to stress that our aim is to map different perspectives on ADHD. The goal is therefore not to the reach consensus when answering the questions. Differing opinions, experiences and stories are interesting to us).
    * Has everyone had the opportunity to read the information letter and the consent form?
    * Are there any questions about the information letters or the consent form?
    * Moment to sign the consent forms.

2. Discussion – Part 1 (+/- 45 minutes).

(Our goal is to ensure that participants can speak openly and freely about their ideas of, perspectives on, and experiences with ADHD. The participants should be guiding the conversation and introducing the topics that are to be discussed. If necessary, the moderators can ask additional questions or redirect the conversation. Below we present the questions that we introduce during the focus groups).

    * Topic 1: How do we understand ADHD?
        - What does having ADHD say about a person?
        - How do you prefer to talk about ADHD? Do you prefer to call it a diagnosis, classification, label or term?

    * Topic 2: Effect of the diagnosis ADHD
        - What effect does the diagnosis ADHD have on the life of a child/adolescent/adult?
        - (if only advantages are mentioned): What are the disadvantages of receiving the label ADHD?
        - (if only disadvantages are mentioned): What are the advantages of receiving the label ADHD?

3. Break (+/- 15 minutes)

4. Discussion – Part 2 (+/- 45 minutes)

    * Topic 3: Effect of 'the term' ADHD (in a societal context).
        - When do you talk about or use (the term) ADHD? (In what context?)
        - In your context, what are the advantages of using the term ADHD?
        - In your context, what are the disadvantages of using the term ADHD?

* Topic 4: alternatives/improvement in the system?
    - In current practice, we give children a diagnosis that has disadvantages, as well as advantages. Are there any improvements that can be made to the use of the term ADHD?

* Have we skipped over or forgotten any important questions or topics?

5. Ending (+/- 10 minutes)

* Thank you for your active participation in this focus group!
* How did you experience the discussion?
* Are there any questions about the continuation of the study?

Supplementary Material 2: Focus group Analyses

Below we describe the steps taken during the analyses and interpretation of the focus group data. For the first part of the analyses (step 1-4), we studied each focus group individually.

In the second part, we integrated the results into an overarching thematic structure. Within this thematic structure, we discussed all themes in the data and how these themes related to each other. We also discussed any themes that were specific to one or several focus groups.

Part 1: Analyses of individual focus groups

1. MvL transcribed all focus group recordings verbatim and imported the transcriptions into NVivo 12 Pro.
2. MvL analysed each of the transcriptions using a bottom-up approach, without preconceived ideas or structures of how the data would be represented. Each focus group was analysed separately, in a new NVivo file. The analyses consisted of a number of steps.

* The first half of each focus group was analysed using open coding; each relevant text excerpt was given a code that summarized its contents. Text excerpts about the same topics were grouped under the same code.
* After coding the first half of the group, the file contained roughly 100-150 codes.

These codes were then grouped into axial codes; open codes with similar content were grouped together. This provided a more elaborate coding hierarchy, with codes split up into overarching topic groups.

* After the first half was sorted into axial codes, the second half of the focus group was also analysed using open codes. Text excerpts fitting previously discussed topics were placed within the pre-existing coding hierarchy. Text excepts addressing new topics were given new open codes.
* After completing open coding of the second half of the focus group, the axial coding hierarchy was reassessed, adding new codes into the hierarchy and creating additional axial codes when necessary.
* The final coding tree was then reassessed and checked for correctness.

3. MvL then visualized the coding hierarchy in a powerpoint presentation and wrote memos about the aspects of the focus groups and axial coding that stood out most.
4. During in-depth discussions between BvH and MvL, the axial coding was explored and discussed. These meetings were also used to discuss preliminary ideas about the interpretation of the analyses. MvL reassessed and added to the written memos after each of the discussion meetings.

Part 2: Integration of the analyses

5. MvL listened to and read along with the transcription of each of the focus groups over the course of four days. This permitted MvL to refamiliarize herself with all the information discussed in the groups. MvL kept memos of information and ideas that stood out.

    * Day 1: focus groups 1 and 2
    * Day 2: focus groups 3 and 4
    * Day 3: focus group 5
    * Day 4: focus groups 6 and 7

6. MvL reread the coding hierarchy, powerpoint presentations and memos for each of the focus groups. Based on all collected information, she integrated the overarching themes of each of the groups. She then combined the coding schemes in Nvivo to support analyses and find relevant text excerpts. Each theme was given a title and elaborately described in a document. After developing this overarching thematic structure, MvL also described those themes that were relevant to only one or several focus groups. These themes were described in a similar fashion.
7. The preliminary thematic structure was read and assessed by BvH. During subsequent

in-depth discussions, MvL and BvH, integrated the thematic structure further and refined descriptions. During back-and-forth commentary and weekly discussion meetings, the thematic structure was written up into the Results section.

Supplementary Material 3: Overview Dutch Quotes and English Translations

Theme 1: ADHD says both nothing and a lot about a person

Quote Focus group 1: Adults with ADHD
While introducing herself, one participant mentioned how important her ADHD diagnosis was to her, that a lot had fallen into place when she was classified and that it had given her a much better understanding of herself. When asked what having ADHD said about a person, she said 'nothing' and questioned what having ADHD said about her.

Participant 1.2	"A *lot fell into place for me and I thought, ah, now I understand a lot of things*"
	(…)
Moderator	"*What does having ADHD say about a person?*"
	(…)
Participant 1.2	"*Well, my first inkling is [to say] nothing. It actually says nothing. If I look at our society, and that is something I struggle with personally, we always need [to get] a classification first, [ascribe] a label or a box, before someone can get the right help. Because then I wonder, but what does it actually say about me?"*

	Participant 1.2	"Er *viel voor mij veel op z'n plek, dat ik dacht, ah en nu begrijp ik heel veel dingen"*
		(…)
	Moderator	"*Wat zegt het hebben van ADHD over een persoon?*"
		(…)
	Participant 1.2	"*Ja, mijn eerste gevoel is uh niks, eigenlijk zegt het niks ….. uhm, als ik , als ik kijk naar onze maatschappij en dat is wat ik persoonlijk zelf lastig vind, is dat er altijd eerst een classificatie, dus een labeltje of een hokje nodig is voordat iemand de juiste hulp krijg …. Want dan denk ik ja, wat zegt het nou over mij?*"

Quote Focus group 3: Clinicians
One participant first stated that she could not say what ADHD says about a person, because it does not say anything. Yet subsequently, she noted that we diagnose ADHD when people get stuck and that the classification ADHD informs us on brain-functioning, citing the ADHD-brain.

Participant 3.0	"*So, what does it say about a person? I cannot answer that question at all, [it] says absolutely nothing.*"
	(…)

Participant 3.0	"*But we have agreed to diagnose ADHD if someone gets stuck in multiple areas [of life], but you can still have an ADHD-brain. At least that is what I would call it, having an ADHD brain.*"

Participant 3.0	"*Dus ja, wat zegt het over een person? Ik kan … Ik kan helemaal die vraag helemaal niet beantwoorden, zegt helemaal niets*"
	(…)
Participant 3.0	"*Maar we hebben wel afgesproken dat je ADHD vaststelt als iemand vastloopt he, op, op verschillende gebieden, maar je kan nog steeds een een ADHD-brein hebben, ten minste ik zou dat dan wel zo noemen, een ADHD-brein hebben..*"

Quote Focus group 2: Parents of children with ADHD
Similarly, one participant in this group said, within a single sentence, that ADHD means nothing and yet it also means that someone has certain characteristics.

Participant 2.2	*"Well technically [ADHD means] nothing, no. Certain characteristics, that a label has been attached to."*
Participant 2.2	*"Nou in principe niets, nee. Bepaalde eigenschappen, waar een labeltje aan gehangen is."*

Theme 2: The impact of the classification ADHD is both positive and negative

Quote Focus group 1: Adults with ADHD
This participant resented the classification ADHD, because of the number of value-judgements she felt are attached to it. She felt the classification does not do her justice. Yet in a subsequent remark, she stated that if only she had known about having ADHD sooner, her life would have been a lot easier.

Participant 1.3	"*I think the term ADHD is horrible. I feel like it [the term ADHD] is totally wrong, because there are so many value judgements attached to it: [in a disparaging voice] 'you are a little hyperactive today…' All of that. While I think, can we please do something that does me justice! [disparaging voice:] 'Oh, and I'm a bit ADHD too'*
Participant 1.5	[disparaging voice] "*I am a little bit depressed too*"
Participant 1.3	*"Yes everybody [goes] 'I am a little bit hyperactive too', I think it's terrible, and then you get these discussions about getting rid of our stickers [labels], and I think, my goodness, if only I had known, my life would have been so much easier. So, that's it really, I think [the term] ADHD is becoming increasingly empty."*

	Participant 1.3	"*Ik vind de term ADHD afschuwelijk. Ik vind hem echt helemaal verkeerd (ja) omdat er zoveel waardeoordelen aan hangen (stemmetje), jij bent ook weer een beetje dr.. Allemaal dat (gelach), terwijl ik denk, laten we in godsnaam iets doen wat recht doet aan mij. Ja, even in dit geval he uh, uh en ADHD dat heeft ook het jongetje in de st.. en oh, ik heb ook een beetje ADHD (gelach)*"
	Participant 1.5	"*Ik ben ook een beetje depressief.*"
	Participant 1.3	"*Iedereen hee.. ik ben ook een beetje druk, ah, ik vind het zo erg en dan zie je die discussies, laten we die stickers eens weghouden, en dan denk ik, my goodness, had ik het geweten, he, dan had ik een veel makkelijker leven gehad, dus, dat is eigenlijk, ik vind ADHD een heel erge leegte worden, zo onderhand.*"

Quote Focus group 2: Parents of children with ADHD
The quote below shows a similar contradiction, where one participant first said the classification ADHD leads to more help, money, and support from schools. Yet in a subsequent statement, the same participant remarked that the classification leads to people only looking for what is wrong with her child rather than for what he needs.

Participant 2.1	"*For me [the classification ADHD] only means that the school and other organizations are willing to help you with that particular bit [of the problem]. Without the label, they won't. The label [only] means money, it does not change a thing about my child".*
	(…)
Participant 2.1	"*Yes, [they] only look at what is wrong with him, instead of what he needs*"

	Participant 2.1	"*Voor mij zegt het alleen maar dat uh de school uh de school en de instanties bereid zijn jou te helpen op dat stukje, zonder dat labeltje, doen ze dat namelijk niet. (D24: geld, herhalen allemaal 'geld'). Dat label zegt geld, het verandert niks aan mijn kind.*"
		(…)
	Participant 2.1	"*ja, der wordt veel meer gekeken van wat heeft ie in plaats van wat hebben ze nodig.*"

Quote Focus group 4: Teachers
One teacher mentioned that having an ADHD classification might lead to more understanding and acceptance of ADHD-related behavior. Then the same teacher stated that ADHD leads to a continued negative association with or negative evaluation of a child and their behavior.

Participant 4.5	*"For some people [it [ADHD] leads to] understanding, for some children it provides [more] understanding of their situation".*
Moderator	"*[understanding] from themselves, from their parents, from their teachers?*"
Participant 4.5	"*Well, from everyone I think*"
Moderator	"*And how does this understanding work? Strange question perhaps, but how…*"

Participant 4.5	"*Well, they know, or they can better place, where their behavior is coming from, or what causes it. That leads to a better understanding of the situation, so [understanding] of that some things don't go well. And some do. And that you maybe feel you are extra special, so yeah, in that way you can gain understanding of your own behavior, as a child.*"
	(…)
Participant 4.5	"*But if you are that 'ADHD-child' who is always messing around in class, and if you are constantly referred to that way, then you can develop a very negative association [with ADHD] and a very negative self-image.*"

Participant 4.5	"*Voor sommige mensen begrip, voor sommige kinderen geeft het begrip in h.. hun eigen situatie*"
Moderator	"*Van zichzelf van ouders van leerkrachten?*"
Participant 4.5	"*Ja, eigenlijk van iedereen denk ik.*"
Moderator	*"En en hoe werkt dat begrip? Rare vraag, maar hoe..*"
Participant 4.5	"*Nou, dan ze uhm, weten wa.. of kunnen plaatsen waar hun gedrag door veroorzaakt wordt, of waar het vandaan komt, maar uh waardoor je dus meer begrip krijg voor een situatie, dus voor dingen die niet goed gaan, of die wel uh, goed gaan, dat je het misschien, ja extra bijzonder vindt, of ja op die manier eigenlijk en dus ook inzicht in je eigen gedrag, als kind.*"
	(…)
Participant 4.5	"*Maar als je altijd die ADHDer bent die loopt te rotzooien in de klas en als dat ook continue zo benoemd wordt uhm, dan kan je daar heel heel negatief uh associatie en een heel negatief zelfbeeld van krijgen.*"

Theme 3: Considering ADHD to be a category is both helpful and harmful

Quote Focus group 1: Adults with ADHD
One participant argued that we should steer clear from labeling everyone, and that people should be allowed to simply be, without bringing in classifications or names. When the moderator tried to verify that we can tell people's story without classifications, she described how she defines everyone in her family by their classification.

Participant 1.3	"*But [if] you want a name [label], you could also just say 'I am human'.*"
Participant 1.1	"*Yes, well, I would like that, but we are not at all ready for that as a society. There is already much, much more room for all the different colors and shapes [than there was]. But we are also taking that too far, in that everyone has to have a color or shape, while at a certain point we'll get to.. we'll just let things be.*"
Moderator	"*That [problems] can exist without a label?*"
Participant 1.1	"*Without a label.*"

Moderator	"*So, what your [Participant 1.3] question was, you say you are 'human', and someone asks 'what kind of human are you?', and then one day, you will be able to tell your whole story, but you won't need that label [ADHD] anymore? Is that possible?*"
Participant 1.1	"*Yes, in our house, my son has autism, I have ADHD, there is nothing wrong with my daughter, but we say 'you have has eczema, and dad is colorblind'. You know, so that's how we..*"

Participant 1.3	"*maar je wilt wel een naam, dan kun je ook zeggen ik ben mens'*
Participant 1.1	"*Ja, maar das. Nou ja dat wil ik, dat wil ik wel.. (praten door elkaar) maar daar zijn we als samenleving nog lang niet aan toe. En der is al heel erg veel, veel meer ruimte voor voor alle kleurtjes (ja) en vormpjes, uhm, maar daar slaan we ook weer in door, dat iedereen een kleurtje of een vormpje moet hebben, maar op een gegeven moment komt er wel denk ik wel, so.. soort van dat het er mag zijn.*"
Moderator	"*Dat 't er mag zijn zonder naam.*"
Participant 1.1	"*Zonder naam..*"
Moderator	*"Dus, wa wa wat jouw vraag was, mens en dan vraagt iemand door welke, nou wat voor mens ben je, en uiteindelijk (ja) kan je je hele verhaal vertellen en dan heb je niet meer die naam nodig. Dat dat ka..*"
Participant 1.1	"*Ja, bij bij bij ons thuis, kijk mijn mijn zoon heeft autisme, ik heb ADHD, dus wij, wij, mij mijn dochter heeft niks, maar die noemt.. die heeft dan, jij hebt eczeem en papa is kleurenblind. Weet je, du dus zo geven wij (gelach)"*

Quote Focus group 6: Policy Makers
In this quote, one of the policy makers described how an ADHD classification should serve as a road map to better determine how to handle and support someone. Yet, subsequently she stated that teachers should not use previous experiences or outdated stereotypes to handle or support children in their classrooms but should rather consider an individual child's needs.

Participant 6.4	"*It [the classification] is a point of departure, and, actually, you should be given a map. The person who gives the diagnosis should give other people a roadmap. That way, we don't just answer the question of whether it is ADHD or not, but it serves as a point of departure, of 'okay we are doing this and this, and it means this for you, this for your teachers and this for your friends'. It can serve as a roadmap.*"
	(…)
Participant 6.4	""*Yes, and often I think that teachers have had experiences in the past, with another student who had a similar label, and that time specific things worked. So, then it is tempting and easy to think that it will be the same now, especially if it [the experience] was like five years ago, when we treated it [ADHD] in a more stereotypical way. Then you might have missed a few steps of what we are referring to; we are trying to stimulate development, and focus more on an individual [child].*"

Participant 6.4	*"Ik ook, het is een soort vertrekpunt, en eigenlijk zal je, weleens de kaart mee moeten krijgen, zodat andere mensen ook okay, de he, degene die dan de diagnose heeft gesteld dat er een soort van meteen een routekaart of iets is, waardoor uh, niet alleen maar okay, i... ik, krijg de vraag is het ADHD of niet, effe heel uh ongechargeerd, nou, dat is het, je hebt vr.. antwoord op je vraag uh, uh alsjeblieft, maar dat daar dan als een vertrekpunt is van okay, nou dan gaan we hier en hier en dan betekent het d (…) Ja, voor jou, voor je leerkrachten voor je vrienden, uh, der is een soort roadmap.."*
(…)	
Participant 6.4	*"Ja, en volgens mij is het ook wel vaak dat leraren vaak dan zo van in het verleden ervaringen hebben gehad uhm, met een andere leerling die ook een vergelijkbaar labeltje had en toen werkte dit of dat, dus, dan is het natuurlijk ook verleidelijk of makkelijk om te denken van dat zal nu ook wel zo zijn, en zeker als een kind de tijd, he als het vijf jaar geleden is ofzo en het toen wat meer stereotiep mee om werd gegaan, dan ja, dan heb je misschien een aantal van die stappen gemist waar jullie het over hebben, van wij proberen ontwikkeling uh te krijgen, dat je meer naar het individu kijkt"*

Theme 4: ADHD is rooted in the brain and in society, both as a cause and as a consequence

Quote Focus group 3: Clinicians

The conversation below gives an example of one such conversation. Participants agreed that children do not get enough time and space to fully develop. Yet they did not believe that this is a cause of ADHD. They then reiterated that children do not get the opportunity to mature and underline that society imposes certain expectations and norms on children, and that this may lead to children developing an impairment. Then cause and consequence were reversed and ADHD was discussed as the cause of impairment. Subsequently, in response to the question of whether ADHD is a cause or a description, one participant brought up the ADHD brain.

Participant 3.9	"*There is nobody here who disagrees with you that we should be attuning [our society] to the needs of those children.*"
Participant 3.5	**"***No, but those children don't get that time and space anymore.*"
Participant 3.9	"*Well, that is the question, so you, you are more or less assuming that children develop ADHD from people not engaging with them properly.*"
Participant 3.7	"*No, that is not true*"
Participant 3.5	"*No, you don't get ADHD from [how people engage with you]*"
Participant 3.7	"*Children don't get the time to grow up*"
Participant 3.0	"*No, which improvements are needed with regard to the term ADHD? Nothing wrong with the term ADHD, I think, that's roughly what we have said here. But we have to realize that in this society, in this moment, the demands we put on children, that...*"
Participant 3.3	"*They lead to them dysfunctioning more quickly, to getting stuck...*"
Participant 3.7	"*But that does not always need to be caused by ADHD*"

Participant 3.6	"*No, but that is the tendency, [to ascribe it to ADHD]"*
Moderator	"*Is ADHD a cause or a description?*"
Participant 3.9	"*Yes, exactly*"
Participant 3.0	"*Well, in my eyes, but we already talked about this at the beginning, I call that an ADHD-brain.*"

Participant 3.9	"*Der is het hier niemand met je oneens dat we ons moeten afstemmen op de behoefte van die kinderen.*"
Participant 3.5	"*Nee, maar daar die die die die die die uh die kinderen krijgen daar de tijd en de ruimte niet meer voor.*"
Participant 3.9	"*Nou ja, dat is, d.. dd.. dat is maar de vraag, dus ja, je je veronderstelt min of meer dat zeg maar uhuh, dat je ADHD krijgt van niet goed benaderd worden.*"
Participant 3.7	"*Nee, dat is echt niet waar.*"
Participant 3.5	"*Nee, je krijgt het er niet van.*"
Participant 3.7	"*Je krijgt de tijd niet, om te rijpen.*"
Participant 3.0	"*Nee, welke verbeteringen in ten behoeve van de term ADHD, niks mis met de term ADHD, volgens mij, was dat volgens mij wat we ongeveer hier gezegd hebben, (die is er), alleen uhm, uh we moeten ons beseffen dat in deze maatschappij, hoe die op dit moment uh uh is, uh, de eisen zo gesteld worden aan uh kinderen, dat uhm, uh.*"
Participant 3.3	"*Dat je eerder uitvalt ,(ja) vastloopt..*"
Participant 3.7	"*Maar niet dat hoeft niet altijd als oorzaak ADHD te hebben.*"
Participant 3.6	"*Nee, maar de de neiging..*"
Moderator	"*Is, is ADHD een oorzaak of een beschrijving?"*
Participant 3.9	"*Ja, precies.*"
Participant 3.0	"*Nou ja, we.. in mijn ogen, maar dat dat daar hadden we het in het begin al over, hadden we het over, hadden we het over, ik noem dat dan toch een een een een ADHD-brein..*"

Quote Focus group 1: Adults with ADHD
This participant explained that individuals with ADHD often only struggle because their environment is not properly attuned to their needs. Yet he then went on to describe how ADHD is an engagement disorder that appears to be inherent to the individual and related to his/her ability to connect and disconnect their attention.

Participant 1.5	*"Because you struggle more with things… But people with ADHD don't have to struggle more, it only works out that way because they are not in the right environment."*
	(…)

Participant 1.5	"*I have a sort of personal hypothesis, that I can't test, because I am no longer a researcher, [that] ADHD is much more of an engagement disorder. So it literally is the connecting and disconnecting of attention, and I see [it] in many cases. If you look at hyperfocus, a bomb could literally explode behind you, but you stay focused, because you are engaged and your brain doesn't disconnect anymore, it gets stuck. And sometimes it [isn't] stuck and it will connect to anything because it doesn't know, well, the reward-seeking part of the brain has something to do with it. I don't know, I am no longer a researcher. But that is kind of how I explain it, it is an engagement disorder and it is just difficult to control what you attend to.*"

Participant 1.5	"*Want je hebt meer moeite met dingen, maar ADHDers die hoeven niet meer moeite met dingen te hebben, alleen vaak resulteert het wel op die manier, omdat ze dan niet in de juiste omgeving zitten of niet..*"
(…)	
Participant 1.5	"*ik heb nu en soort van uh, persoonlijke hypothese, ja die ik niet kan testen, want ik ben geen wetenschapper meer, uhm, dat ADHD veel meer een engagement disorder is, dus het is letterlijk het het koppelen en loskoppelen van aandacht, en ik zie het met heel veel dingen, a.. als je kijkt naar de hyperfocus, der kan een bom achter je ontploffen en je bent nog steeds geconcentreerd, want je bent gewoon bezig, jouw'n brein die koppelt niet meer los, als het eenmaal vast zit en soms dan zit het vast en dan koppelt het overal naartoe los, omdat het gewoon niet weet wanneer het nou ja, net als misschien ook met dat reward seeking gedeelte in je hersenen heeft, misschien ergens mee te maken. Ik weet het niet, ik ben geen wetenschapper meer. Maar, dat is hoe ik het nu een beetje uitleg van, het is een engagement stoornis, het is gewoon moeilijk om te reguleren waar je aan vasthoudt,..*"

Quote Focus group 2: Parents of children with ADHD.
This participant first explained that medication helps her son focus on his tests at school. Yet subsequently, she made a point of stating that it is 'bizarre' that we give children medication to change who they are and what they can and cannot do.

Participant 2.3	"*Yes, Ritalin, that is the solution. Oh ADD, well, then you're given Ritalin, then everything is okay*"
Participant 2.1	*"Well, but that's not a..."*
Participant 2.3	"*Maybe it does help him, I don't know*"
Participant 2.1	"*Yes, it does help my son, a lot, to only focus on his tests, while [he's] taking the test. Instead of [thinking about] video games and those sorts of things*"
	(…)
Participant 2.1	"*But with children, we say, okay, so now we know that you are not a blue flower, you are a pink flower. So we give you pills, so that you can have blue flowers anyway. Well, that is bizarre, right? I think that is completely insane. [Why can't we] just embrace that this child has pink flowers. It's great right? It changes things up*".

Participant 2.3	"*Ja, ritalin, dat is de oplossing. Oh ADD, nou, dan krijg je een ritalin, dan uh is 't goed.*"
Participant 2.1	"*nouja, maar goed das geen das geen..*"
Participant 2.3	"*Misschien helpt hem wel hoor, dat weet ik niet.*"
Participant 2.1	"*Jaja, dat helpt bij mijn zoon heel erg om uh alleen aan zijn toets te denken tijdens zijn toets, in plaats van aan de games en dat soort dingen.*"
	(…)
Participant 2.1	"*maar van kindjes zeggen we, okay, we weten nu dat jij geen blauwe bloem bent, maar roze bloem, dus we geven jou pillen zodat je toch blauwe bloemen, nou das toch bizar. Ik vind dat echt van de zotten. Omarm, gewoon dat dat kind roze bloemen heeft, leuk toch. Das weer eens wat anders.*"

Chapter 3

Lost in Explanation

Internal conflicts in the discourse of ADHD psychoeducation

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Abstract

Introduction. Psychiatric classifications are understood in many different ways. For children with ADHD and their parents, psychoeducation is an important source of information for shaping their understanding. Moreover, psychoeducation is often taken by children and parents to represent how their story is understood by the therapist. As a result, the way psychoeducation is formulated may affect the therapeutic alliance, one of the most robust mediators of treatment outcome. In addition, psychoeducation may indirectly influence the way we understand psychological differences as a society. *Methods*. To better understand how the classification ADHD is given meaning through psychoeducation, we analyzed 41 written psychoeducational materials from four different countries; the USA, UK, Netherlands and Hungary. *Results*. We identified five patterns of how the materials construct the discourse on ADHD. Notably, tension between biomedical and psychosocial perspectives resulted in conflict within a single thematic stance on ADHD as opposed to a conflict between parties with a different vision on ADHD. There were only few differences between countries in the way they constructed the discourse in the materials. *Conclusion*. These conflicts cause confusion, misrepresentation and decontextualization of ADHD. Ultimately, for those diagnosed with ADHD and their parents, conflicting information in psychoeducation materials may hamper their ability to understand themselves in the context of their difficulties.

Introduction

Psychiatric classifications are terms that refer to clusters of symptoms (American Psychiatric Association, 2013; World Health Organization, 2004). Such classifications have extensive impact, as they are often taken by a person to represent how their story is understood by the therapist (Hens & Langenberg, 2017). As a consequence, the way a classification is given meaning, including through psychoeducation, may affect the therapeutic alliance. This therapeutic alliance is well known to be the most robust mediator of treatment outcome (Baier et al., 2020; Flückiger et al., 2018; Goldsmith et al., 2015; Karver et al., 2018; van Benthem et al., 2020). Moreover, the impact of psychiatric classifications stretches well beyond a strict healthcare perspective (Corrigan & Watson, 2002; First et al., 2019; Hacking, 2007). Psychiatric classification and concurrent psychoeducation may indirectly influence the way we understand psychological differences in society.

Psychoeducation on ADHD is a special case, as the ongoing debate on ADHD exemplifies tensions between biomedical and psychosocial perspectives on mental health (Danforth & Kim, 2008; Freedman, 2016; Mitchell & Read, 2012). Notably, these two perspectives together form the basis of one of the most widely accepted approaches to mental health: the biopsychosocial model (Engel, 1980). The biomedical perspective considers ADHD to have a biological cause, and understands it as a heritable, persistent neurodevelopmental disorder (Anckarsäter, 2010; Frances, 2016; Pilecki et al., 2011; Wilson, 1993). The psychosocial perspective understands ADHD as a dynamic outcome of how an individual interacts with his or her individual circumstances, including at home and school or work on a day-to-day basis (Batstra et al., 2020; Singh, 2002). These perspectives are not mutually exclusive. However, the way they are integrated and represented in psychoeducation is likely to impact both the therapeutic alliance and societal ideas on inattention and hyperactivity. Yet very little is known about how the classification ADHD is given meaning through psychoeducation.

Studies assessing biomedical and psychosocial perspectives in various texts on ADHD have mostly applied discursive analytic techniques. They start from the crucial assumption that information provided in psychoeducational materials mirrors the discourse around ADHD, while simultaneously constructing that same discourse (Carbó et al., 2016; Johnstone, 2017; McClimens, 2007). Previous studies have often found the biomedical perspective to be overrepresented. In Dutch youth information books on ADHD, text on both psychosocial and biomedical perspectives was included (Batstra et al., 2020). However, biomedical text elements were overrepresented in two ways, with greater variety in the information offered (eight biomedical versus five psychosocial categories) and more instances of it being offered (207 biomedical versus 91 psychosocial text elements) (Batstra et al., 2020). A similar discrepancy was reported for English language websites on ADHD: 96,5% of websites were found to emphasize bio-genetic over psychosocial causes (Mitchell & Read, 2012). For French media and tv programs (Bourdaa et al., 2015; Ponnou

& Gonon, 2017), findings were more nuanced: although French tv-programs did over-represent biomedical perspectives, popular and professional literature were found to often combine both perspectives. Furthermore, one study found psychosocial repertoires to be overrepresented in UK newspaper articles (72 psychosocial versus 16 biomedical repertoires) (Horton-Salway, 2011). Whereas, these studies have investigated the extent to which biomedical and psychosocial perspectives were represented, they did not analyze the integration of these perspectives. A study by Erlandsson et al, (2016) did address this complex integration of information: the authors analyzed a single document on ADHD (National Institute of Mental Health, 2015) and found a clear bias towards biomedical explanations, as well as a focus on expert knowledge and circular reasoning.

To better understand how the classification ADHD is given meaning through psychoeducation, we analyzed 41 written psychoeducational materials from four different countries; the USA, the UK, the Netherlands and Hungary. Our primary aim was to analyze how the explanatory framework of ADHD is constructed through language use in these psychoeducational materials. We therefore carried out an exploratory study of patterns in how ADHD is framed and contextualized. In addition, we performed a cross-national analysis. Based on literature showing cross-cultural variation in the understanding and interpretation of ADHD (Asherson et al., 2012; Bergey et al., 2018), we hypothesized that we would find differences between countries in how psychoeducational materials constructed the discourse on ADHD, even though they operate from the same diagnostic handbook (the DSM-5). Overall, this paper aims to describe prominent discursive patterns in psychoeducational materials on ADHD, differences between countries in this discourse and to discuss the impact of the discourse on how stakeholders may understand and interpret information on ADHD.

Methods

Procedure

In this discourse analysis, we assessed American English, British English, Dutch and Hungarian psychoeducational materials on ADHD. We selected 8 - 12 materials in each language and assessed the commonalities and variation in how these materials constructed the discourse on ADHD.

Selection Psychoeducational Materials

First, we performed an online scoping search to determine appropriate inclusion and exclusion criteria. Our psychoeducational materials reflect a broadly selected set of psychoeducational texts, including webpages, downloadable PDF-files with psychoeducational text and downloadable flyers. We performed a broad internet search using the following search terms or combinations thereof: ADHD, Attention Deficit Hyperactivity Disorder, psychoeducation, material, flyer, and diagnosis. Supplemented

with a search term matching the appropriate language area: Great Britain, UK, United States, US, Netherlands, Dutch, Hungary, Hungarian. Search-terms were translated to search for Dutch and Hungarian materials.

We used the following inclusion criteria:

* Standalone materials (materials that were not solely part of a broader psychoeducational program or therapeutic manual).
* Materials that were freely accessible online
* Materials written in American English, British English, Dutch and Hungarian or translated into these languages
* Materials written for parents of children with an ADHD classification

We used the following exclusion criteria:

* Materials written by the same author and/or published by the same organization
* Materials over 5000 words (approximately 10 pages - to keep data analysis manageable)

We subsequently selected the first 8-12 materials in each language. This selection resulted in a convenience sample adapted to online-searchability. This sample is not representative of all psychoeducational material on ADHD but rather roughly mirrors the likelihood that materials will be found online by parents.

Data Processing

We collected and stored all psychoeducational materials in the original lay-out. We then transcribed materials into plain text files and entered them into a software package for qualitative data analysis (Nvivo 12). Descriptive data was summarized for each of the selected materials (see Supplementary Material 1), including: type of document, word count, author and/or publishing organization, year of publication and intended audience.

Discourse Analysis

Discourse analysis was performed by three independent raters (RS, DR & MvL). A detailed overview of our analysis plan is provided in Supplementary Material 2. First, we conducted a practice analysis on two independent Canadian materials. Second, all researchers rated the UK materials simultaneously in order to further standardize our working procedure. Finally, we rated the US (DR), Hungarian (RS) and Dutch (MvL) materials independently. All analytical steps were completed together for the British English materials and independently for the other materials.

To familiarize ourselves with the data, we read each of the materials four times. We kept notes and held discussion meetings about our findings. We then coded the data in three steps. First, we strictly coded the content of the material to gain insight into the

information provided. Second, we carried out a critical interpretation of the data: we coded how the discourse on ADHD was constructed and how implicit ideas and understanding of ADHD were manifest in the text. Third, we coded for language use and phrasing in the text and selected relevant excerpts. After coding every two materials we discussed our findings. When coding was complete, we held a number of conclusive discussion sessions. We discussed our findings and settled on the interpretation of major themes, discursive patterns and associated text excerpts. We then analyzed the data again, coding for these predefined discursive patterns, to reassess our results and generate a comprehensive list of relevant text excerpts.

Results

In the sections below, we describe the results of our analysis of 41 psychoeducational materials from the United Kingdom (10), the Netherlands (10), Hungary (10) and the United States (11). Our results are presented in three sections: first, we discuss the content and major themes in the materials. Second, we discuss the five discursive patterns we found in the materials. Third, we present a cross-cultural comparison of the discursive patterns in the materials.

Thematic Content

In the first step of the analysis, we examined the content of the materials. We identified three themes: (1) Definition and Diagnosis, (2) Causes and Risk Factors, and (3) Treatment and Prognosis. Below we describe these themes to introduce the information provided in the materials.

The first theme was Definition and Diagnosis. Most materials started with a description and introduction of ADHD. ADHD was described as a chronic, neurobiological, neurodevelopmental, psychiatric, behavioral disorder or condition. It was described as a real disorder recognized internationally by professionals. Children were said to receive a diagnosis if they exhibited symptoms of ADHD. The materials discussed a wide variety of symptoms, many of which could be categorized as inattention, hyperactivity or impulsivity. Materials often mentioned that symptoms should occur in multiple environments for more than six months, should start at an early age and should cause impairment in everyday life. They also noted that a diagnosis is helpful and necessary for adequate and effective treatment. They stated that ADHD is very common among children and adolescents and it is diagnosed more often in boys than in girls. They also described that ADHD often co-occurs with comorbid disorders and additional problems.

The second theme was Causes and Risk Factors. Most materials provided a thorough description of the etiology of ADHD. This etiological description usually discussed both neurobiological and environmental factors. Neurobiological factors mentioned included genetics and differences in brain regions, brain functioning, or neurotransmitter systems.

Environmental factors mentioned included premature birth, pregnancy complications and substance abuse during pregnancy, as well as parenting styles and family stress. Neurobiological factors usually took precedence over environmental factors in the way they were described. Many materials explicitly mentioned that environmental factors may contribute to, but do not cause, ADHD. Materials often referred to neurobiological factors as causes and environmental factors as risk factors.

The third theme was Treatment and Prognosis. Most materials mentioned that there is no cure for ADHD. However, most indicated that prognosis improves greatly with adequate treatment. Some materials mentioned that children can outgrow ADHD while other materials stated that affected children will have ADHD for life. Materials discussed a large variety of treatment options. These included behavioral treatments, parent training, environmental adaptations as well as a number of pharmacological options. Materials varied in how important they deemed behavioral treatment, environmental adaptations and pharmacological treatments to be. Most materials agreed that treatment prevents children from derailing and helps them to reach their full potential. Most argued that without adequate guidance, children would experience serious negative consequences of their ADHD.

Discursive Results

In the second step of the analysis, we examined how the discourse on ADHD was constructed within these three themes. We identified five discursive patterns that are described below. In addition, we found that four out of five of these patterns contained an element of internal conflict. We defined internal conflict as a situation where different elements of the same explanatory framework are in (apparent) disagreement with each other. The term 'internal' therefore refers to a conflict that is present within an overarching explanatory framework. Sometimes this was even present within a single psychoeducational document, but this conflict was certainly present across materials with similar thematic stances on ADHD. These conflicts were usually not explicit in the materials, but rather implicit in the information provided. To illustrate the discursive patterns, we have added exemplary quotes for each of the discursive patterns. An extensive list of exemplary quotes is provided in Supplementary Material 3.

Pattern 1: Cause versus Consequence.

We found that ADHD was presented as both a cause and a consequence of the same phenomenon, sometimes even in the same material. This was particularly noticeable for the themes Definition and Diagnosis, and Causes and Risk Factors. ADHD was described as a name given to a cluster of symptoms and simultaneously as the cause of those same symptoms. An example is given below, where ADHD is said to cause neurobiological differences, and to be caused by those same neurobiological differences.

"Attention deficit hyperactivity disorder is a condition, which affects those parts of the brain which control attention, impulses and concentration (a neurobiological condition)." - UK Material 11

> *"ADHD is thought to be caused by an imbalance of two neurotransmitters, dopamine and noradrenaline, which are believed to play an important role in the ability to focus and pay attention to tasks." - UK Material 11*

Pattern 2: Uncertain Complexity versus Certain Simplicity.

We noted that ADHD was often presented as a complex and multifactorial disorder that is not yet fully understood. Yet the information on causes and risk factors was simple, certain and clear, suggesting that ADHD is in fact well-understood. For example, materials mentioned that ADHD is complex, yet they would often go on to delineate simple categories that cause (neurobiology, genetics) or modulate (environment) ADHD. In a similar vein, materials often mentioned that the causes of ADHD are unknown, but just as often explained the causes of ADHD. The uncertainty and the intricacy of interplay between these factors were left out of the explanations. As such, materials constructed a simplified image of ADHD that contradicted the complexity they acknowledged elsewhere.

"Scientists have not yet identified the specific causes of ADHD." - US material 2

> *"ADHD is a disorder in certain areas of the brain and is inherited in the majority of cases. It is not caused by poor parenting or a chaotic home environment" – US material 7*

Pattern 3: Normality versus Abnormality.

We noted that materials both normalized and abnormalized ADHD. This pattern was particularly evident in the themes Definition and Diagnosis and Treatment and Prognosis. In these themes, behavior related to ADHD was referred to as a common variation of normal childhood behavior. Materials noted that every child displays these behaviors to some extent during their development and these behaviors should be considered normal. Yet, at the same time, the psychoeducational materials stressed that ADHD is a real and serious disorder. It was described as a distinct category of behavior that has a major impact on a child's life. These abnormal behaviors should be dealt with adequately. Both of these realities seem to exist simultaneously across materials, without their inconsistencies being acknowledged.

"Its core symptoms are hyperactivity, impulsivity and inattention. These common childhood behaviours occur on a continuum from normal to abnormal. It can be very difficult to judge what 'normal' behaviour is in children;

therefore when evaluating children for ADHD, many doctors try to assess the degree of impairment caused by these behaviors." - UK Material 10

> *"The recognition of ADHD as a serious medical condition continues to grow by physician groups and government health agencies around the world." – UK Material 3*

Pattern 4: Specificity versus Generality.

We identified a pattern in the theme Definition and Diagnosis where materials specifically defined what ADHD entails and simultaneously provided a general and extensive list of (associated) symptoms. The initial definition mostly adhered to DSM-5, mentioning three categories: inattention, hyperactivity and impulsivity. However, in a subsequent description of ADHD, materials included such a wide variety of symptoms, that this description broadened and blurred the definition. We have illustrated this pattern in Table 1 by providing a list of all ADHD-related symptoms mentioned in the materials from the UK. The result is a list of symptoms of which one or more will be experienced by many, if not all, children while growing up.

"ADHD is a well-defined clinical condition. All the major medical authorities recognise it, including the World Health Organisation and the American Psychiatric Organisation." – UK Material 7

Table 1

List of all ADHD-related symptoms mentioned in the UK Materials

Impulsiveness	Unable to listen or concentrate	Neurological problems (tics or epilepsy)
Hyperactivity/Being overactive	Slow to start tasks	Can't sit still, walks, runs
Inattention/ short attenion span	Struggle to finish tasks and often don't	Can't do any one thing for very long
Restlessness	Creative	Climbs around when others are seated
Fidgety	Intelligent	Daydreaming /seeming to be in another world
Full of energy	Determined	Sidetracked by what is going on in surroundings
Loud and Noisy	Good at problem-solving	Mood swings
Continuous chatter/Talking excessively	Lack of coordination	Being careless
Talks when others are talking	Lack of social skills/social clumsiness	Making too many mistakes at school
Doing things repeatedly without thinking	Learning difficulties/ disabilities	Making silly or careless mistakes
Finding it hard to wait their turn in games or a queue	Autism	Disruptive in play
Interrupting others in conversation or in play	Conduct disorder/ Oppositional defiant disorder	Always on the go
Hardworking	Anxiety	Often lose their belongings
Persevere at tasks	Depression	Lacking attention to details
Eager to try new things	Dyslexia,	Being impatient
Appear overly forgetful	Language problems	Poor self-esteem/feeling insecure
Distracted	Difficulties with handwriting	Clumsiness
Disorganized		Temper outbursts
		Academic underachievement

Pattern 5: Necessity of the expert view.

Materials constructed ADHD as a very impactful, serious, negative and dangerous disorder that required proper treatment. It was described as a largely individual and usually biological problem: something in the child's biology causes problematic behavior. In addition, materials described that the consequences of ADHD stretch well beyond the individual child. These consequences affect not only the child's development, but also parents, siblings, peers, school and even society at large. In all, ADHD was explained as an individual problem that has far-reaching societal consequences. Due to this extensive impact, materials emphasized the necessity for children to receive proper care and treatment, for which expert knowledge is required in every step of the process. Expert status was assigned to professionals and clinicians. Materials paid limited attention to the experiences and knowledge of children and their parents. Children with ADHD were usually not mentioned as active agents in the process and were not mentioned in the communication about their experiences. Likewise, the child's positive characteristics received little attention. In all, psychoeducation materials did not attribute a form of expert-status to parents or children (although parent were assigned a more proactive role in American-English psychoeducation, see the section below on Agency of Parents).

> *"The knock-on effects of poorly managed or even unidentified ADHD, most notably the potential decline into the criminal justice system, highlight that early intervention is essential." - UK Material 3*

> *"Left untreated, ADHD in some children will continue to cause serious, lifelong problems, such as poor grades in school, run-ins with the law, failed relationships, and the inability to keep a job." – US Material 4*

Differences between countries

Overall, we found many more similarities than differences between countries. All of the patterns discussed above were present in materials from all countries. In this section we will briefly discuss two prominent differences we did find.

Variability in etiological explanations

We identified a difference in the discourse on ADHD etiology across countries. Dutch and Hungarian materials represented different perspectives or different 'explanatory frameworks', whereas materials in American and British English started from a more homogeneous, neurobiologically oriented perspective. In Dutch, some materials did not discuss etiology at all; some framed ADHD as entirely biological, while others described many different causal and risk factors. These included a variety of neuropsychological profiles, biological maturation, classroom pressure, and the impact of the direct and indirect

environment. Hungarian materials were equally variable and in addition introduced more controversial hypotheses. Some mentioned how our current "hyperactive society" shapes ADHD and how trauma, stress or toxins can contribute to its development. UK materials were relatively consistent. They usually discussed three distinct factors; genetics, neurobiology and environment. Genetic and neurobiological factors were presented as causes of ADHD, whereas environmental factors were presented as risk-factors. Numerous environmental factors were mentioned, including perinatal factors, bad parenting and family stress. In US materials, ADHD was usually explained as a genetic disorder that "runs in families". ADHD was framed as a genetic disorder that would subsequently impact the neurobiology of the child.

Agency of the parents

We identified a discursive pattern on parental agency in US materials, distinct from those in other materials. Specifically, parents were actively addressed as important agents in diagnosis and treatment. Parents were advised to read up on ADHD before going to a clinician to get help. Similarly, they were encouraged to actively manage their child's care and ensure that different parties communicate properly. To this end, US materials point to a law that gives parents and children the right to treatment and additional support. In the other countries, parents were assigned a much less proactive role, especially in the diagnostic process. Contacting an expert was usually recommended as a first step. Parents were told to rely on the expert throughout. With regard to treatment, a number of materials did emphasize the importance of parents and teachers. After learning more about the disorder, they would become "the key" to success.

Discussion

We carried out a discourse analysis of 41 psychoeducational materials on ADHD from the US, the UK, the Netherlands and Hungary. We explored how the explanatory framework of ADHD is constructed through the use of language. The materials contained a number of internal conflicts in how ADHD was framed and contextualized. Notably, these conflicts remained unaddressed in the documents. Conflicts arose from tension between 1) cause versus consequence, 2) uncertain complexity versus certain simplicity, 3) normality versus abnormality and 4) specificity versus generality. In addition, there was a clear pattern of the materials emphasizing 5) the necessity of the expert view.

By and large, we did not confirm our hypothesis of cross-cultural differences in how materials constructed the ADHD discourse. However, we did identify two differences between countries in the discourse on ADHD: we found differing etiological preferences and differing preferences for the agency of parents across countries. Here, American-English and British-English materials favored more straight-forward biomedical etiological explanations, while Dutch and Hungarian materials were more likely to include other, environmental explanations. Furthermore, American materials put greater emphasis on

the agency of parents than materials from other countries. These differences are likely to reflect differences in national perspectives on mental health (Asherson et al., 2012; Béliard et al., 2021; Bergey et al., 2018; Smith, 2017), such as legal differences in the right to care. Overall, however, we found that the similarities in the discourse on ADHD from different countries were much greater than the differences between them. This may well be the consequence of increased global discourse on classifications in general, and DSM in particular (Conrad & Bergey, 2014; Mills, 2014; Singh et al., 2013).

We found internal conflicts in the discourse on ADHD, across psychoeducational materials from four different countries. Such conflicts may have a number of consequences. One possible consequence is that children diagnosed with ADHD and their parents might be confused. One of the main aims of psychoeducation is to help children and parents better understand their problems and subsequently promote better coping (Dahl et al., 2020; Montoya et al., 2011; Oliveira & Dias, 2018). Yet, if the information provided is conflicting, children and parents may well be left with incoherent integration of the information provided and feel confused as to how to understand themselves or their children. Subsequently, this could affect expectations of coping, recovery and future development (Butlin & Wilson, 2018; Corrigan & Watson, 2004; Freedman, 2016; Lam & Salkovskis, 2007; O'Connor & McNicholas, 2020).

A second possible consequence stems from the conflict between uncertain complexity and certain simplicity in psychoeducational materials. Materials often stated that the causes of ADHD were complex and unknown. Yet, in the simplified information they subsequently provided on causes and risk factors, they omitted details and nuance, nearly always in favor of biomedical causes. One example of such a misrepresentation is materials stating that neurobiological research has shown indisputable and consistent differences between children with and without a classification (Batstra et al., 2014; Meerman et al., 2017). However, these differences referred to are only found at a group level and the effect sizes are very small (Hoogman et al., 2017; Sowell et al., 2003). As such, it is not an indisputable fact that an individual child with a classification differs neurobiologically from a child without a classification. Statements suggesting otherwise can lead parents to believe (and communicate) that their child's brain is different from that of their peers. Yet, a more nuanced interpretation of the neurobiological literature would be that the likelihood of an actual difference is small at the individual level. As such, parents may conclude from the educational materials that the causes of ADHD are definite and conclusive, while they in fact are not.

A third possible consequence stems from the conflict between cause and consequence. We found a form of circular reasoning where ADHD was described as a term given to a cluster of symptoms and, simultaneously, as the cause of those symptoms. This finding is

a replication of earlier studies describing this process (Batstra et al., 2014; Erlandsson et al., 2016; Hyman, 2010; Meerman et al., 2017; Pérez-Álvarez, 2017). Naming ADHD as a cause of symptoms implies that problems lie with or within the child with ADHD and leaves little space for exploring the context in which problematic behaviors occur (Freedman, 2016; Meerman et al., 2017; Singh, 2002; Timimi, 2017). This decontextualization is reflected in the language we use to discuss ADHD. For example, Statements such as 'ADHD is part of the child's make-up and doesn't suddenly appear out of the blue – UK Material 7' underline how we individualize ADHD.

Three of the internal conflicts we have described, relate directly to tensions between the biomedical and psychosocial perspectives. In the biomedical framework, defining ADHD as a cause of behaviors is justified as a direct biological mechanism is believed to underlie the symptoms (Anckarsäter, 2010; Frances, 2016). Such a framework may warrant simple and certain explanations, whereas the integration of different perspectives requires more nuance and complexity. Furthermore, taking a biomedical approach to ADHD justifies the theory that children with ADHD are distinctly different from other children. A psychosocial approach allows for more normalization of problematic behaviors, specifically for the individual child (Corrigan & Watson, 2004; Erlandsson et al., 2016; Freedman, 2016; O'Connor & McNicholas, 2020).

Notably, we found that tensions between biomedical and psychosocial perspectives have resulted in conflict within a single thematic stance on ADHD in psychoeducational materials, as opposed to conflict between parties with different visions on ADHD. We speculate that these unaddressed, internal conflicts arise from a covert tension within the biopsychosocial model. The biopsychosocial model is one of the most widely accepted approaches to mental health (Engel, 1980). According to this model the interplay between biological, psychological and social factors underlies behavioral and emotional problems (Engel, 1980; Ghaemi, 2009). Within the context of this biopsychosocial model, there seems to be a covert preference for biology (Batstra et al., 2020; Benning, 2015; Bourdaa et al., 2015; Freedman, 2016; Mitchell & Read, 2012; Ponnou & Gonon, 2017). In the materials we analyzed, neurobiological and genetic factors were prioritized: they were discussed ahead of environmental factors, received more attention and were assigned more definitive terminology. In other words: we found a covert primacy of biology. This primacy is illustrated in the notion, found in many materials, that ADHD is caused by neurobiological difficulties in the context of environmental risk factors. The opposite was never considered: could ADHD be caused by environmental difficulties in the context of biological risk factors? According to the biopsychosocial model, neurobiological and environmental factors should be considered equally. Yet the ordering and terminology in the materials prioritize biology. This covert primacy of biology may well lead to tension in the biopsychosocial model and in turn lead to inconsistent and incoherent information on ADHD.

In sum, we found a number of internal conflicts in how ADHD is framed and contextualized in psychoeducational materials. Notably, these conflicts remained unaddressed in the materials themselves and may potentially lead to confusion, misrepresentation and decontextualization of ADHD. Ultimately, for those diagnosed with ADHD, and their parents, these conflicts may hamper their ability to understand themselves in the context of their attentional difficulties.

Limitations

A limitation of our study is that we did not involve children with ADHD and their parents. We therefore could not verify that our interpretation of the materials aligns with how parents and children understand and interpret the information. An important next step in this line of research would be to evaluate how psychoeducational materials are interpreted by lay readers.

A second limitation in our study is the use of convenience sampling. We selected the first materials that we came across in our internet search (and that fitted our selection criteria). We chose to select the materials in this way, because we felt that parents of children with ADHD would be most likely to interact with those materials first presented by search engines. However, our sample is not representative of all psychoeducational materials on ADHD. We would have to carry out a much more extensive study to verify such claims. Moreover, we were unable to collect information on funding for psychoeducational materials, as information on websites was often missing or incomplete.

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Supplementary Material 1. List of Psychoeducational Materials

Table 1.

Materials from the United States

#	Type of material	Title	Author	Institution/ Publisher
1	website	Attention-deficit/ hyperactivity disorder (ADHD) in children	Mayo Clinic Staff	Mayo Clinic
2	website	What is ADHD?	Physician Review: Ranna Parekh, M.D.	American Psychiatric Association (APA)
3	website	Attention-Deficit/ Hyperactivity Disorder	National Institute of Mental Health (NIMH)	National Institute of Mental Health (NIMH)
4	website	Understanding ADHD: Information for Parents	American Academy of Pediatrics	American Academy of Pediatrics
5	website	ADHD – Attention Deficit Hyperactivity Disorder in Northern New Jersey	Psycho-Educational Associates	Psycho-Educational Associates
6	website	What is ADHD?	Centers for Disease Control and Prevention	Centers for Disease Control and Prevention
7	website	Parenting a Child with ADHD	Children and Adults with Attention-Deficit/ Hyperactivity Disorder (CHADD)	Children and Adults with Attention-Deficit/ Hyperactivity Disorder (CHADD)
8	website	What is ADHD?	American Academy of Child and Adolescent Psychiatry (AACAP)	American Academy of Child and Adolescent Psychiatry (AACAP)
9	website	ADHD: What is ADHD	Nemours KidsHealth. Reviewed by: Shirin Hasan, M.D.	Nemours KidsHealth
10	website	Tell Me All I Need To Know About ADHD	Jennifer Tzeses Reviewed By: Randy Bressler	Psycom
11	website	What is ADHD?	Understood Team	Understood

	Published in	*Audience*	*Word Count*	*Link*
	2019	adults	3298	https://www.mayoclinic.org/diseases-conditions/adhd/diagnosis-treatment/drc-20350895
	2017	adults	1455	https://www.psychiatry.org/patients-families/adhd/what-is-adhd
	2019	adults	2617	https://www.nimh.nih.gov/health/topics/attention-deficit-hyperactivity-disorder-adhd/index.shtml
	Written in 2007. Last updated in 2019.	parents	894	https://www.healthychildren.org/English/health-issues/conditions/adhd/Pages/Understanding-ADHD.aspx
	Not mentioned	parents	515	http://www.psycho-edassociates.com/disorders/attention-deficit-hyperactivity-disorder-adhd-in-new-jersey/
	Last reviewed in 2021	parents	1021	https://www.cdc.gov/ncbddd/adhd/facts.html
	2018	parents	1530	https://chadd.org/wp-content/uploads/2018/03/aboutADHD.pdf
	Not mentioned	parents	623	https://www.aacap.org/AACAP/Families_and_Youth/Resource_Centers/ADHD_Resource_Center/ADHD_A_Guide_for_Families/What_is_ADHD.aspx
	Last reviewed in 2020	parents	963	https://kidshealth.org/en/parents/adhd.html
	Last Reviewed in 2021	adults	3477	https://www.psycom.net/adhd
	Not mentioned	youth and adults	1239	https://www.understood.org/en/learning-thinking-differences/child-learning-disabilities/add-adhd/what-is-adhd?_ul=1*1k32del*domain_userid*YW1wLTNzY25OQ1lJa3NTLXNTUjB0ajRtVnc.

Table 2.

Materials from the United Kingdom

#	*Type of material*	*Title*	*Author*	*Institution/ Publisher*
1	online flyer	Advice and Information for Parents and Carers: ADHD	Young Minds	Young Minds
3	website	Q&A What is ADHD	The UK ADHD Partnership (UKAP)	The UK ADHD Partnership (UKAP)
4	website	ADHD and hyperkinetic disorder: for parents and carers	Royal College of Psychiatrists	Royal College of Psychiatrists
5	website	Attention deficit hyperactivity disorder (ADHD)	The Child and Adolescent Mental Health Service in collaboration with the Child and Family Information Group	NHS - Great Ormond Street Hospital for Children
6	website	Attention Deficit Hyperactivity Disorder (ADHD)	Mental Health Foundation	Mental Health Foundation
7	online flyer	ADHD: A compact guide for parents	Living with ADHD	Living with ADHD
8	website	ADHD in children and teenagers	Clinical Partners	Clinical Partners
9	website	ADHD in children	ADHD Care LTD	ADHD Care LDT
10	website	Attention Deficit Hyperactivity Disorder (ADHD)	ADHD Voices	ADHD Voices
11	website	Information Centre	ADHD Information Services (ADDISS)	ADHD Information Services (ADDISS)

	Published in	*Audience*	*Word Count*	*Link*
	2019	parents	1293	https://youngminds.org.uk/media/3671/adhd-updated-dec-2019.pdf
	Information not provided	adults	1134	https://www.ukadhd.com/questions-and-answers.htm?category=112#What%20is%20ADHD?
	Information not provided	adults	2192	https://www.rcpsych.ac.uk/mental-health/parents-and-young-people/information-for-parents-and-carers/attention-deficit-hyperactivity-disorder-and-hyperkinetic-disorder-information-for-parents-carers-and-anyone-working-with-young-people
	Last Reviewed in 2016	adults	2044	https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/attention-deficit-hyperactivity-disorder-adhd
	Information not provided	adults	543	https://www.mentalhealth.org.uk/a-to-z/a/attention-deficit-hyperactivity-disorder-adhd
	2019	parents	4012	https://janssenwithme.co.uk/en-gb/living-with-adhd-parents/adhd-resources
	Information not provided	adults	494	https://www.clinical-partners.co.uk/child-adolescents/child-teen-adhd/adhd-in-children#what-is-adhd
	Information not Provided	adults	540	https://www.adhdcare.co.uk/?p=adhd.in.children
	Information not Provided	adults	301	http://www.adhdvoices.com/adhd/
	Information not provided	adults	1774	http://www.addiss.co.uk/adhd.htm

Table 3.

Materials from the Netherlands

#	Type of material	Title	Author	Institution/ Publisher
1	website	"Psycho-educatie ADHD" [Psychoeducation ADHD]	"Zorgpad ADHD" [Carepath ADHD]	Zorgpad ADHD [Carepath ADHD]
3	website	„Richtlijn / Info voor Ouders ADHD" [Guideline / Info for Parents ADHD]	Frits Boer, Barbara van den Hoofdakker, Pier Prins, Wil Hogeman-Weijers, Matthijs Oud Geurt van de Glind & Henny Sinnema	"Richtlijnen jeugdhulp en jeugdbescherming" [Guidelines for youthaid and youthprotection]
4	website	"ADHD: wat werkt? "w [ADHD: what works?]	"Nederlands Jeugdinstituut (NJI) " [Netherlands Youth Institute]	"Nederlands Jeugdinstituut (NJI) " [Netherlands Youth Institute]
5	Online Flyer / Website	"Kinderen en druk gedrag" [Children and hyperactive behavior]	"ADHD wat nu" [ADHD what now]	"ADHD wat nu" [ADHD what now]
6	Online Flyer	"ADHD – Kinderen met aandachts-tekortstoornis met of zonder hyperactiviteit" [ADHD – Children with Attention Deficit Disorder with or without hyperactivity]	Balans	Balans
7	Online Flyer	„ADHD bij volwassenen: aandachtstekort-hyperactiviteits stoornis" [ADHD in adults: Attention Deficit Hyperactivity Disorder]	"Nederlandse Vereniging voor Psychiatrie" [Dutch Psychiatry Association]	"Nederlandse Vereniging voor Psychiatrie" [Dutch Psychiatry Association]
8	website	"ADHD bij kinderen" [ADHD in Children]	Hersenstichting [Brain Foundation]	Hersenstichting [Brain Foundation]
10	Online flyer	"Onrustig, impulsief of onoplettend; ADHD of iets anders? " [Restless, impulsive or inattentive: ADHD or something else?]	„Monique Verburg, Sanne te Meerman en Leden van de Academische Werkplaats voor ADHD en Druk Gedrag" [Monique Verburg, Sanne te Meerman and Members of the Academic Workplace for ADHD and hyperactive behavior]	„Academische Werkplaats voor ADHD en Druk Gedrag" [Academic Workplace for ADHD and hyperactive behavior.]
11	website	ADHD	Youz	Youz

	Published in	*Audience*	*Word Count*	*Link*
	2020	adults	3077	https://www.adhd-traject.be/nl/pagina/adhd
	2016	parents	1618	https://richtlijnenjeugdhulp.nl/adhd/wat-is-adhd/adhd-beloop/
	Information not provided	adults	721	https://www.nji.nl/adhd/wat-werkt
	2019	parents	1378	https://adhdwatnuweb.nl/
	Information not provided	parents	810	https://balansdigitaal.nl/wp-content/uploads/2021/08/Balans-Folder-ADHD.pdf
	2002	adults	3243	https://praktijk-hagedoorn.nl/assets/uploads/files/In_gesprek_over_ADHD_bij_volwassenen.pdf
	2020	adults	282	https://www.hersenstichting.nl/hersenaandoeningen/adhd-bij-kinderen/
	2019	parents	2435	https://www.karakter.com/assets/uploads/Downloads/Brochure20voorlichting20versie2011.pdf
	Information not provided	adults & children	2250	https://www.youz.nl/adhd

Table 4

Materials from Hungary

#	Type of material	Title	Author	Institution/ Publisher
1	website	Hiperaktivitás -Olyan, mint akit felhúztak- [Hyperactivity- As if they were wound up]	Dr. Garas Péter & Vidomusz Réka	Vadaskert Child and Adolescent Psychiatric Clinic & Fitt Békés- Békési egészség monitoring rendszer
2	booklet	tájékoztató füzet ADHD-s gyermekek szülei részére [Booklet for parents of children with ADHD]	lilly szülőknek [Lilly for parents]	Ignáci pedagógiai műhely [Ignác Pedagogical Workroom]
3	website	„Amikor nem járni tanul meg, hanem rohanni először, **és** amint megtanul beszélni, be nem **áll** a szája" -avagy mi **áll** az ADHD hátterében? [„When they don't learn to walk, but run first. And when as soon as they learn to speak, they don't shut their mouth"- or what is behind ADHD?]	Sófi-Ősz Veronika	Heim Pál Children's Hospital
4	Magazine article	ADHD hipergyerekek [ADHD hyperchildren]	Bárnosi Eszter	Vadaskert Child and Adolescent Psychiatric Clinic
5	website	Figyelemzavaros hiperaktivitás gyermekkorban (ADHD) [Attention deficit hyperactivity in childhood]	Egészségkalauz [Health Guide]	Egészségkalauz [Health Guide]
6	website	ADHD [ADHD]	Virág Henrietta	Családinfó [Family info]
7	website	Hiperaktivitás, ADHD [Hyperactivity, ADHD]	Budai Egészségközpont [Buda Health Center]	Budai Egészségközpont Kft [Buda Health Center]
8	website	ADHD, avagy Figyelemhiányos hiperaktivitás zavar [ADHD, or Attention Deficit Hyperactivity Disorder]	Arbor Egészségfejlesztő központ [Arbor Health promotion Center]	Arbor Egészségfejlesztő központ [Arbor Health promotion Center]
9	website	ADHD [ADHD]	Csíky Miklós	ADHDoki [ADHDoc]
10	website	Az ADHD/ADD-ról részletesen [About ADHD/ ADD in detail]	ADHD Központ [ADHD Center]	ADHD Központ[ADHD Center]

	Published in	*Audience*	*Word Count*	*Link*
	2015	adults	650	http://www.bekesmegyeiegeszseg.hu/tudastar/cikk/471 https://vadaskert.hu/hiperaktivitas/
	2015	adults	790	http://ignacipedagogia.hu/wp-content/uploads/2017/03/ADHD-T%C3%A1j%C3%A9koztat%C3%B3-f%C3%BCzet-ADHD-s-gyermekek-csal%C3%A1djai-r%C3%A9sz%C3%A9re_hajtogat%C3%B3s.pdf
	2018	adults	819	https://gyogyhirek.hu/figyelemkontroll-adhd/
	2019	adults	1259	http://vadaskert.hu/wp-content/uploads/2019/03/gyerekle%CC%81lek_adhd.pdf
	2015	adults	1112	https://www.egeszsegkalauz.hu/betegsegkereso/mentalis-betegsegek-viselkedeszavarok/figyelemzavaros-hiperaktivitas-gyermekkorban-adhd/38mqj42
	2019	adults	1228	https://csaladinfo.hu/2019/11/adhd/
	Information not provided	adults	788	https://bhc.hu/betegsegek/hiperaktivitas/
	Information not provided	adults	1484	http://www.arborek.hu/adhd-avagy-figyelemhianyos-hiperaktivitas-zavar
	Information not provided	adults	1653	http://adhdoki.blogspot.com/p/adhd.html
	Information not provided	adults	1786	https://www.adhdkozpont.hu/az-adhd-rol/

Supplementary Material 2. Data analysis plan

We (RS, DR & MvL) designed an analysis plan and carried out a practice analysis on two Canadian materials. We then rated the British-English materials simultaneously in order to reach further consensus on methodology and findings. Subsequently we rated the American-English (DR), Hungarian (RS) and Dutch (MvL) materials independently. These are the steps taken during the analysis of the materials from each of the countries.

1. Logging of preconceived notions

   * We independently logged our preconceived notions.

2. Reading of the materials

   * We carried out a detailed reading of the materials four times over.
     - We read each of the 10 materials twice in the following order: 1, 2, 1, 2, 3, 4, 3, 4, 5, 6, 5, 6, 7, 8, 7, 8, 9, 10, 9, 10. The reading of the materials was spread across two days in order to ensure that we were able to stay focused.
     - During and after the reading of the materials, we kept notes of our thoughts and findings. We also discussed our first impressions.
     - Without looking at the materials again we wrote down what we remembered from the contents of the materials title by title. We had a short discussion meeting about what we remembered.
     - We read through the materials again in the same order. We continued to keep notes and had another discussion meeting at the end.

3. Coding of the materials

   * We coded two materials a day. Coding was split up into three steps. We went through these steps for each material consecutively.
     - Content coding. In the first step we strictly coded the content of the material to establish an overview of the information included in the materials.
     - Interpretative coding. The second step involved a more critical interpretation of the data. We coded how the classification ADHD was explicated and framed, how meaning was given to concepts and how implicit ideas and understanding of ADHD were transferred through the text.
     - Linguistic coding. In the third step we coded for language use, wording and phrasing in the text. We did not code all language use in the text, but focused on those phrases that stood out and referred back to the interpretative coding of step 2.
   * We had daily discussion meetings to talk about the two previously coded materials.

We took some time to talk about our findings, how we coded the text and what stood out to us most.

4. Structuring of the coding

   * After the coding of the text, we individually went through our coding and structured our findings. In this individual evaluation we answered the following three questions:

     - What codes in the content coding did you use most frequently and how can we best summarize and generalize the content of the ten materials? Give an accurate general description of the content of the materials.
     - What are the most relevant/important/noticeable codes in the interpretative coding? If you could compliment or critique the materials we have read so far, what would you want to point out?
     - What are the most noticeable linguistic features in the text and how do they link to the interpretative findings? What are the text quotes and examples that best represent the established interpretation in the previous question?

5. Discussion meeting

   * We had an extensive discussion meeting. In this meeting we presented how we individually answered the questions in step four. After we each presented our individual evaluation of the coding, we then found consensus on how to summarize and interpret our findings. We came to a conclusion about the most relevant patterns in the data and how these patterns constructed the information and explanatory frameworks being shared with parents and children.

6. Preliminary result section

   * We composed a preliminary version of our results, in which we wrote down our findings. We linked these to the most relevant text quotes. This preliminary version was then critically discussed with BvH who had deliberately not read the materials at this point in time. This was to warrant that critique was aimed at clarity and not content of the discursive patterns. We made adjustments to the preliminary results accordingly.

After completing these steps for the British English materials, we carried them out independently for the American English, Dutch, Hungarian materials. We had intermittent discussion meetings, but as we were all coding different materials, these meetings were less detailed. After all materials were coded, analyzed and interpreted, we had overarching discussion meetings to evaluate our findings and discuss differences between the languages. These findings were integrated in the preliminary result section.

7. Quantitative description

After defining the major patterns in the data, we reanalyzed the materials to check our findings and count the number of occurrences in the data. This analysis consisted of the following steps:

* We defined how to count/code our themes
* We piloted these definitions on one material from each language
* We analysed the British English materials by coding
* We discussed how to count each theme and reached consensus on the occurrences
* We individually analyzed the other languages
* We discussed any uncertainties and reached consensus on the occurrences within and across materials. We integrated these findings in the result section.

Supplementary Material 3. Examples of internal conflicts in ADHD psychoeducation

Pattern 1: Cause vs. Consequence

"Attention deficit hyperactivity disorder is a condition, which affects those parts of the brain which control attention, impulses and concentration (a neurobiological condition)." - UK Material 11

"Studies show that ADHD may affect certain areas of the brain that allow us to solve problems, plan ahead, understand others' actions, and control our impulses." - US Material 8

"ADHD stands for Attention Deficit Hyperactivity Disorder, which is a chronic psychiatric behavioural disorder that manifests as a persistent pattern of inattention and or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development." - UK Material 3

"ADHD can present with different behaviours depending on the age, setting (i.e. school, home, playground) and even motivation (e.g. when doing an activity or something a child likes)." - UK Material 4

"ADHD op volwassen leeftijd kan goed worden behandeld. Het feit dat er een verklaring is voor de jarenlange klachten geeft vaak al opluchting" [ADHD in adult age can be adequately treated. The

fact that there is an explanation for years of complaints usually provides relief] - DU Material 7

"ADHD is thought to be caused by an imbalance of two neurotransmitters, dopamine and noradrenaline, which are believed to play an important role in the ability to focus and pay attention to tasks." - UK Material 11

"ADHD is a common condition that's caused by differences in the Brain" - US Material 11

"ADHD is geen verklaring voor het gedrag, een kind doet niet druk omdat hij ADHD heeft, maar ADHD geeft een naam aan onrustig, impulsief en onoplettend gedrag" [ADHD is not an explanation/justification for behavior, a child is not hyperactive because he has ADHD, but ADHD gives a name to restless, impulsive or inattentive behavior] - DU

Material 10

Pattern 2: Uncertain Complexity vs. Certain Simplicity

"Scientists have not yet identified the specific causes of ADHD." - US Material 2

"ADHD is caused by a complicated combination of multiple factors" - UK Material 1

"Az ADHD okai és kockázati tényezői egyelőre ismeretlenek, de a jelenlegi kutatások szerint a genetika mindenképpen szerepet játszik." [The causes and risk factors for ADHD are still unknown, but current research suggests that genetics certainly play a role] - HU Material 4

"Researchers are not sure what causes ADHD." - US Material 3

"Wat precies de oorzaak van ADHD is, weten we niet" [We don't know what exactly the cause of ADHD is] - DU Material 3

"A figyelemhiányos hiperaktivitási zavar okai nincsenek teljesen tisztázva." [The causes of Attention Deficit Hyperactivity Disorder are not fully clarified] - HU Material 7

"It's not clear what causes the brain differences of ADHD" - US Material 9

"ADHD is a disorder in certain areas of the brain and is inherited in the majority of cases. It is not caused by poor parenting or a chaotic home environment" - US Material 7

"Bij mensen met ADHD werkt een bepaald hersengebied namelijk niet goed". [In people with ADHD, one particular brain area doesn't function well] - DU Material 12

"WAT ZIJN DE OORZAKEN VAN ADHD? 75-88% van de onderlinge verschillen is te wijten aan genetische (erfelijke) factoren" [What are the causes of ADHD? 75-88% of the individual differences can be attributed to genetic (inheritable) factors] - DU Material 1

"Kiemelendő, hogy az ADHD kialakulásához idegrendszeri működésbeli eltérések járulnak hozzá, ezért el kell különíteni azokat az ADHD-hoz hasonlító viselkedési problémákat, melyeket környezeti hatások biztosítanak: mint például nevelési problémák, jelentős iskolai leterheltség, vagy a gyermek életében bekövetkező negatív életesemény." [It should be emphasized that neurodevelopmental abnormalities contribute to the development of ADHD. It is therefore necessary to distinguish between behavioral problems similar to ADHD that result from environmental effects: such as educational problems, significant school workload, or a negative life events in the child's life] - HU Material 7

"It is not caused by poor parenting or a chaotic home environment, although the home environment can make the symptoms of ADHD better or worse." US Material 7

"Brain scan studies and psychological studies have found subtle but distinct differences between the brains of people with and without ADHD, in their structure, the way in which they develop and the ways that they work."- UK Material 7

"Bij ADHD werken de remmende systemen in de hersenen onvoldoende en hebben de hersenen moeite met het verwerken van informatie." [In ADHD the inhibitory systems in the brain work insufficiently and the brain has difficulties with processing information] - DU Material 5

Pattern 3: Normality vs. Abnormality

"Its core symptoms are hyperactivity, impulsivity and inattention. These common childhood behaviours occur on a continuum from normal to abnormal. It can be very difficult to judge what

'normal' behaviour is in children; therefore when evaluating children for ADHD, many doctors try to assess the degree of impairment caused by these behaviors." - UK Material 10

"In de bevolking komen al deze symptomen "dimensioneel" voor. Je kan ze dus meer of minder vertonen, eerder dan wèl of niet. Enkel wanneer een bepaalde ernstgraad wordt overschreden wordt het ADHD genoemd" [In the population all of these symptoms occur 'dimensionally'. The extent to which you exhibit them may vary, rather than them being entirely present or absent. Only when a certain level of severity is reached, will it be called ADHD] - DU Material 1

"a figyelemzavar és hiperaktivitás tünetei normális esetben is gyakran előfordulhatnak. Ha valakinek egy izgő-mozgó gyermeke van, akkor laikusként azt gondolhatja, hogy igazából nincs is azzal semmi probléma, hogy valaki gyerekként nagyon aktív vagy éppen sokat szaladgál. Ez valójában egészségesnek is tekinthető egy bizonyos szintig, ám itt mindig a mérték a kérdés." [Symptoms of ADHD commonly occur in normal cases too. If someone has a fidgety child, you may think, as a layman, that there is really nothing wrong with being very active as a child or just running around a lot. It can actually be considered healthy to a certain level. But the question here is always to what extent.] - HU Material 8

"The recognition of ADHD as a serious medical condition continues to grow by physician groups and government health agencies around the world." - UK Material 3

"ADHD is a clearly defined clinical condition and not just a label for naughty or badly brought-up children." - UK Material 7

"Left untreated, ADHD in some children will continue to cause ¬serious, lifelong ¬problems, such as poor grades in school, run-ins with the law, failed relationships, and the inability to keep a job" - US Material 4

"When ADHD is not treated, it can be hard for kids to succeed. This may lead to low self-esteem, depression, oppositional behavior, school failure, risk-taking behavior, or family conflict." - US Material 9

Pattern 4: Specificity vs. Generality

"ADHD is a well-defined clinical condition. All the major medical authorities recognise it, including the World Health Organisation and the American Psychiatric Organisation." - UK Material 7

"ADHD can be categorised by three areas – attention, hyperactivity and impulsivity." - UK Material 6

ADHD can take different forms in different children but there are three common characteristics which include: Inattention, Hyperactivity and Impulsivity)." - UK Material

"Healthcare professionals use a list of symptoms to officially diagnose ADHD (known as the diagnostic criteria of the American Psychiatry Association DSM-IV or the World Health

Organisation ICD10)." - UK Material 11

Table 1

List of all ADHD-related symptoms mentioned in the UK Materials

Impulsiveness	Unable to listen or concentrate	Neurological problems (tics or epilepsy)
Hyperactivity/Being overactive	Slow to start tasks	Can't sit still, walks, runs
Inattention/ short attenion span	Struggle to finish tasks and often don't	Can't do any one thing for very long
Restlessness	Creative	Climbs around when others are seated
Fidgety	Intelligent	Daydreaming /seeming to be in another world
Full of energy	Determined	Sidetracked by what is going on in surroundings
Loud and Noisy	Good at problem-solving	Mood swings
Continuous chatter/Talking excessively	Lack of coordination	Being careless
Talks when others are talking	Lack of social skills/social clumsiness	Making too many mistakes at school
Doing things repeatedly without thinking	Learning difficulties/ disabilities	Making silly or careless mistakes
Finding it hard to wait their turn in games or a queue	Autism	Disruptive in play
Interrupting others in conversation or in play	Conduct disorder/ Oppositional defiant disorder	Always on the go
Hardworking	Anxiety	Often lose their belongings
Persevere at tasks	Depression	Lacking attention to details
Eager to try new things	Dyslexia,	Being impatient
Appear overly forgetful	Language problems	Poor self-esteem/feeling insecure
Distracted	Difficulties with handwriting	Clumsiness
Disorganized		Temper outbursts
Academic underachievement		

Pattern 5: Necessity of the expert view

"The knock-on effects of poorly managed or even unidentified ADHD, most notably the potential decline into the criminal justice system, highlight that early intervention is essential." - UK Material 3

"Left untreated, ADHD in some children will continue to cause serious, lifelong problems, such as poor grades in school, run-ins with the law, failed relationships, and the inability to keep a job." - US Material 4

"Het voor ADHD zo kenmerkende levenslange patroon van klachten en mislukkingen moet in kaart worden gebracht" [The lifelong pattern of complaints and failures that is so characteristic of ADHD needs to mapped] - DU Material 7

„Későbbi életkorban egyre gyakoribb az agresszív cselekedet, drog- és alkoholfogyasztás, közlekedési balesetek okozása, kisebb-nagyobb bűncselekmények. Az ilyen esetekben elkövetett, meggondolatlan cselekedetek miatt börtönbe került fiatalok több, mint felénél pszichiátriai betegségeket találtak, melynek 90 százaléka ADHD volt. A fiú-lány megoszlási arány: 9:1 a fiúk „javára"[Later in their life, aggressive actions, drug- and alcohol use, causing traffic accidents, smaller or larger crimes become more frequent. Children sent to prison for these recklessly committed crimes were found to be diagnosed with a psychiatric disorder in half of the cases, 90% of which were ADHD] - HU Material 3

"Az ADHD egy krónikus zavar, mely hozzátartozik gyermekéhez, és okát az agyban kell keresni."[ADHD is a chronic disorder, that is part of your child, and the causes need to be searched in the brain.] - HU Material 2

"Some of the challenges that children with ADHD can face and the wider impact on the family, school staff and other children include: difficulties in school and friendships, underperforming in school and engaging in antisocial activities." - UK Material 1

"Je ADHD kan je in de weg zitten in je dagelijks leven. Je concentratieproblemen, je impulsiviteit en je drukte zorgen voor problemen. Voor jou, maar ook voor de mensen om je heen. Onze behandelaars kunnen, samen met jou, zorgen dat je je weer kunt ontwikkelen." [Your ADHD can get in your way in daily life. Your concentration difficulties, your impulsivity and your hyperactivity cause problems. For you, but also for the people around you. Our clinicians can, together with you, ensure that you can start developing again] - DU Material 12

"Ook is aangetoond dat kinderen met ADHD, gedrag uitlokken bij hun ouders dat het ADHD-gedrag nog gaat versterken (dit noemt men een evocatief gen-omgevingsinteractie-effect)"[It has also been demonstrated that children with ADHD can provoke behavior in their parents that reinforce even more ADHD-related behaviors (this has been called the evocative gene-environment- interaction effect)] - DU Material 1

"Those who receive specialist support plans tailored to their needs, see the benefits in their learning, friendships, employability and life skills as they understand how best to cope and adapt." - UK Material 1

"Om erachter te komen of een kind ADHD heeft is een gespecialiseerd onderzoek nodig. Dit onderzoek vindt pas plaats als er een duidelijke aanleiding is"[To find out if a child has ADHD, specialized testing is needed. This testing only takes place if there is a clear reason] - DU Material 5

"De diagnose ADHD wordt gesteld door een medisch specialist: meestal is dit een (kinder- en jeugd)psychiater." [The diagnosis ADHD is given by a medical specialist, usually a (child and adolescent) psychiatrist] - DU Material 8

"A child suffering from ADHD needs treatment across all situations where the difficulties occur. This means support and help at home, school, with friends and community." - UK Material 4

"A child will need the right treatment and support to ensure they are able to make the most of their education and life in the long-term" - UK Material 5

"However, early identification so that treatment (whether behavioural, psychological or medication) can be started is very important, so that the child is able to achieve his/her full potential"- UK Material 11

Chapter 4

Should I share my diagnosis?

How our attitude towards other people is colored by knowledge of their psychiatric classifications

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Abstract.

Introduction. Individuals with a psychiatric classification regularly face the dilemma of whether to share their diagnosis with others. This was the starting point for our study. *Methods.* We investigated whether affective, cognitive and behavioral attitudes differed between people who did and did not know the psychiatric classifications of a young woman sharing a short personal story. Participants watched a real-life video vignette and filled in a short questionnaire on their attitudes towards her. *Results.* In the final dataset of 1605 participants, we found differences in cognitive and behavioral attitudes. Participants with knowledge of her classifications preferred more social distance than people without it. Moreover, we found that people with personal experience of psychiatric classification held more positive attitudes than people without. *Conclusion.* For someone dealing with mental health issues, these are important considerations in deciding whether to share one's classifications. Ultimately, open communication about mental health should lead to less social distance, not more.

Introduction

People with mental health problems encounter a range of difficulties in daily life. One dilemma they face is whether to share the name of their disorder - or their psychiatric classification - with the people surrounding them. On the one hand, sharing may lead to increased understanding, leniency, and help. On the other, it may lead to stigma. We took this dilemma as a starting point for our study. We investigated whether sharing one's psychiatric classifications affected others' attitudes towards an individual.

Psychiatric classifications are names that refer to clusters of behavioral symptoms commonly observed together (American Psychiatric Association, 2013; World Health Organization, 2004). These classifications were developed to improve mental health care and are assigned to individuals with the intent of providing a shorthand to: (1) understand and communicate about experienced difficulties and (2) understand how these difficulties might best be treated (Anckarsäter, 2010; Angermeyer & Matschinger, 2003; Frances, 2016; Pilecki et al., 2011; Sanders, 2011). Yet, classifications have come to be used by a variety stakeholders in widely varying contexts, including scientific, therapeutic, pedagogical, social and administrative ones (Werkhoven et al., 2022). As such, their impact has come to stretch well beyond that of mental health care (Corrigan & Watson, 2002; First et al., 2019; Hacking, 2007).

Mental health stigma encompasses negative and unfair beliefs about individuals with psychiatric classifications (Corrigan & Watson, 2002; Hinshaw, 2005). The most common form of stigma is public stigma (Corrigan & Watson, 2002; Kaushik et al., 2016), which is directed from the public towards individuals with a psychiatric classification. Public stigma has three components: (1) stereotypes; the social knowledge structures shared and learned by members of a group, (2) prejudice; the endorsement of and emotional reaction to negative stereotypes, and (3) discrimination; the behavioral reaction to prejudice (Corrigan & Watson, 2002; Kaushik et al., 2016). For instance, the perception that an individual with a psychiatric classification is dangerous (stereotype), leads to fearfulness (prejudice), which in turn causes avoidance and social distancing behavior (discrimination) (Angermeyer & Matschinger, 2003; Corrigan & Watson, 2002; Martin et al., 2007). Positive pathways have also been described: if the absence of personal responsibility for a psychiatric classification is stressed, this can lead to increased understanding and acceptance, and will in turn exacerbate helping behaviors and sympathy (Angermeyer & Matschinger, 2003). The interaction between psychiatric classifications and stigma is complex. Empirical research has led to conflicting results and, as such, has been largely inconclusive (O'Connor et al., 2022).

Individuals with psychiatric classifications regularly face the decision whether or not to share their classification with others (Fowler & O'Connor, 2021; Huws & Jones, 2008). If the environment endorses largely negative attitudes towards classifications, sharing is

likely to negatively affect how others perceive them and behave towards them. However, if attitudes are more positive, sharing may increase social acceptance and understanding. Yet, studies on the impact of classifications on stigma have shown mixed results (Benson et al., 2015; dosReis et al., 2010; Kinnear et al., 2016; Lebowitz, 2016; Selman et al., 2018). Some studies have suggested that sharing classifications places individuals and their behaviors in a more negative light, and hence leads to more stigmatization (Angermeyer & Matschinger, 2003; Klasen, 2000; Lebowitz, 2016; Martin et al., 2007; Ohan et al., 2011). Others have suggested that it is not the classification that leads to stigma, but rather the behaviors associated with it (Dolphin & Hennessy, 2017; Kaushik et al., 2016; Law et al., 2007; Swaim & Morgan, 2001). These studies suggest that classifications may counteract stigmatization by redirecting blame away from the individual (Chambres et al., 2008; Klasen, 2000).

Mental health stigma can be studied in roughly two ways (Link et al., 2004). On the one hand, there are studies on perceived stigma, where researchers ask individuals with classifications about their personal experiences with stigma through surveys, questionnaires or interviews (Golberstein et al., 2008; Latalova et al., 2014; Link et al., 2004; Mickelson, 2001). On the other hand, there are studies using experimental vignettes, where a story is manipulated in order to assess stigma associated with different conditions in an experimental set-up (Lebowitz, 2016; Link et al., 2004). Studying perceived stigma allows for ecologically more valid measures of the experiences of individuals with classifications, while experimental designs permit the assessment of the impact of classifications on public attitudes more directly.

We used an experimental vignette design to study how attitudes of the public were colored by psychiatric classifications. However, in contrast to previous studies that employed fictional vignettes, we used a video interview of a young female adult with several psychiatric classifications sharing a personal story (we called her Lena, a pseudonym). We reasoned that the use of a real-life interview would strongly support the ecological validity or our experiment. We invited visitors at different events and festivals in the Netherlands throughout 2022 to watch the video-vignette of Lena and subsequently fill out a questionnaire about their feelings, thoughts and expected behavior towards her. We experimentally manipulated at which stage of the vignette they learned her classifications. We hypothesized that knowledge of her classifications would impact attitudes toward Lena. As results from previous studies have largely been inconclusive, we had no specific predictions on the nature or size of the effect.

Methods

This project combined outreach with science. The outreach involved a collaboration with artist Florentijn Hofman, who designed a large inflatable artwork that participants could enter and that had a temporary disorientating effect, as an invitation to discuss changes

Figure 1. Scientific outreach using large inflatable artwork by Florentijn Hofman.

*Photo 1 by Dienke Bos & Photo 2, 3, and 4 by Max Kneefel.

in perception (Figure 1). For the scientific study, participants watched a video of a young woman sharing a short personal story. We studied differences in attitude between people who did and did not know of her psychiatric classifications.

The project was designed to be part of the science program at the 2020 Lowlands festival. Lowlands is an annual large festival (~60.000 visitors) in Biddinghuizen, the Netherlands. In addition to music and art, it stages a scientific program that allows researchers to perform projects with and collect data from Lowlands visitors. We were selected to participate in the 2020 and 2021 editions, but both were canceled due to continued COVID-19 restrictions. In early 2022, we therefore expanded our project to collect data at any kind of festival or outreach event that permitted the collection of data.

During a series of events over the course of 2022 (Supplementary Material 1), we invited people to watch the video and to fill out a questionnaire on their mobile devices. We also shared links to our questionnaire through various social media platforms (e.g., LinkedIn, Twitter) asking people to fill out our questionnaire at home. The Medical Ethical Committee of the University Medical Centre Utrecht judged that the overall research project was not subject to the Medical Research Involving Human Subject Act (WMO) and that it complied with the Netherlands Code of Conduct for Research Integrity. Participation in the study was completely anonymous.

Table 1. Descriptive characteristics of participants

Gender	**Female**	**Male**	**Other**					
N	980	596	29					
Age	< 16	16-20	21-25	26-30	31-35	36-40	**41-45**	**46-50**	**> 50**
N	4	133	432	534	256	86	54	38	68
Alcohol[a]	**None**	**1 - 2[b]**	**< 2[b]**	**Unknown**				
N	467	560	346	8				
Drugs[a]	None	Cannabis	Stimul-ants[c]	Halluci-nogens[d]	Unknown			
N	1209	65	87	15	5			

[a] Items were added for the Lowlands Music Festival and retained from that point forward (Total N = 1381)
[b] Number of Consumptions
[c] E.g. cocaine, speed, XTC, MDMA
[d] E.g. LSD, 2C-B, ketamine

Participants

A total of 1830 people participated in our study. We excluded participants who did not give permission for participation (N = 5), who did not complete all questions (N = 216), who explicitly reported not being able to hear the video (N = 3) and one participant who had not taken participation seriously (nonsense answers in the description of Lena and only zeros or tens in response to the rating scale questions). As a result, 225 participants were excluded, resulting in a final dataset of 1605 participants. Gender and age of the sample are given in Table 1. We anticipated the consumption of alcohol or drugs during some of the festivals (most notably, the Lowlands festival). This was not an exclusion criterion for participation, but participants were asked to report what and how much they had consumed (Table 1). The effects of alcohol and/or drug use on our findings are explored in post-hoc analyses described below.

Vignette

We created a 90-second vignette using a videorecording of an interview with a young adult woman (pseudonym: Lena). She was previously assigned the following psychiatric classifications: autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), post-traumatic stress disorder (PTSD), major depressive disorder and an eating disorder. During the interview, she answered several questions about her real-life experiences in social interactions. In the vignette, Lena does not refer to any of her psychiatric classifications, but only discusses her experiences with others. She gave explicit permission for the video-material to be used in this study.

Questionnaire

Our questionnaire was presented to participants using the online platform Qualtrics (Qualtrics, Provo, UT). An English translation is provided in Supplementary Material 2. Participants filled out the questionnaire on their own mobile device or computer. The

questionnaire started with a few questions about demographics (e.g., gender, age in bins). Participants then watched the vignette and answered questions about their attitude to Lena. These questions were split into three categories, based on the three components of the ABC-model of attitude (Aronson et al., 2013; Breckler, 1984; Nolen-Hoeksema et al., 2009). We asked participants about their affect (feelings), cognitions (thoughts) and expected behavior towards Lena. Subsequently, the questionnaire included three questions about participants' general perception of psychiatric classifications. The questionnaire ended with several additional questions about participants' personal experiences with psychiatric classifications and finally with feedback in the form of Lena's own answers to some of the questions.

Study Design

The aim of this study was to investigate whether knowledge of Lena's psychiatric classifications affected how respondents perceived her. Therefore, the experimental manipulation was to control participants' knowledge of these classifications. Participants were automatically randomized into one of three conditions:

1. Aware of classification before video (aware before): participants learned of Lena's psychiatric classifications before watching the video and answering the questions.
2. Aware of classification after video (aware after): participants learned of Lena's psychiatric classifications after watching the video, but before answering the questions.
3. Unaware of classification (unaware): participants learned of Lena's psychiatric classifications at the very end and were therefore unaware of them when while answering the questions.

Randomization was performed by the Qualtrics randomizer, which ensured that participants were roughly distributed evenly across conditions. In the sample that was carried forward to analysis there were N = 540 participants in the 'aware of classification before video' condition, N = 530 participants in the 'aware of classification after video' condition and N = 535 participants in the 'unaware of classification' condition.

Analyses

We carried out the qualitative analyses using NVivo Version 12 and the quantitative, statistical analyses using SPSS Version 25. For the first question on affect, participants described Lena in three words. We entered these words into NVivo and assessed which words were used most and with what frequency. We then carried out chi-square tests to determine if the frequency of words varied across the three experimental conditions (i.e., aware of classification before video, aware of classification after video, unaware of classification).

Table 2. Quantitative assessment of words used to describe Lena

Word (Dutch)	Total	Aware Before	Aware After	Unaware	Chi-Square	Sign
Insecure (onzeker)	755	273	233	249	4,747	.093
Sweet (lief)	280	97	92	91	0,174	.917
Calm (rustig)	247	92	97	68	4,503	.105
Friendly (vriendelijk)	202	71	67	64	0,346	.841
Open (open)	239	71	98	70	8,091	.018
Kind (aardig)	181	61	60	60	0,003	.998
Sociable (sociaal)	198	52	60	86	11,078	.004
Self-aware (zelfbewust)	86	35	19	32	5,04	.080
Honest (eerlijk)	108	30	38	40	1,825	.401
Smart (slim)	56	24	13	19	3,16	.206
Normal (normaal)	73	23	28	22	0,997	.607
Introverted (introvert)	68	21	20	27	1,306	.520
Shy (verlegen)	77	20	25	32	3,064	.216
Vulnerable (kwetsbaar)	74	20	30	24	2,357	.308
Thoughtful (bedachtzaam)	50	17	15	18	0,255	.880
Sensitive (gevoelig)	54	15	24	15	3,287	.192

For the quantitative analyses, we carried out three separate MANOVAs, where we grouped the three affect questions, the two cognition questions and the four behavior questions and determined if overall affect, cognition and behavior varied by condition. We then ran post-hoc ANOVA analyses to determine which specific questions contributed to any differences. We also ran post-hoc analyses with the following covariates to determine if these affected our results or interacted with assigned condition: gender, consumption of alcohol, consumption of drugs, lived experience with psychiatric classifications and experience with classifications through family and friends.

Finally, we carried out exploratory post-hoc analyses, to investigate correlations between all continuous response variables and to determine if there were any main effects of categorical variables, using additional ANOVA analyses. A full overview of all post-hoc analyses is provided in Supplementary Material 3.

Results

Qualitative and quantitative assessment of words used to describe Lena

In the top 20 words, 16 words overlapped between conditions and the frequency largely corresponded. The word most used to describe Lena, regardless of condition, was insecure. Otherwise, she was described as sweet, calm, friendly, open, kind, and sociable. Chi-square analyses showed that there were two words that differed between conditions. Lena was described as open more frequently by participants in the 'aware after' condition and she was described as sociable more frequently by participants in the 'unaware' condition.

Effects of knowing classifications on affect, cognition, and behavior

Affect.

We found no differences between conditions on the combined affect questions (MANOVA: F (6, 3200) = .795, p = .574; Wilk's Λ = .997, partial η2 = .001). Participants in the different conditions (aware before, aware after, unaware) reported similar scores on their affect towards Lena. Adding gender, consumption of alcohol or drugs and people's own experiences with classifications did not change these findings.

Cognition.

We found a difference between conditions on the combined cognition questions (MANOVA: F(4, 3202) = 12.319, p < .001; Wilk's Λ = .970, partial η2 = .015. Specifically, participants differed in whether they thought Lena would take medication for the problems she describes (F(2) = 18.287, p < .001; Figure 2). Participants were least likely to think Lena would take medication in the 'unaware' condition, compared to the 'aware before' condition (p = .008) and the 'aware after' condition (p < .001). Participants in the 'aware before' condition were also less likely to think she would want medication than in the 'aware after' condition (p = .001).

Post-hoc ANOVA analyses showed main effects of gender and personal experience with classifications on these results, but not of alcohol or drug consumption (see Supplementary Material 3). The most notable result was that men were less likely to think Lena would want medication than women or participants who self-identified as other. Moreover, we found an interaction effect between participants who had personal experience with classifications and condition on how likely participants thought Lena was to want medication (see Supplementary Material 3).

We also found differences between conditions on whether participants thought Lena feels vulnerable (F(2) = 8.893, p < .001; Figure 2). Participants were least likely to think Lena feels vulnerable in the 'unaware' condition compared to the 'aware before' condition (p < .001) and the 'aware after' condition (p < .001). The 'aware before' and 'aware after' conditions did not differ (p = .797).

Post-hoc ANOVA analyses showed no effects of gender, lived experience with classification or the consumption of alcohol or drugs on whether participants thought Lena felt vulnerable.

Behavior

We found a difference between conditions on the combined behavior questions (MANOVA: F (8, 3198) = .2.077, p = .035; Wilk's Λ = .990, partial η2 = .005). Specifically, participants in the 'aware before' condition (p = .021) and 'aware after' condition (p < .001) – i.e. those who knew of the psychiatric classifications while filling in the questionnaire – were less

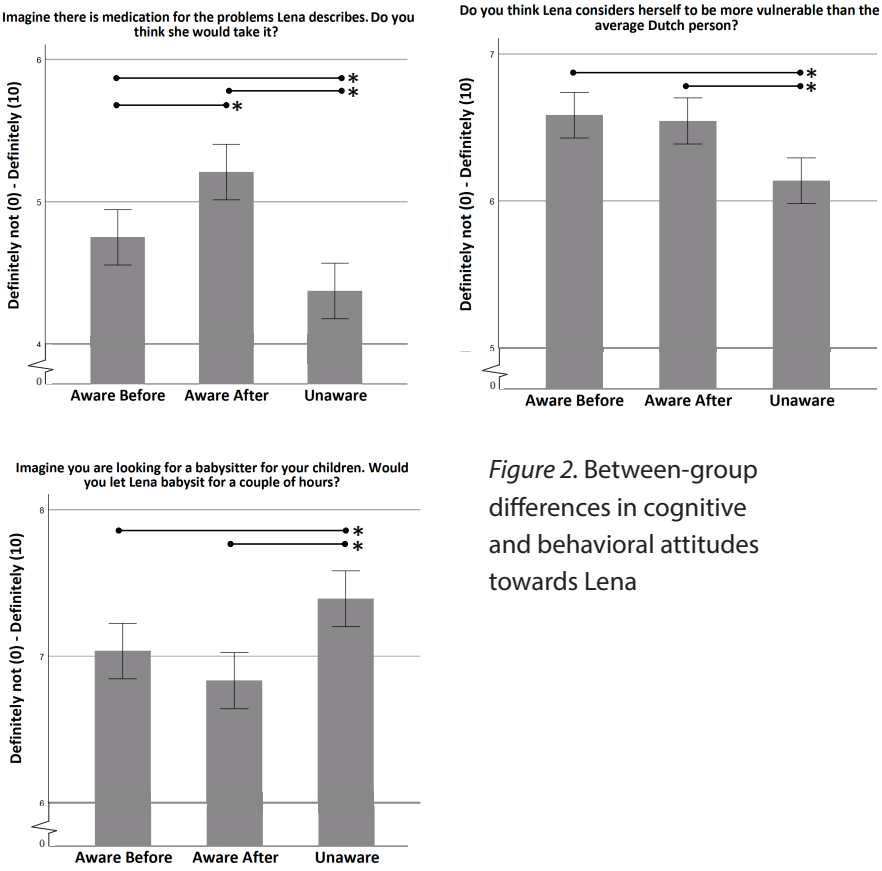

Figure 2. Between-group differences in cognitive and behavioral attitudes towards Lena

comfortable with Lena babysitting their children ($F(2) = 7.772$, $p < .001$; Figure 2) than those in the 'unaware' condition, who did not know Lena's classifications. Participants in the 'aware before' and 'aware after' condition did not differ from each other ($p = .458$).

Post-hoc ANOVA-models showed main effects of gender and personal experience with classifications on these results, but not of alcohol or drug consumption (see Supplementary Material 3). The most notable result was that participants who had personal experience with classifications, either themselves or through family and friends, were more likely to want Lena as a babysitter than participants who did not have personal experience with classifications (see Supplementary Material 3).

Exploratory Analyses

In further exploratory post-hoc analyses, we carried out separate ANOVA-analyses to investigate differences between groups as defined by: (1) gender (male/female/other), (2) having a psychiatric classification themselves (yes/no), (3) having family or friends with a

classification (yes/no), (4) alcohol consumption (none/1 or 2 consumptions/more than 2 consumptions) and (5) drug consumption (none/cannabis/stimulants/hallucinogens). The experimental conditions ('aware before', 'aware after', 'unaware') were not considered in these post-hoc analyses. A full overview of these analyses can be found in Supplementary Material 3. Most notably, we found differences between people who had personal experiences with classifications (either themselves or through friends and family). Overall, those with personal experience of classification reported more positive attitudes to Lena. We include these post-hoc results because they support the main analyses above and to inform further studies formulating new hypotheses. However, they need to be interpreted with caution, as we carried out 60 such post-hoc ANOVA-analyses and the chance of type I error is therefore high.

Discussion

In this study, we investigated differences in attitude between people who did and did not know the psychiatric classifications of a young adult (Lena) sharing a short personal story, in a large, real-life vignette study (N=1605). We found between-group differences in cognitive and behavioral attitudes, with people who were aware of her psychiatric classifications preferring more social distance. Furthermore, people with direct or indirect personal experience of psychiatric classification had more positive attitudes towards her than those who had no such experience.

Participants who knew of Lena's psychiatric classifications had a different cognitive attitude towards her than those who did not know of her classifications. Participants who knew of the classifications were more likely to think Lena would want medication for her difficulties and they were more likely to think of her as vulnerable. Notably, we also found that classifications affected the participants' descriptions of Lena. She was described as sociable more often by people who did not know of her classifications. This difference may well be driven by knowledge of Lena's autism classification, as autism is commonly associated with deficits in social skills. Lena was described as open more frequently by people who knew of her classifications, suggesting that people associate the sharing of such personal information with being open.

In addition, we found that participants who knew of Lena's psychiatric classifications had a more negative behavioral attitude towards her than those who did not. This trend was present across all items but was most prominent in our final behavior item: participants who knew Lena's classifications, were least likely to want her to babysit their children. This links to previous research on the preference for increased social distance from persons with a psychiatric classification (Abdullah & Brown, 2020; Ohan et al., 2013). Social distance has been defined as 'the degree of intimacy and understanding that exists between individuals or social groups' (Hughes et al., 1950; Wark & Galliher, 2007). The behavioral items in our questionnaire are related to items from a widely used and adapted measure

of social distance, the social distance scale (Bogardus, 1933). As such, our study replicates previous evidence that classifications lead to increased desire for social distance and more negative behavioral attitudes (Angermeyer & Matschinger, 2003; Klasen, 2000; Lebowitz, 2016; Martin et al., 2007; Ohan et al., 2011). Moreover, we show that this effect holds true in the more ecologically valid situation of a real-life person sharing a real-life story.

Finally, we found that individuals with direct and indirect personal experience of psychiatric classification expressed more positive attitudes towards Lena, irrespective of which condition they were assigned to. This finding suggests that even indirect experience with classifications impacts the desire for social distance. Therefore, stimulating social contact and promoting interaction with people with a lived experience of classifications may help change public attitudes towards mental health and ultimately reduce stigma. Our results align with previous research showing that one of the most promising strategies to combat stigma, is the increase and improvement of social contact between the 'general public' and stigmatized individuals (Corrigan et al., 2012; Stuart et al., 2011). When people with lived experience share their stories and experiences, this decreases stigma and promotes increased understanding (Blascovich et al., 2001; Corrigan, 2000; Couture & Penn, 2003; Pettigrew & Tropp, 2008; Ungar et al., 2016).

Limitations

Strengths of our study included the use of an ecologically valid real-life vignette that permitted us to study the impact of classification on attitudes towards a young woman's real story. Moreover, we were able to gather a large and varied dataset by collecting data at numerous large-scale events. Nevertheless, data-collection did also pose some challenges that may have impacted the results of our study. At some of the events, participants may have struggled to hear the audio on the vignette properly. This was specifically the case at Lowlands, where headlining acts performed nearby our location and the Betweter Festival, where we had a limited number of headphone sets available. We addressed this issue by ensuring that participants turned on the subtitles (prepared by us) on the vignette, whether or not they were wearing headphones. Naturally, we excluded participants who reported not having been able to hear or understand the vignette. While we cannot ensure that the subtitles guaranteed that information in the vignette was fully understood, participant feedback and overall data quality suggest that the impact of the use of subtitles was limited. A second limitation of our study is that we designed it to include only a single vignette of a young woman discussing her personal experiences. We can therefore not guarantee that the results would have been similar with a different person, different story or different classifications. Further studies with a variety of 'real-life' vignettes could extend our findings. We believe that our study is useful as a proof of principle and shows that real-life vignettes can successfully be used in this type of experimental design.

Conclusion

Our study shows the possible impact of sharing one's own psychiatric classifications. We were able to collect data at a series of unique events attended by the public. After listening to Lena tell her story, participants with knowledge of her classifications preferred more social distance than those without such knowledge. For someone dealing with mental health problems, such a change in people's attitude can be an important factor when deciding whether to share one's classifications with others. Ultimately, open communication about mental health should lead to less social distance, not more. Promoting social contact between individuals with and without lived experience of mental health problems and psychiatric classification may help combat these negative effects.

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Supplementary Material 1. Events where data was collected

	Event	*Type of Event*	*Date*	*N*
1	Dies Natalis Utrecht University	Annual Celebration, Utrecht University	25-03-22	41
2	Hijmans van den Bergh-Building	Art and Science Exposition, Utrecht University	04-04-22	116
3	Dutch Innovation Days	Technology Festival on Innovation, Enschede	23-04-22	24
4	Lowland Science	Science Program at Lowlands Music Festival, Biddinghuizen	19-08-22, 20-08-22 & 21-08-22	1218
5	Betweter Festival	Popular Science Festival, Utrecht	30-09-22	326
7	Other	Other (social media) outreach	n.a.	105

Supplementary Material 2 – Dutch Questionnaire and English Translation.

English translation of Dutch Questionnaire

In this study you will watch a short video (2 minutes) of Lena talking about her psychological vulnerability in real life. We will then ask you a few questions about the video and about you.

There are no right or wrong answers. We would like to know what you think.

All data will be collected and analyzed anonymously and securely. In the next screen, we will ask you for your permission for participation in this study.

I understand that I am participating in this study voluntarily. That means that I can stop at any moment. By clicking OK, I give permission for my participation in this study.

- o Ok
- o I would prefer not to participate.

How old are you?

- o < 16 years
- o 16 – 20 years
- o 21 – 25 years
- o 26 – 30 years
- o 31 – 35 years
- o 36 – 40 years
- o 41 – 45 years
- o 46 – 50 years
- o 51 – 55 years
- o 56 – 60 years
- o 61 – 65 years
- o 66 – 70 years
- o 71 – 75 years
- o 76 – 80 years
- o > 81 years

What is your gender?

- o Male
- o Female
- o Non-binary
- o I would prefer not to say
- o Other, namely …….

Are you completing this questionnaire at an event or somewhere else (at home, at work, at school, etc)?

- o At an event
- o Somewhere else

Are you completing this questionnaire at Lowlands Science?

- o Yes
- o No

Did you consume any alcohol before filling out this questionnaire?

- o No
- o Yes, 1 or 2 consumptions
- o Yes, more than 2 consumptions
- o I would prefer not to say

Did you consume any drugs before filling out this questionnaire?

- o Yes, cannabis
- o Yes, uppers/stimulating substances (for example: cocaine, speed, XTC, MDMA)
- o Yes, trippers/hallucinatory substances (for example: LSD, 2C-B, ketamine)
- o I would prefer not to say

4

You will now watch a short interview with Lena. Just listen to the interview, don't try to pay attention to anything in particular. Afterwards, you will answer a number of questions.

Now watch the video

Describe Lena in three words. Don't think too hard, just fill in your first impression.

1……..

2……..

3……..

Do you feel a click with Lena?

Not at all A little Completely

Do you recognize yourself in what Lena describes?

Not at all A little Completely

Does your inner life resemble Lena's?

Not at all A little Completely

Imagine you are renting out a room. Would you consider renting it to Lena?

Definitely not Probably not Probably Definitely

Imagine you are looking for a new colleague at work. Would you want Lena to be your new colleague?

Definitely not Probably not Probably Definitely

Imagine the house next to yours is being rented out. Would you want Lena as a neighbor?

Definitely not Probably not Probably Definitely

Imagine you are looking for a babysitter for your children. Would you let Lena babysit for a couple of hours?

Definitely not Probably not Probably Definitely

Imagine there is medication for the problems Lena describes. Do you think she would take it?

Definitely not Probably not Probably Definitely

How do you think Lena would describe her vulnerabilities? Select the words that you think are appropriate. You can select more than one.

- o A disorder
- o A handicap
- o A vulnerability
- o A psychiatric illness
- o A diagnosis
- o A special quality
- o Nothing special
- o A brain that works differently

How do you think Lena would describe herself? Select the words that you think are appropriate. You can select more than one.

- o Different
- o Unusual
- o Normal

- o Strange
- o Unusual
- o Ordinary
- o Divergent
- o Average
- o Peculiar
- o Okay
- o Eccentric
- o Unique
- o Who I am
- o Neurodiverse
- o Myself
- o Authentic

Do you think Lena considers herself to be more vulnerable than the average Dutch person?

Definitely not Probably not Probably Definitely

So far, the questions have been specifically about Lena. The upcoming questions are about psychological vulnerability in general.

Does a psychiatric diagnosis or classification change your willingness to adapt to somebody else's needs?

No Probably not Probably Yes

Do you think the brain of someone with a psychiatric diagnosis or classification works differently than the brain of someone without a psychiatric diagnosis or classification.

No Probably not Probably Yes

What are the contributions of environmental factors and biological predisposition to psychiatric problems?

The cause of psychiatric problems lies:

Completely with the environment Equally with environment and disposition Completely with disposition

Finally, we have a few questions about your background and experience with psychiatric problems. Feel free to share as little or as much as you like.

Have you ever had any psychiatric problems?

- o Yes
- o No
- o I would rather not say

Have you ever been diagnosed with a psychiatric classification?
- o Yes
- o No
- o I would rather not say

If so, which psychiatric classification (such as ADHD or depression) do you have now or have you had in the past?
- o Describe in a couple of words: ……
- o I would rather not say

Do you have friends or family with a psychiatric classification?
- o Yes
- o No
- o I would rather not say

Do you think Lena has had a psychiatric diagnosis? If so, which ones do you think?
- o Yes, ……
- o Probably, …….
- o Probably not
- o No

To answer that question immediately: Lena currently has a number of psychiatric classifications, namely autism, ADHD and post-traumatic stress disorder (PTSD). In the past, she was classified with depression and an eating disorder.

These were our questions. Thank you very much for participating in our study and feel free to discuss any questions with the researchers present.

Original Dutch Questionnaire

In dit onderzoek zie je een kort filmpje (2 minuten) waarin Lena vertelt over psychische kwetsbaarheid in het dagelijks leven. Vervolgens stellen we een aantal vragen over het filmpje en over jou.

De vragen hebben geen goede of foute antwoorden. We willen graag weten wat jij denkt.

Alle gegevens worden anoniem en beveiligd verzameld en verwerkt. In het volgende scherm vragen we je om toestemming voor je deelname aan dit onderzoek.

Ik begrijp dat ik vrijwillig meewerk aan dit onderzoek. Dat betekent dat ik op elk gewenst moment mag stoppen. Door OK aan te vinken geef ik toestemming voor mijn deelname aan dit onderzoek.
- o Ok
- o Ik wil toch niet meedoen

Hoe oud ben je?
- o < 16 jaar
- o 16 – 20 jaar
- o 21 – 25 jaar
- o 26 – 30 jaar
- o 31 – 35 jaar
- o 36 – 40 jaar
- o 41 – 45 jaar
- o 46 – 50 jaar

- o 51 – 55 jaar
- o 56 – 60 jaar
- o 61 – 65 jaar
- o 66 – 70 jaar
- o 71 – 75 jaar
- o 76 – 80 jaar
- o > 81 jaar

Wat is je geslacht?

- o Man
- o Vrouw
- o Non-binair
- o Zeg ik liever niet
- o Anders, namelijk …….

Vul jij deze vragenlijst in op een evenement of ergens anders (thuis, op werk, op school, etc)?

- o Op een evenement
- o Ergens Anders

Vul je deze vragenlijst in op Lowlands Science

- o Ja
- o Nee

Heb je voor het invullen van deze vragenlijst alcohol gedronken?

- o Nee
- o Ja, 1 of 2 consumpties
- o Ja, meer dan 2 consumpties
- o Zeg ik liever niet

Heb je voor het invullen van deze vragenlijst drugs gebruikt?

- o Ja, cannabis
- o Ja, uppers oftewel stimulerende middelen (bijvoorbeeld: cocaine, speed, XTC, MDMA)
- o Ja, trippers oftewel waarnemings-veranderende middelen (zoals LSD, 2C-B, ketamine)
- o Zeg ik liever niet

Je krijgt nu een kort interview te zien met Lena. Luister gewoon naar het interview, je hoeft nergens speciaal op te letten. Na afloop krijg je een aantal vragen.

Kijk nu het videofragment.

Beschrijf Lena in drie woorden. Denk niet te lang na, vul je eerste indruk in.

1. …….
2. …….
3. …….

Voel je een klik met Lena?

Helemaal niet — Een beetje — Helemaal wel

Herken jij je in wat Lena vertelt?

Helemaal niet | Een beetje | Helemaal wel

Lijk je innerlijk op Lena?

Helemaal niet | Een beetje | Helemaal wel

Stel je verhuurt een kamer. Zou jij die aan Lena willen verhuren?

Zeker niet | Waarschijnlijk niet | Waarschijnlijk wel | Zeker wel

Stel je zoekt een nieuwe collega. Zou je Lena als nieuwe collega willen?

Zeker niet | Waarschijnlijk niet | Waarschijnlijk wel | Zeker wel

Stel het huis naast je wordt verhuurd. Zou jij Lena als buurvrouw willen?

Zeker niet | Waarschijnlijk niet | Waarschijnlijk wel | Zeker wel

Stel je zoekt een oppas voor je kinderen. Zou je Lena een paar uur laten oppassen?

Zeker niet | Waarschijnlijk niet | Waarschijnlijk wel | Zeker wel

Stel er is een medicijn voor de problemen die Lena beschrijft. Denk je dat ze het medicijn zou nemen?

Zeker niet | Waarschijnlijk niet | Waarschijnlijk wel | Zeker wel

Hoe denk jij dat Lena haar kwetsbaarheden zou beschrijven? Omcirkel de woorden die je vindt passen. Meerdere antwoorden zijn mogelijk.

- o Een stoornis
- o Een handicap

- o Een kwetsbaarheid
- o Een psychische ziekte
- o Een diagnose
- o Een bijzondere eigenschap
- o Niets bijzonders
- o Een anders werkend brein

Hoe denk jij dat Lena zichzelf zou beschrijven?? Omcirkel de woorden die je vindt passen. Meerdere antwoorden zijn mogelijk.

- o Anders
- o Ongewoon
- o Normaal
- o Vreemd
- o Zeldzaam
- o Gewoon
- o Afwijkend
- o Gemiddeld
- o Eigenaardig
- o In orde
- o Excentriek
- o Uniek
- o Wie ik ben
- o Neurodivers
- o Mezelf
- o Authentiek

Denk je dat Lena zichzelf kwetsbaarder vindt dat de gemiddelde Nederlander?

Zeker niet Waarschijnlijk niet Waarschijnlijk wel Zeker wel

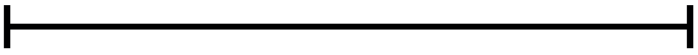
Tot nu toe gingen de vragen specifiek over Lena. De volgende vragen gaan over psychische kwetsbaarheid in het algemeen

Verandert een psychiatrische diagnose of classificatie in hoeverre jij je aan wil passen aan de behoeften van iemand?

Nee Waarschijnlijk niet Waarschijnlijk wel Ja

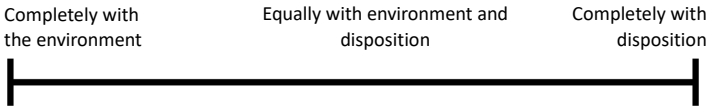
Denk je dat de hersenen van iemand met een psychiatrische diagnose of classificatie, anders werken dan de hersenen van iemand zonder psychiatrische classificatie?

Nee Waarschijnlijk niet Waarschijnlijk wel Ja



Wat is het aandeel van omgevingsfactoren en biologische aanleg in het veroorzaken van psychiatrische problemen?

De oorzaak van psychiatrische problemen ligt:



We hebben als laatste een aantal vragen over je eigen achtergrond en ervaring met psychische klachten. Je mag uiteraard zelf bepalen hoeveel je hier over wilt delen.

Heb je zelf wel eens psychische klachten ervaren?
- o Ja
- o Nee
- o Daar zeg ik liever niets over

Ben je ooit zelf gediagnosticeerd met een psychiatrische aandoening?
- o Ja
- o Nee
- o Daar zeg ik liever niets over

Zo ja, welke psychiatrische classificaties (zoals bijvoorbeeld ADHD of depressie) heb je nu of in het verleden gehad?
- o Beschrijf in een aantal woorden: ……
- o Daar zeg ik liever niets over

Heb je vrienden of familie met psychiatrische classificaties?
- o Ja
- o Nee
- o Daar zeg ik liever niets over

Denk je dat Lena een psychiatrische diagnose heeft? En zo ja, waar denk je aan?
- o Ja, ……
- o Waarschijnlijk wel, ……..
- o Waarschijnlijk niet
- o Nee

Om die vraag gelijk te beantwoorden: Lena heeft momenteel een aantal verschillende psychiatrische classificaties, namelijk autisme, ADHD en post-traumatische stress stoornis (PTSS). In het verleden is zij geclassificeerd met een depressie en een eetstoornis

Dit waren onze vragen. Bedankt voor je deelname aan onze vragenlijst en praat rustig na met de aanwezige onderzoekers.

Supplementary Material 3: Overview of Post-hoc Analyses

In the result section of our manuscript, we found three questions that differed significantly between the conditions: the cognition question on medication, the cognition question on vulnerability and the behavior question on babysitting. Below we elaborate on these results through post-hoc analyses, in which we entered the covariates gender, own personal experience, personal experience through friend and family, alcohol consumption and drug use into the ANOVA-models. In the tables below we describe the effects and statistical significance of each of the covariates.

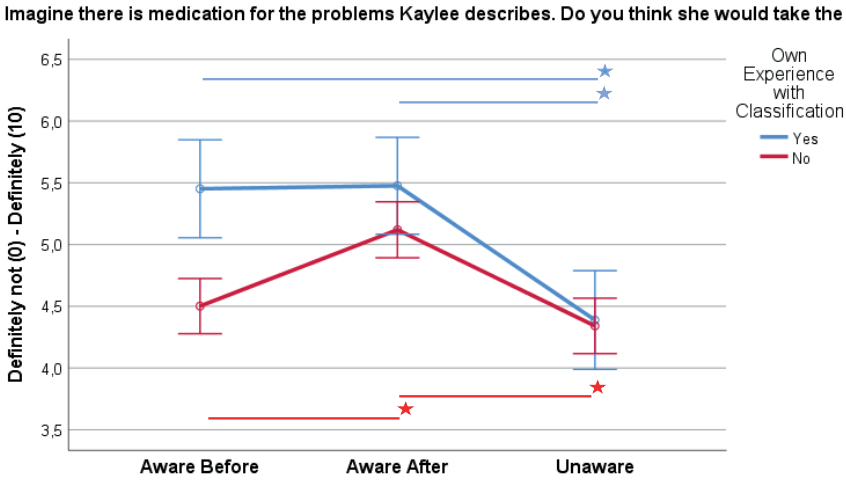
Supplementary Table 1. Post Hoc Analyses – Cognition Question 1 – Medication

Co-variate added to model	Description of effect	Statistical significance
Gender	Main effect of gender, with no interaction effect. Men were less likely to think Lena would want medication (4.55 ± 2.43) than women (4.86. ± 2.25, *p* = .029) and participants who self-identified as other (5.82 ± 2.96, *p* = .011). Women and participants who self-identified as other did not differ from each other (*p* = .68).	F(2) = 5.898, p = .003
Personal experience with classifications – Own classification	Main effect of personal experience and an interaction effect between personal experience and condition. The main effect showed that participants with personal experience (5.11 ± 2.38) were more likely to think Lena would want medication than participants without personal experience (4.65 ± 2.31). The interaction effect is shown in the Supplementary Figure 1.	Main Effect: F(1) =11.206, p < .001 Interaction Effect: F(2) = 3.752, p = .024
Personal experience with classifications – Family and Friends	Main effect of experience of classifications through family and friends, without an interaction effect. Participants with experience through family and friends (4.86 ± 2.30) were more likely to think Lena would want medication than participants without experience through family and friends (4.59 ± 2.40).	F(1) =4.134, p = .042
Alcohol consumption	No effect	NS
Drug use	No effect	NS

Supplementary Table 2. Post Hoc Analyses – Cognition Question - Vulnerability

Co-variate added to model	Description of effect	Statistical significance
Gender	No effect	NS
Personal experience with classifications – Own classification	No effect	NS
Personal experience with classifications – Family and Friends	No effect	NS
Alcohol consumption	No effect	NS
Drug use	No effect	NS

Supplementary Figure 1. Interaction Effect



Supplementary Table 3. Post Hoc Analyses – Behavior Question - Babysitter

Co-variate added to model	Description of effect	Statistical significance
Gender	Main effect of gender, without an interaction effect. Participants who self-identified as other (5.96 ± 2.97) were less likely to want Lena as a babysitter than men (7.03 ± 2.32, $p = .013$) or women (7.18 ± 2.22, $p = .004$).	F(2) = 4.075, p = .017
Personal experience with classifications – Own classification	Main effect of personal experience, without an interaction effect. Participants who had personal experiences with classifications (7.35 ± 2.22) were more likely to want Lena as a babysitter than participants without personal experience (7.02 ± 2.29).	F(1) = 6.510, p = .011
Personal experience with classifications – Family and Friends	Main effect of personal experience through family and friends, without an interaction effect. Participants who had experiences through family and friends (7.17 ± 2.27) were more likely to want Lena as a babysitter than participants without experiences (6.95 ± 2.31).	F(1) = 4.096, p = .043
Alcohol consumption	No effect	NS
Drug use	No effect	NS

Supplementary Table 4. Exploratory ANOVA-analyses exploring the effect of groups defined by categorical variables other than those defined by experimental condition

Question	Gender	Own Experience
Affect 2: Connection	$F(2.1602) = 9.878$; $p = .000$ Men: M = 5.45, SD = 2.41 Women: M = 5.99, SD = 2.27 Other: M = 5.64, SD = 3.09	$F(1.1592) = 26.019$; $p = .000$ Yes: M = 6.30, SD = 2.27 No: M = 5.61, SD = 2.35
Affect 3: Recognition	$F(2.1602) = 15.830$; $p = .000$ Men: M = 5.73, SD = 2.68 Women: M = 6.48, SD = 2.58 Other: M = 5.55, SD = 3.78	$F(1.1592) = 67.176$; $p = .000$ Yes: M = 7.13, SD = 2.41 No: M = 5.89, SD = 2.67
Affect 4: Resemblance	$F(2.1602) = 26.962$; $p = .000$ Men: M = 4.20, SD = 2.59 Women: M = 5.19, SD = 2.55 Other: M = 4.96, SD = 3.11	$F(1.1592) = 76.414$; $p = .000$ Yes: M = 5.81, SD = 2.47 No: M = 4.50, SD = 2.58
Cognition 1: Medication	$F(2.1602) = 6.244$; $p = .002$ Men: M = 4.55, SD = 2.43 Women: M = 4.86, SD = 2.25 Other: M = 5.82, SD = 2.96	$F(1.1592) = 11.524$; $p = .001$ Yes: M = 5.11, SD = 2.38 No: M = 4.65, SD = 2.32
Cognition 4: Vulnerability	$F(2.1602) = 0.453$; $p = .636$ Men: M = 6.44, SD = 1.99 Women: M = 6.41, SD = 1.75 Other: M = 6.74, SD = 2.00	$F(1.1592) = 0.449$; $p = .503$ Yes: M = 6.49, SD = 1.80 No: M = 6.42, SD = 1.85
Behavior 1: Renting Room	$F(2.1602) = 1.708$; $p = .181$ Men: M = 7.25, SD = 2.30 Women: M = 7.07, SD = 2.25 Other: M = 6.69, SD = 2.59	$F(1.1592) = 3.617$; $p = .057$ Yes: M = 7.33, SD = 2.20 No: M = 7.08, SD = 2.29
Behavior 2: Colleague	$F(2.1602) = 0.631$; $p = .532$ Men: M = 6.21, SD = 2.17 Women: M = 6.31, SD = 2.09 Other: M = 6.00, SD = 2.91	$F(1.1592) = 15.987$; $p = .000$ Yes: M = 6.65, SD = 2.00 No: M = 6.16, SD = 2.15
Behavior 3: Neighbor	$F(2.1602) = 9.826$; $p = .000$ Men: M = 7.72, SD = 1.94 Women: M = 8.09, SD = 1.67 Other: M = 7.27, SD = 2.25	$F(1.1592) = 16.301$; $p = .000$ Yes: M = 8.26, SD = 1.64 No: M = 7.84, SD = 1.82
Behavior 4: Babysitter	$F(2.1602) = 4.534$; $p = .011$ Men: M = 7.03, SD = 2.32 Women: M = 7.18, SD = 2.22 Other: M = 5.96, SD = 2.97	$F(1.1592) = 6.312$; $p = .013$ Yes: M = 7.35, SD = 2.22 No: M = 7.02, SD = 2.29
General 1: Adapt	$F(2.1602) = 0.737$; $p = .479$ Men: M = 6.06, SD = 2.40 Women: M = 6.21, SD = 2.35 Other: M = 6.09, SD = 3.21	$F(1.1592) = 2.735$; $p = .098$ Yes: M = 5.98, SD = 2.64 No: M = 6.21, SD = 2.29
General 2: Brain works differently	$F(2.1602) = 5.961$; $p = .003$ Men: M = 6.49, SD = 2.70 Women: M = 6.93, SD = 2.35 Other: M = 7.05, SD = 2.44	$F(1.1592) = 5.144$; $p = .023$ Yes: M = 7.02, SD = 2.44 No: M = 6.70, SD = 2.50
General 3: Nature vs. Nurture	$F(2.1602) = 0.680$; $p = .507$ Men: M = 5.06, SD = 1.98 Women: M = 5.07, SD = 1.62 Other: M = 5.45, SD = 1.83	$F(1.1592) = 6.576$; $p = .010$ Yes: M = 4.87, SD = 1.65 No: M = 5.13, SD = 1.78

	Experience Family & Friends	Alcohol Consumption	Drug Use
	$F(1.1575) = 4.270$; $p = .039$ Yes: M = 5.87, SD = 2.32 No: M = 5.62, SD = 2.36	$F(2.1370) = 5.220$; $p = .006$ None: M = 5.83, SD = 2.37 1 or 2: M = 5.66, SD = 2.23 More: M = 5.29, SD = 2.61	$F(3.1372) = 6.543$; $p = .000$ None: M = 5.72, SD = 2.34 Cannabis: M = 4.78, SD = 2.62 Stimulants: M = 4.86, SD = 2.53 Hallucinogens: M = 5.41, SD = 3.11
	$F(1.1575) = 3.265$; $p = .071$ Yes: M = 6.26, SD = 2.70 No: M = 6.01, SD = 2.62	$F(2.1370) = 10.768$; $p = .000$ None: M = 6.25, SD = 2.71 1 or 2: M = 6.37, SD = 2.56 More: M = 5.54, SD = 2.88	$F(3.1372) = 1.528$; $p = .205$ None: M = 6.18, SD = 2.70 Cannabis: M = 5.86, SD = 2.66 Stimulants: M = 5.62, SD = 2.90 Hallucinogens: M = 5.60, SD = 2.91
	$F(1.1575) = 17.062$; $p = .000$ Yes: M = 5.02, SD = 2.61 No: M = 4.46, SD = 2.61	$F(2.1370) = 10.812$; $p = .000$ None: M = 5.00, SD = 2.59 1 or 2: M = 4.84, SD = 2.56 More: M = 4.17, SD = 2.78	$F(3.1372) = 4.346.$; $p = .005$ None: M = 4.81, SD = 2.66 Cannabis: M = 4.06, SD = 2.64 Stimulants: M = 3.98, SD = 2.55 Hallucinogens: M = 4.09, SD = 2.82
	$F(1.1575) = 4.914$; $p = .027$ Yes: M = 4.86, SD = 2.31 No: M = 4.59, SD = 2.40	$F(2.1370) = 0.019$; $p = .982$ None: M = 4.78, SD = 2.40 1 or 2: M = 4.76, SD = 2.32 More: M = 4.79, SD = 2.51	$F(3.1372) = 0.890$; $p = .446$ None: M = 4.76, SD = 2.35 Cannabis: M = 4.77, SD = 2.82 Stimulants: M = 5.16, SD = 2.65 Hallucinogens: M = 4.39, SD = 2.85
	$F(1.1575) = 0.316$; $p = .574$ Yes: M = 6.46, SD = 1.81 No: M = 6.41, SD = 1.87	$F(2.1370) = 2.303$; $p = .100$ None: M = 6.40, SD = 1.83 1 or 2: M = 6.38, SD = 1.80 More: M = 6.64, SD = 1.94	$F(3.1372) = 0.706$; $p = .548$ None: M = 6.46, SD = 1.81 Cannabis: M = 6.16, SD = 2.16 Stimulants: M = 6.49, SD = 2.24 Hallucinogens: M = 6.13, SD = 1.95
	$F(1.1575) = 3.083$; $p = .079$ Yes: M = 7.21, SD = 2.25 No: M = 7.01, SD = 2.30	$F(2.1370) = 0.188$; $p = .829$ None: M = 7.12, SD = 2.31 1 or 2: M = 7.05, SD = 2.23 More: M = 7.02, SD = 2.48	$F(3.1372) = 1.138$; $p = .333$ None: M = 7.11, SD = 2.28 Cannabis: M = 6.72, SD = 2.56 Stimulants: M = 6.76, SD = 2.56 Hallucinogens: M = 6.97, SD = 3.27
	$F(1.1575) = 0.006$; $p = .937$ Yes: M = 6.26, SD = 2.13 No: M = 6.25, SD = 2.14	$F(2.1370) = 2.921$; $p = .054$ None: M = 6.20, SD = 2.15 1 or 2: M = 6.29, SD = 2.03 More: M = 5.94, SD = 2.37	$F(3.1372) = 0.523$; $p = .667$ None: M = 6.17, SD = 2.13 Cannabis: M = 6.06, SD = 2.39 Stimulants: M = 6.16, SD = 2.25 Hallucinogens: M = 5.49, SD = 3.56
	$F(1.1575) = 7.050$; $p = .008$ Yes: M = 8.04, SD = 1.75 No: M = 7.79, SD = 1.85	$F(2.1370) = 4.218$; $p = .015$ None: M = 7.86, SD = 1.75 1 or 2: M = 8.05, SD = 1.74 More: M = 7.69, SD = 2.06	$F(3.1372) = 4.335$; $p = .005$ None: M = 7.96, SD = 1.78 Cannabis: M = 7.27, SD = 2.18 Stimulants: M = 7.58, SD = 2.12 Hallucinogens: M = 7.31, SD = 2.60
	$F(1.1575) = 3.439$; $p = .064$ Yes: M = 7.17, SD = 2.27 No: M = 6.95, SD = 2.31	$F(2.1370) = 1.825$; $p = .162$ None: M = 6.98, SD = 2.27 1 or 2: M = 7.26, SD = 2.21 More: M = 7.11, SD = 2.44	$F(3.1372) = 1.730$; $p = .159$ None: M = 7.10, SD = 2.26 Cannabis: M = 7.21, SD = 2.50 Stimulants: M = 7.19, SD = 2.48 Hallucinogens: M = 8.43, SD = 2.60
	$F(1.1575) = 2.608$; $p = .107$ Yes: M = 6.24, SD = 2.41 No: M = 6.04, SD = 2.33	$F(2.1370) = 2.399$; $p = .091$ None: M = 6.13, SD = 2.36 1 or 2: M = 6.32, SD = 2.33 More: M = 5.96, SD = 2.55	$F(3.1372) = 0.929$; $p = .426$ None: M = 6.17, SD = 2.38 Cannabis: M = 6.13, SD = 2.65 Stimulants: M = 5.89, SD = 2.55 Hallucinogens: M = 6.95, SD = 2.22
	$F(1.1575) = 3.936$; $p = .047$ Yes: M = 6.87, SD = 2.48 No: M = 6.62, SD = 2.50	$F(2.1370) = 0.601$; $p = .548$ None: M = 6.85, SD = 2.52 1 or 2: M = 6.78, SD = 2.40 More: M = 6.65, SD = 2.78	$F(3.1372) = 0.734$; $p = .532$ None: M = 6.82, SD = 2.48 Cannabis: M = 6.57, SD = 2.85 Stimulants: M = 6.53, SD = 2.94 Hallucinogens: M = 6.25, SD = 3.66
	$F(1.1575) = 3.109$; $p = .078$ Yes: M = 5.02, SD = 1.71 No: M = 5.18, SD = 1.87	$F(2.1370) = 5.803$; $p = .003$ None: M = 5.18, SD = 1.61 1 or 2: M = 4.94, SD = 1.66 More: M = 5.34, SD = 2.16	$F(3.1372) = 5.777$; $p = .001$ None: M = 5.12, SD = 1.72 Cannabis: M = 4.53, SD = 1.99 Stimulants: M = 5.57, SD = 2.41 Hallucinogens: M = 4.13, SD = 1.97

Chapter 5

Which child will benefit from a behavioral intervention for ADHD?

A pilot study to predict intervention efficacy from individual reward sensitivity

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Abstract

Introduction. This article aims to assess whether individual differences in reward sensitivity can be used to predict which children with attention-deficit/hyperactivity disorder (ADHD) will benefit most from behavioral interventions that include reinforcement. *Methods*. A 12-week behavioral intervention was offered to 21 children with ADHD and their parents. Reward sensitivity was assessed prior to the intervention using a combination of psychological and physiological measures. ADHD symptoms were assessed pre- and posttreatment using the Strengths and Weaknesses of ADHD and Normal behavior (SWAN) rating scale. *Results.* Lower scores on one of the questionnaire scales were associated with greater pre/posttreatment differences in ADHD symptoms. *Conclusion.* We found that pre/posttreatment change was associated with one measure of parent-rated reward sensitivity. Children with low impulsive negative behavior toward gaining reward improved most during treatment. This result suggests that aspects of reward-related behaviors in ADHD may be useful to predict the effectiveness of treatment.

Introduction.

Behavioral interventions are recommended for the treatment of children with ADHD (American Academy of Pediatrics, 2011). These interventions rely on teaching behavioral strategies to parents, teachers or therapists, and on using reward contingencies to reinforce desirable behaviors (Barkley, 2002). Despite their popularity, the effects of these interventions on core symptoms of ADHD have been reported to be moderate at best (Daley et al., 2014; Sonuga-Barke et al., 2013). Interestingly, reward processing is a neuropsychological domain that seems to be affected differentially in children with ADHD (Durston, Van Belle, & De Zeeuw, 2011; Luman, Oosterlaan, & Sergeant, 2005; Luman, Tripp, & Scheres, 2010). This heterogeneity may therefore provide a clue to the limited effectiveness of behavioral interventions.

Sensitivity to reward and reinforcement has been reported to be changed in children with ADHD compared to typically developing children. Both in behavioral data and in neuropsychological- and imaging data, differences have been found at the group level (Durston et al., 2011; Luman et al., 2005, 2010). Children with ADHD respond positively to reward and tend to show greater improvement in task performance following reward than typically developing children (Luman et al., 2005, 2010). Hence, once a reward has been 'delivered', it generates a relatively large response. The anticipation of reward on the other hand seems to be diminished, which may result in a lower behavioral control of reinforcers in ADHD. Children with ADHD exhibit delay aversion, where they prefer smaller immediate rewards over larger delayed ones compared to typically developing children. (Sonuga-Barke, Sergeant, Nigg, & Willcutt, 2008). Similarly, fMRI studies have found decreased activity of the ventral frontostriatal reward circuitry, specifically during the anticipation of reward (Durston et al., 2011; Paloyelis, Mehta, Faraone, Asherson, & Kuntsi, 2012; Plichta et al., 2009; Scheres, Milham, Knutson, & Castellanos, 2007; Van Hulst et al., 2017). Neurobiological theories suggest that the dopaminergic system is likely involved; either through a general reduction of synaptic dopamine resulting in reduced sensitivity to delayed reward (Sagvolden, Johansen, Aase, & Russell, 2005; Volkow et al., 2009, 2011), or through what has been termed the dopamine transfer deficit, a reduced firing of dopamine cells in the ventral striatum in anticipation of a reward (Tripp & Wickens, 2008).

Based on this information, recommendations for clinical practice are that children with an ADHD classification may benefit most from immediate reward and need more frequent and consistent reinforcement than typically developing children for reward to be effective (Tripp & Wickens, 2008; Volkow et al., 2009, 2011). These recommendations have been integrated into behavioral interventions for children with ADHD (Van der Oord, Prins, Oosterlaan, & Emmelkamp, 2008). As such, behavioral interventions, including the one in this study, typically contain similar evidence-based elements. Contingency management training, offered to parents and teachers, has been shown to be particularly effective. Child-sessions additionally incorporate reward contingencies and are used as motivation

and stimulation for the training.

Despite the integration of these clinical recommendations, the utility of research findings has been limited in clinical practice, likely due to the highly heterogeneous nature of ADHD. While at the group level ADHD has been linked to changes in reward sensitivity, these findings may not be relevant to all children with ADHD, due to large inter-individual differences (American Psychiatric Association, 2013). This idea is underscored by the neurobiological heterogeneity found in the (dys)function of the ventral frontostriatal reward system (De Zeeuw, Weusten, Van Dijk, Van Belle, & Durston, 2012; Durston et al., 2011; Lecei et al., 2019; Makris, Biederman, Monuteaux, & Seidman, 2009; Nigg & Casey, 2005). In all, due to the variability in reward processing, it may only be a relevant area of dysfunction for some children with ADHD. The modest effect of behavioral interventions on core symptoms of ADHD may be due to differences in sensitivity to reward in children with ADHD. For those children with greater sensitivity these interventions may be effective, while they are less so for children with less sensitivity. Therefore, we conducted a pilot study that aimed to use current knowledge about individual reward processing to predict the effectiveness of behavioral interventions for individual children. Additionally, to test the construct validity of our reward sensitivity measures, we assessed correlations between the various measurement modalities.

In this study we attempted to use neuroscientific knowledge to inform clinical practice. We assessed whether individual measures of reward sensitivity could be used to predict the effectiveness of a behavioral intervention in reducing core-symptoms of ADHD (Scoren met ADHD; Schuurman, Hoppe & Teeuw, 2011). The intervention contained all evidence-based elements common to behavioral interventions in ADHD. We hypothesized that children with the greatest reward sensitivity would benefit most from the behavioral intervention.

Methods

Study design

The Medical Ethical Committee of the UMC Utrecht approved the study. Participant recruitment took place through the outpatient clinic of the Developmental Disorders Unit of the Department of Psychiatry (UMC Utrecht) and Altrecht Center for Mental Healthcare (Altrecht Jeugd, outpatient clinic for child- and adolescent psychiatry in Utrecht). Data was collected at the UMC Utrecht.

Psychiatrists and clinical psychologists asked parents referred to the 'Scoren met ADHD' (Scoring with ADHD) treatment program (Schuurman, Hoppe & Teeuw, 2011) for permission to share contact details with the study investigators. If granted, we contacted parents, provided them with information about the study and asked them to participate. We asked parents for written informed consent and invited participants to come to the UMC Utrecht

with their parents to complete the pre-treatment measurements. After completion of the behavioral intervention, we sent participants post-treatment questionnaires, which we asked them to complete at home.

In/exclusion criteria

All participants had a clinical DSM-IV classification of ADHD that was confirmed using the Diagnostic Interview Schedule for Children (DISC-IV, parent version) (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000). Participants were aged 8 through 13 years. Exclusion criteria for participation were: an estimated IQ below 80 (as the behavioral intervention is indicated only for children with an IQ over 80), any known cardiovascular or neurological disorder and insufficient parental command of either written or spoken Dutch, as we asked parents to fill in a number of questionnaires and complete a structured diagnostic interview. We did not consider psychiatric comorbidity or medication-use exclusion criteria, as we aimed for a typical clinical sample in a naturalistic setting.

Participants

A total of 21 children with an average age of 10 years (range: 8.4 – 12.9) met full inclusion criteria for this study; 18 boys and three girls. We used DISC-IV scores to further classify participants. Children met criteria for the following DSM-IV subtypes: 13 combined type, 1 inattentive type and 7 hyperactive/impulsive type. We classified 12 participants as having comorbid oppositional defiant disorder (ODD), two of whom also met criteria for conduct disorder (CD). Nine participants were not receiving any psychopharmacological treatment, five were taking methylphenidate, one participant was receiving atomoxetine and the remaining six participants were taking other medication. Parents of one participant did not complete the post-treatment questionnaires. Consequently, the main outcome measures could not be computed for this participant and we excluded these data from all analyses.

Intervention

Children participated in the behavioral intervention entitled 'Scoren met ADHD' (Scoring with ADHD). This is a group-based behavioral therapy program for children with ADHD and their parents, that incorporates all major components of typical behavioral child/parent interventions in ADHD (Van der Oord et al., 2008). The name is based on the football-theme applied throughout the program. Group-sessions are fully protocolized and include approximately four to six children per group. Child sessions take place on a weekly basis over the course of 12 weeks, with concurrent biweekly parent sessions. The program also offers a teacher session, where teachers are informed about the program and instructed to apply similar techniques and language in the classroom as used during the intervention. Child sessions focus on developing impulse control and social problem solving skills. A reward-contingency program is used as an incentive to work on assignments. Parent sessions focus on teaching parents to offer structure and effectively

use reinforcement contingencies and on training them to help their child achieve better social problem solving skills.

Pre/post-treatment change

We measured pre/post-treatment change in ADHD symptoms using the Strengths and Weaknesses of ADHD and Normal Behavior (SWAN) rating scale (Lakes, Swanson, & Riggs, 2012) administered before and after treatment. Parents rated the behavior of their child on 18 items based on the symptoms listed in the DSM-IV definition of ADHD. The SWAN is designed for parents to rate behavior relative to peers on a seven-point scale ranging from 'far below average' via 'below average', 'somewhat below average', 'average', 'somewhat above average', 'above average' to 'far above average'. We coded the scale from minus three to plus three and computed average scores for the inattention and hyperactivity subscales. Subsequently, we computed a change score by subtracting the pre-treatment score from the post-treatment score. We computed a total change score by averaging the attentional and hyperactivity change scores.

Reward sensitivity measures

We operationalized reward sensitivity using three modalities. Behaviorally, using a questionnaire, neuropsychologically, using two neuropsychological tasks and psychophysiologically, using heart rate measures. We used these measures to capture a variety of indices of reward-sensitivity and to assess preliminarily which of these modalities was most predictive of pre/post-treatment change.

Questionnaire

We used the Dutch translation of the Sensitivity to Punishment and Sensitivity to Reward Questionnaire for children (SPSRQ-C) (Colder & O'Connor, 2004) as a parental rating of reward related behavior. The Dutch version was validated by Luman, Van Meel, Oosterlaan, & Geurts (2012). It has been shown to differentiate between typically developing children and children with ADHD, specifically on measures of sensitivity to reward. It contains 33 items scored on a 5-point rating scale. The Dutch translation of the questionnaire is best categorized by five factors: social fear, reward responsivity, impulsivity/fun seeking, drive and punishment sensitivity. We averaged the items in each factor to compute overall factor scores. We expected the factors reward responsivity, impulsivity/fun seeking and drive to be most closely related to the construct of reward processing and therefore used these as the main measures of reward sensitivity. The reward responsivity factor captures how excited and motivated a child is by reward. The drive factor has a strong social component and captures how motivated and competitive a child is to stand out or be the best. The impulsivity/fun seeking factor provides an index for risky, unfair or unwanted behavior to gain reward or social status. The name of the factor 'impulsivity/fun seeking' suggests a relationship with the broader category of impulsive behaviors, and may lie on the continuum of that spectrum. However, this factor mostly captures impulsive negative

behaviors intended to gain reward and may therefore be more closely related to reward sensitivity than impulsivity as intended in the core symptoms of ADHD. The two additional factors; social fear items and punishment sensitivity index anxiety and fearful behaviors. We included these two factors in post-hoc analyses to assess their association with pre/post-treatment differences.

Neuropsychological tasks

We used two neuropsychological tasks to probe different aspects of reward processing. The Hungry Donkey Task (HDT) (Crone & Van der Molen, 2004) is a computerized child-friendly version of the Iowa Gambling Task (Bechara, Damasio, Damasio, & Anderson, 1994). This task is a hallmark in the field of decision making and learning based on reward feedback and measures this specific aspect of reward sensitivity. The objective is to earn the Donkey as many apples as possible by repeatedly choosing one of four doors. There were two disadvantageous doors that resulted in high gains, but infrequently led to very high losses. The two other doors resulted in lower gains, but also in far less loss and were therefore advantageous overall. The task consisted of a total of 200 trials. Before administration of the HDT, we instructed children that they would receive their end score (number of apples won) in treats at the end of the testing session. The reward sensitivity measure derived from this task was the percentage of advantageous doors chosen throughout the task.

The Spongers task is a child-friendly version of the Monetary Incentive Delay Task (MID), where reward frequency and magnitude are experimenter-controlled (De Zeeuw et al., 2012; Knutson, Adams, Fong, & Hommer, 2001). This task probes for reward sensitivity by contrasting response times of rewarded trials to response times of unrewarded trials and has been shown to activate the ventral frontostriatal reward system (Durston et al., 2011). During the task, children saw a cue of a wallet containing either 0, 5 or 15 cents (reward magnitude), indicating the amount of money they could earn in the upcoming trial. Subsequently, the task required subjects to guess as fast as they could which of the two cartoon figures (SpongeBob or Patrick Star) was hiding the wallet containing the reward. If they guessed correctly, participants saw a thumbs up and the reward was added to their overall reward. If they guessed incorrectly, they saw a thumbs down and no money was added to the overall reward. To reinforce quick responses, the maximum response window was 1250 ms. Participants received no reward for responses after this window. The task was rigged to produce two reward frequency conditions; two blocks where participants' guesses were correct 80% of the time and two blocks where they were correct 20% of the time. Across the task, all participants earned a total of 10 euros, which they received in the form of a gift-certificate at the end of the task. Response times are a measure of approach behavior, as earlier studies using this task have shown that faster response times occur for higher rewards, an effect that is attenuated in ADHD (Van

Hulst, De Zeeuw, & Durston, 2015). We used response time differences between reward magnitude conditions (0 cents versus 5 or 15 cents) as reward sensitivity measures. This was computed using a regression procedure designed to limit the effect of response time variability (as described by De Zeeuw et al., 2012). The manipulation of both reward magnitude (2x) and reward frequency (2x) resulted in four outcome measures: RegB_20_1 (difference between response times in 0 and 5 cent trials in blocks with a 20% reward frequency), RegB_20_2 (difference between response times in 0 and 15 cent trials in blocks with a 20% reward frequency), RegB_80_1 (difference between response times in 0 and 5 cent trials in blocks with an 80% reward frequency) and RegB_80_2 (difference between response times in 0 and 15 cent trials in blocks with an 80% reward frequency). These regression coefficients indicate the level of reward sensitivity; if the regression coefficient is smaller than 1, the response times in the reward condition are faster than the response times in the non-reward conditions, hence reward has a stronger influence on performance, indicating reward sensitivity.

Physiological measures

The measurement of physiological responses to reinforcement have a long history in research of disruptive disorders (Fowles, 1980; Luman et al., 2005; Matthys, Vanderschuren, & Schutter, 2013; Raine, 1996). They have been used to study the fearlessness-hypothesis of more anti-social disorders (Oppositional Defiant Disorder or Conduct Disorder). Differences in heart rate variability in response to reward between normally-developing participants and participants with ADHD have frequently been described. (Bubier & Drabick, 2008; Crone, Jennings, & van der Molen, 2003; Crowell et al., 2006; Iaboni, Douglas, & Ditto, 1997; Luman, Oosterlaan, Hyde, Van Meel, Catharina, & Sergeant, 2007). As such, we decided to include heart measures as a commonly used psychophysiological proxy of reward sensitivity. We measured heart rate (with a two-lead electrocardiogram) using the VU-AMS Ambulatory Monitoring System (De Geus, Willemsen, Klaver, & Van Doornen, Lorenz, 1995) as a marker for physiological response to reward. We recorded heart rate data during a baseline period and during both tasks as the inter-beat-interval (IBI) in milliseconds. We found a number of gaps in the datasets of three participants due to temporary signal losses in heart rate recordings. Therefore we individually checked all datasets and structured them to ensure that all available data could be used. Subsequently, we replaced outlying IBIs from the datasets, defined as IBIs shorter than 400ms, longer than 1500ms or over three standard deviations away from the average IBI of that individual's own dataset. We set the baseline period as 90 IBIs prior to the instruction-phase of the first task. We computed heart rate variability (HRV) as the root mean square of successive differences (RMSSD) in IBIs during baseline, the HDT, total Spongers task, Spongers 20%-frequency blocks and Spongers 80%-frequency blocks. Similarly, we computed average heart rate (AHR) in each of these conditions. For both AHR and HRV, we computed difference scores by subtracting baseline values from task values and by

subtracting values in the Spongers 20% reward condition from values in the Spongers 80% reward condition. These variables will be referred to as HRVHungryDonkey-Baseline, HRVSpongers-Baseline, HRVSpongers80%-Spongers20%, AHRHungryDonkey-Baseline, AHRSpongers-Baseline, AHRSpongers80%-Spongers20%.

Statistical analysis

Quality checks and pre/post-treatment change

We tested all variables for missing values, normality of distribution (using the Shapiro-Wilk test) and outliers (using an interquartile range larger than three). Two participants missed a question on the pre-treatment SWAN questionnaire and three participants missed a question on the post-treatment SWAN questionnaire. We omitted these scores when computing average scale scores. The majority of the data was normally distributed and included no univariate outliers. For some measures, we ran regression analyses with non-normally distributed data, and additionally tested these using spearman correlations. This was the case for the SPSRQ-C scales Reward Sensitivity and Drive, the percentage advantageous doors in the HDT, and the HRV data. Since the non-parametric analyses for these measures did not differ meaningfully from the parametric ones, we report only the parametric analyses. To assess pre/post-treatment change we used paired samples t-tests to compare parent-rated symptoms of ADHD before and after treatment.

A-priori reward sensitivity and pre/post-treatment change

We tested for associations between reward sensitivity measured prior to treatment and pre/post-treatment change in ADHD symptoms. To do so, we used linear regression with SWAN change scores as outcome variables (pre/post-treatment change in attention, hyperactivity and total scores) and reward sensitivity measures as predictor variables. Primary predictor variables included: the SPSRQ-C subscales Reward Sensitivity, Impulsivity/Fun Seeking and Drive; the HDT percentage advantageous doors, Spongers RegB_20_2, Spongers RegB_80_2, HRVHungryDonkey-Baseline, HRVSpongers-Baseline and HRVSpongers80%-Spongers20%. In exploratory, post-hoc analyses we entered a number of additional reward sensitivity variables. We entered heart rate measures (AHRHungryDonkey-Baseline, AHRSpongers-Baseline, AHRSpongers80%-Spongers20%) and two additional factors of the SPSRQ-C questionnaire (Social Fear and Punishment Sensitivity) as predictor variables.

Multi-method correlational analyses of reward sensitivity measures

To assist hypothesis-generation for future research, we tested associations between the reward sensitivity measures in different modalities, using correlational analyses. Further information on these analyses can be found in Supplementary Material 1.

Sensitivity Analyses

Table 1. Demographic Variables and SWAN-Scores

Demographic Variables			
N	Boys/Girls	Age	Age Range
21	18/3	10.0	8.4-12.9
Parent-Rated Symptoms of ADHD			
SWAN-Score	Overall	Hyperactivity	Attention
Pretreatment	-1.38	-1.47	-1.29
Posttreatment	-.66	-.72	-.60
Change-Score	.72	.76	.69

Note: N, Number of Participants; ADHD, Attention-Deficit/Hyperactivity Disorder; SWAN, Strengths and Weaknesses of ADHD and Normal Behavior.

We ran sensitivity checks for the influence of IQ and baseline heart rate on our main analyses. As some of the original heart rate datasets included temporary signal losses, we assessed whether the quality of heart rate data influenced the results. We did this by entering a dummy variable of heart rate data quality (complete datasets vs incomplete datasets) in the regression analyses with significant results. We found no evidence of these measures affecting our outcome and therefore reported our results without them.

Results

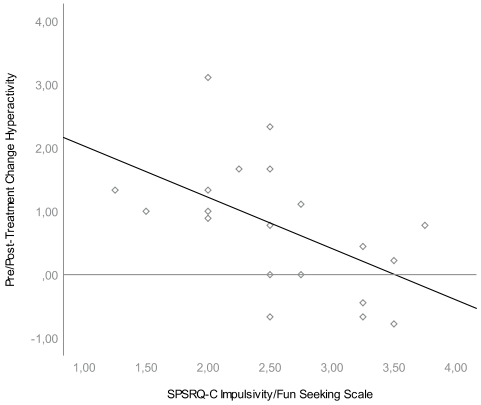
Pre/post-treatment change

Values of pre- and posttreatment measurements of the SWAN questionnaire can be found in table 1. Parent-rated symptoms of ADHD (measured by the SWAN-questionnaire) differed significantly between pre- and posttreatment. Parents rated their children as less inattentive M = -.60, SD = 1.01) and less hyperactive (M = -.72, SD = .79) after treatment, than they did before treatment (M = -1.29, SD = .78 and M = -1.47, SD = .67 respectively; t(19) = -3.59, p < .05 and t(19) = -3.29, p < .05).

A-priori reward sensitivity and pre/post-treatment change

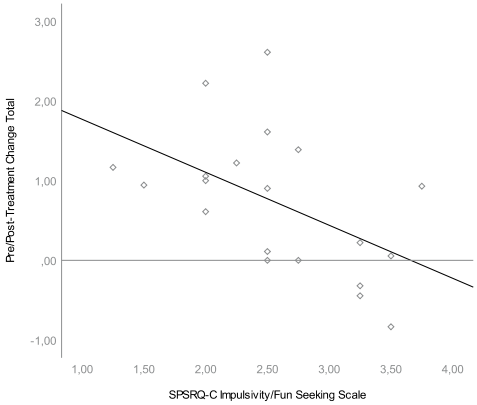
We found that pre/post-treatment change was associated with one scale of the parent-rated reward sensitivity questionnaire. Lower scores on the SPSRQ-C Impulsivity/Fun seeking scale were associated with larger change scores on both the SWAN Hyperactivity Scale (b = -.809, t(20) = -2.717, p= .014) and the SWAN Total Scale (b = -.665, t(20) = -2,551, p= .020) (See Figure 1 and Figure 2). Effect sizes for both associations were large (r = .54 and r = .52 respectively). This means that hyperactive behavior was more likely to diminish during treatment in children with low parental ratings on the impulsivity/fun seeking scale. The impulsivity scale consists of four slightly divergent items that focus on gaining social status through unfair means, not being able to resist the temptation to do forbidden things, showing risky behavior to get a reward and not doing things you enjoy so as to not be rejected or criticized. We found no relationship between pre/post-treatment change

Figure 1. Association SPSRQ-C Impulsivity/Fun Seeking Scale and Pre/Post-Treatment Difference in SWAN Hyperactivity.



Note. Association between SPSRQ-C scale and pre/post-treatment difference in SWAN hyperactivity. Children who scored lower on the impulsivity/fun seeking scale, showed a larger pre/post-treatment difference. SWAN, Strengths and Weaknesses of ADHD and Normal Behavior; SPSRQ-C, the Sensitivity to Punishment and Sensitivity to Reward Questionnaire for children.

Figure 2. Association SPSRQ-C Impulsivity/Fun Seeking Scale and Pre/Post-Treatment Difference in SWAN Total.



Note. Association between SPSRQ-C scale and total SWAN pre/post-treatment difference. Children who scored lower on the impulsivity/fun seeking scale, show a larger pre/post-treatment difference. SWAN, Strengths and Weaknesses of ADHD and Normal Behavior; SPSRQ-C, the Sensitivity to Punishment and Sensitivity to Reward Questionnaire for children.

in ADHD symptoms and task performance, heart rate variability or the other SPSRQ-C subscales. In an exploratory, post-hoc regression analyses we found no relationship between pre/post-treatment change in ADHD symptoms and heart rate measures (i.e. $AHR_{HungryDonkey-Baseline}$, $AHR_{Spongers-Baseline}$, $AHR_{Spongers80\%-Spongers20\%}$) or the two additional SPSRQ-C sub-scales. Results of these regression analyses can be found in Table 2.

Correlations between different measures of reward sensitivity

In correlations between variables of the same modalities, we found different heart rate measures to be highly positively intercorrelated, with only a few significant correlations in the questionnaire and task data. Across modalities, measures of reward sensitivity mostly did not correlate. Further information on these correlations is provided in the supplementary materials.

Discussion

The aim of this pilot study was to assess whether reward sensitivity, as assessed a-priori, can predict pre/post-treatment differences in core ADHD symptoms in the context of a behavioral intervention using reward contingencies. Our treatment was a reward contingency assisted behavioral intervention incorporating evidence-based elements of typical behavioral interventions. We hypothesized that those children with ADHD

Table 2. Regression Analyses of Reward Sensitivity Measures and Pre/Post Treatment Differences

	SWAN Attention			SWAN Hyperactivity			SWAN Total		
	F	Sign.	ES (r)	F	Sign.	ES (r)	F	Sign.	ES (r)
Primary Analyses									
SPSRQ-C Reward Responsivity	.104	.751	.076	.306	.587	.129	.026	.873	.038
SPSRQ-C Impulsivity/Fun Seeking	3.725	.070	.414	**7.384**	**.014**	**.539**	**6.508**	**.020**	**.515**
SPSRQ-C Drive	.191	.667	.102	.442	.514	.155	.029	.867	.040
HDT Percentage Advant. Doors	.002	.968	.009	.541	.471	.171	.196	.663	.104
RegB_20_2	.000	.985	.005	.030	.863	.041	.008	.928	.022
RegB_80_2	.003	.954	.014	1.137	.300	.244	.333	.571	.135
$HRV_{Spongers\text{-}Baseline}$	.002	.964	.011	.880	.361	.216	.313	.583	.131
$HRV_{HungryDonkey\text{-}Baseline}$	.566	.461	.175	.047	.831	.051	.056	.816	.056
$HRV_{Spongers80\%\text{-}Spongers20\%}$	.952	.342	.224	.480	.497	.161	.773	.391	.203
Average Heart Rate Analyses									
$AHR_{Spongers\text{-}Baseline}$	.910	.353	.219	2.435	.136	.345	1.880	.187	.308
$AHR_{HungryDonkey\text{-}Baseline}$	.293	.595	.127	1.575	.226	.284	.974	.337	.227
$AHR_{Spongers80\%\text{-}Spongers20\%}$	4.422	.050	.444	2.133	.161	.325	3.546	.076	.406

ADHD, Attention-Deficit/Hyperactivity Disorder; SWAN, Strengths and Weaknesses of ADHD and Normal Behavior; ES, Effect Size; r, Pearson's Correlation; SPSRQ-C, the Sensitivity to Punishment and Sensitivity to Reward Questionnaire for children; HDT, Hungry Donkey Task; RegB_20_2, difference between response times in 0 and 15 cent trials in blocks with a 20% reward frequency; RegB_80_2, difference between response times in 0 and 15 cent trials in blocks with an 80% reward frequency, HRV, Heart Rate Variability; AHR, Average Heart Rate.

who had the greatest sensitivity to reward, would benefit most from the behavioral intervention. To test this hypothesis, we collected reward sensitivity data from different modalities; a questionnaire, two neuropsychological tasks and heart rate measurements, and assessed their predictive relationship with pre/post-treatment differences in parental ratings of ADHD symptoms. Children showed improvement overall, as parents rated their children less inattentive and hyperactive after treatment. These findings are in line with previous research that has shown that behavioral interventions are moderately effective (Daley et al., 2014; Sonuga-Barke et al., 2013). Children who had low parental ratings of reward sensitivity, specifically on the impulsivity/fun seeking scale of the SPSRQ-C, improved most during treatment. No other measure of reward sensitivity predicted pre/post-treatment change in ADHD symptoms.

The name of the scale 'impulsivity/fun seeking', was introduced during previous iterations of factor analyses of the SPSRQ-C (Colder & O'Connor, 2004; Luman et al., 2012), but perhaps does not fully represent the four items in the Dutch version of this scale (Luman et al., 2012). These items are related to accomplishing social status through unfair means,

not being able to resist the temptation to do things that are forbidden, showing risky behavior to get a reward and avoiding rejection and criticism by not doing things that are considered fun. The scale measures impulsive negative behavior to gain (social) reward, even if through unfair means. It may be argued that there is overlap between this subscale and the broader spectrum of impulsive behaviors, on which the impulsive behaviors described in the criteria for ADHD also fall. However, we found only low to moderate and not-significant correlations between this subscale and ADHD symptoms as measured by the SWAN-questionnaire pre-treatment. Moreover, the impulsivity/fun-seeking subscale appears predictive of pre/post-treatment change in our data, even when forcing pre-treatment SWAN measures into the analysis as a covariate. The impulsivity/fun seeking subscale can be understood in terms of the reward and punishment sensitivity theory by Gray & McNaughton (2000) which describes a behavioral activation system (BAS) and a behavioral inhibition system (BIS). Focusing on reward while ignoring the negative associations with or consequences of actions may be in line with a predominantly active BAS in combination with an inactive BIS. This imbalance has previously been described in children with a classification of ODD (Matthys, Van Goozen, Snoek, & Van Engeland, 2004; Newman & Wallace, 1993).

Although the association between impulsive negative behaviors to gain reward and the effectiveness of treatment is promising, these results should be interpreted with caution. First, in view of the exploratory nature of our study, we chose not to correct for multiple testing. This increases the likelihood of false positive findings. Moreover, both measures were based on parental ratings. The lens through which parents view and rate their children may affect outcome as questionnaire data completed by the same rater are not entirely independent. This phenomenon has been called common method variance (Richardson, Simmering, & Sturman, 2009). Its impact on outcome is inherently difficult to assess, but a suggested solution to detecting common method variance is employing numerous different measurement modalities when gathering data. In this study, we did in fact include a number of reward sensitivity measures that did not rely solely on the parental perspective. However, we found no associations between these measures and pre/post-treatment change. In sum, both common method variance and increased likelihood of false positive findings may play a part in our results. As such, these findings should be taken as an incentive for further research with larger samples, rather than as definitive knowledge on (children with) ADHD.

In addition to the matters discussed above, there is the initial value-problem: those children who show the most severe symptoms on pre-treatment measures may be most likely to improve, whereas children with milder symptoms may show less improvement. We carried out additional analyses where we defined treatment outcome simply as post-treatment SWAN scores. These analyses showed similar results to the ones in the main paper, although two additional regression analyses reached statistical significance: the

SPSRQ-C Impulsivity/Fun Seeking scale was associated not only with the post-treatment SWAN Hyperactivity Scale, but also with the post-treatment SWAN Attention Scale. Furthermore, we found that differences in heart rate variability between the Spongers 80% condition and the Spongers 20% condition were associated with the post-treatment SWAN Hyperactivity scale. Detailed information on these analyses can be found in Supplementary Material 1.

All our measures of reward sensitivity have previously been used successfully in research on reward sensitivity. The SPSRQ-C-questionnaire is the most ecologically valid measure, commonly used in research on reward sensitivity. It has been shown to differentiate between typically developing children and children with an ADHD classification (Luman, Van Meel, Oosterlaan, & Geurts, 2012). Our two neuropsychological tasks have been extensively used in the literature on reward sensitivity. The Spongers task is a relatively direct measure of children's response time to reward, whereas the HDT is a proxy of decision making and learning based on reward feedback. Similarly, our psychophysiological measures (heart rate and heart rate variability) have been shown to relate to reward processing and to differentiate between typical and clinical populations (Bubier & Drabick, 2008; Crone, Jennings, & Molen, 2003; Crowell et al., 2006; Iaboni et al., 1997; Luman et al., 2007). Although all of these measures have been related to reward processing in various ways, it is not clear whether they measure one and the same construct. We found only few correlations between the different operationalizations of reward sensitivity (parent-rated reward sensitivity, task-based reward sensitivity and heart-rate data). This is in line with other studies noting that different measures of theoretical constructs often have no or very low correlations (Fuermaier et al., 2015; Potvin, Charbonneau, Juster, Purson, & Tourjman, 2016; Toplak, West, & Stanovich, 2013). One potential explanation for this lack of associations can be found in concerns about the assumption that such different modalities measure the same underlying concept. This assumption is usually made after various (objective and subjective) measures of a construct show differences between clinical and typical populations, differences that are assumed to prove construct validity (Barkley & Fischer, 2011; Biederman et al., 2008; Tucha et al., 2011, 2009). For example, this is the case for executive functioning, where task-based measures and parental rating scale measures are implicitly thought to measure the same underlying construct, but in fact have few meaningful correlations (Toplak et al., 2013). The same may be the case for the measures of reward sensitivity in the current study. Faridi et al. (2014) remarked that construct labels attached to instruments or scales may lead to the unjust assumption that there is overlap in constructs measured by different instruments. In all, it is uncertain if the different measures of reward sensitivity used, tapped into one overall construct of reward processing.

We found no evidence for the predictive value of heart rate measures or neuropsychological task performance on pre/post-treatment change. Other studies have previously tried to

identify and quantify clinically relevant biomarkers of reward sensitivity (Fosco, Sarver, Kofler, & Aduen, 2018; Luman et al., 2007; Tripp & Wickens 2008; Van De Wiel, Van Goozen, Matthys, Snoek, & Van Engeland, 2004; Volkow et al., 2001). To date, there is no evidence for robust links between neurobiological markers and clinically relevant outcome measures. Finding common ground between the clinical and neuroscientific fields as such, is proving to be difficult, as needs for specificity and reliability in measures differ across the fields. Moreover, both the tendency of clinical psychology to adjust slowly to paradigm shifts and the lack of neurosciences to employ clinically relevant methods (Beauchaine, Neuhaus, Brenner, & Gatzke-kopp, 2008) result in limited interchangeability between the fields (Pine, 2011). A mere call from the field of neuroscience to apply its insights in clinical practice ignores the need to think about which neuroscientific contribution would be most meaningful and helpful in clinical practice. The relevance of heavily controlled neuroscientific research in a clinical environment, that is inherently strongly influenced by context, is not a given. Reward sensitivity might be a clinically relevant measure if we can better delineate when, where and how it can be meaningfully measured in clinical practice and whether it can inform treatment choices independent of individual patient context.

Limitations

This study was set up as a pilot study and accordingly, we included only a small number of participants. As such, our power to detect more subtle differences in reward sensitivity was limited. Furthermore, we used a single-arm design and lacked a control condition for pre/post-treatment change. Therefore, it is difficult to discern if pre/post-treatment differences are due to the behavioral intervention or whether other factors played a role. Due to the small-scale design of our study, we did not assess the impact of psychopharmacological treatment on the relationship between reward sensitivity and treatment outcome. This may be an important factor to study more thoroughly in future studies.

Conclusion

In this pilot study, we made a first attempt to connect the extensive neuroscientific literature on reward processing in children with ADHD to clinical practice. We found that pre/post-treatment change was associated with one specific aspect of parent-rated pre-treatment reward sensitivity. This result suggests that children with low impulsive negative behavior to gain reward, may benefit most from a behavioral intervention using reward contingencies. This preliminary finding is promising in that it suggests individual neuropsychological profiles in ADHD may perhaps be applicable for predicting the effectiveness of treatments. However, this is a small pilot study and larger studies are warranted before translating these findings to everyday clinical practice.

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Supplementary Material 1

Additional Outcome Measure- Post-Treatment SWAN

The definition of treatment outcome as pre-post treatment change has a potential pitfall, often coined the initial value problem. Children who are more 'impaired' have more room to improve, whereas children who are closer to the norm, are less likely to reach similar levels of improvement, because of a lack of room for improvement. In order to account for this problem, we carried out additional analyses where we defined treatment outcome as the post-treatment score. Although this definition also has flaws (individual differences in pre-treatment scores, carrying over into post-treatment scores may now unjustly be correlated with reward sensitivity), we wanted to provide an overview of the results for comparison.

The additional analyses, using SWAN Attention and SWAN Hyperactivity post-treatment scores, can be found in supplementary table 1. The majority of the analyses did not reach statistical significance, similar to the analyses with pre-post treatment change scores. We found three associations between reward-sensitivity measures and SWAN post-treatment scores. The SPSRQ-C Impulsivity/Fun Seeking scale is now associated not only with the post-treatment SWAN Hyperactivity Scale, but also the post-treatment SWAN Attention Scale. Lower scores on the SPSRQ-C Impulsivity/Fun seeking scale were associated with higher scores on both the post-treatment SWAN Hyperactivity Scale (b = -.589, t(20) = -2.522, p= .021) and the post-treatment SWAN Attention Scale (b = -.959, t(20) = -3,626, p= .002). In addition, we found that a larger difference in heart rate variability between the Spongers 80% condition and the Spongers 20% condition, was associated with higher scores on the post-treatment SWAN Hyperactivity scale (b = .054, t(20) = 2,750, p= .013).

Correlations between different measures of reward sensitivity

We tested for correlations between the various measures of reward sensitivity (SPSRQ-C factor scores, spongers performance measures, HDT performance measures, heart rate data and heart rate variability data). We used Spearman correlations for analyses of non-normally distributed variables (the SPSRQ-C scales Reward Sensitivity and Drive, the percentage advantageous doors in the HDT, and the HRV data) and Pearson correlations for all normally distributed data. Statistically significant correlations were further explored in scatterplots to identify bivariate outliers. If present, we re-ran the analyses without the outliers to assess their effect on the model.

Results of all correlational analyses can be found in Supplementary Table 2. Correlations between reward sensitivity measures were split into two categories: correlations between variables from the same modality (within questionnaires, behavioral task data, or heart rate data) and correlations between different modalities. Within the same modalities, we found heart rate data to be highly positively correlated, and only few significant

Supplementary Table 1. *Regression Analyses of Reward Sensitivity Measures and Post Treatment ADHD symptoms*

	SWAN Attention Post-treatment			SWAN Hyperactivity Post-treatment		
	F	Sign.	ES (r)	F	Sign.	ES (r)
Primary Analyses						
SPSRQ-C Reward Responsivity	.390	.540	.146	.103	.752	.075
SPSRQ-C Impulsivity/Fun Seeking	13.149	.002*	.650	6.361	.021*	.511
SPSRQ-C Drive	1.838	.192	.304	.702	.413	.194
HDT Percentage Advant. Doors	.242	.629	.115	2.793	.112	.366
RegB_20_2	.266	.612	.121	.105	.750	.076
RegB_80_2	.272	.608	.122	.406	.532	.148
$HRV_{Spongers\text{-}Baseline}$	.485	.495	.162	.366	.553	.141
$HRV_{HungryDonkey\text{-}Baseline}$	.107	.748	.077	.466	.503	.159
$HRV_{Spongers80\%\text{-}Spongers20\%}$	.695	.415	.193	7.563	.013*	.544
Average Heart Rate Analyses						
$AHR_{Spongers\text{-}Baseline}$	.251	.622	.117	.453	.510	.157
$AHR_{HungryDonkey\text{-}Baseline}$	.024	.878	.037	.010	.921	.024
$AHR_{Spongers80\%\text{-}Spongers20\%}$	3.231	.089	.390	3.251	.088	.391

ADHD, Attention-Deficit/Hyperactivity Disorder; SWAN, Strengths and Weaknesses of ADHD and Normal Behavior; ES, Effect Size; r, Pearson's Correlation; SPSRQ-C, the Sensitivity to Punishment and Sensitivity to Reward Questionnaire for children; HDT, Hungry Donkey Task; RegB_20_2, difference between response times in 0 and 15 cent trials in blocks with a 20% reward frequency; RegB_80_2, difference between response times in 0 and 15 cent trials in blocks with an 80% reward frequency, HRV, Heart Rate Variability; AHR, Average Heart Rate.

correlations in the questionnaire and task data. Across modalities, measures of reward sensitivity mostly did not correlate. Out of the 67 associations we tested, four were found to be nominally significant. Questionnaire data did not correlate with any of the other measures, nor did the behavioral measures of the HDT and Spongers task. We found only few correlations between behavioral measures and physiological data (e.g. HDT and task data).

Supplementary Table 2. *Correlation Table for Reward Sensitivity Measures.*

			1.	2.	3.	4.	5.	6.
1	SPSRQ-C Reward Responsivity	Cor	-	,014	**,740****	-,317	-,183	,029
		Sig.	-	,954	**,000**	,173	,441	,904
2	SPSRQ-C Impulsivity/Fun Seeking	Cor		-	-,087	-,190	-,148	-,134
		Sig.		-	,716	,422	,534	,575
3	SPSRQ-C Drive	Cor			-	-,170	-,214	,149
		Sig.			-	,472	,364	,531
4	SPT RegB_20_1	Cor				-	**,529***	,129
		Sig.				-	**,016**	,588
5	SPT RegB_20_2	Cor					-	-,127
		Sig.						,594
6	SPT RegB_80_1	Cor						-
		Sig.						-
7	SPT RebB_80_2	Cor						
		Sig.						
8	HDT	Cor						
		Sig.						
9	$HRV_{Spongers\text{-}Baseline}$	Cor						
		Sig.						
10	$HRV_{HungryDonkey\text{-}Baseline}$	Corr						
		Sig.						
11	$HRV_{Spongers80\%\text{-}Spongers20\%}$	Cor						
		Sig.						
12	$AHR_{Spongers\text{-}Baseline}$	Cor						
		Sig.						
13	$AHR_{HungryDonkey\text{-}Baseline}$	Cor						
		Sig.						
14	$AHR_{Spongers80\%\text{-}Spongers20\%}$	Cor						
		Sig.						

This table shows all correlations between reward sensitivity measures. Spearman correlations are in the gray boxes and Pearson correlations are in the white boxes. Significant correlations within the same measurement-modalities are in bold. Significant correlations between different measurement modalities are in bold and underlined. SPSRQ-C, the Sensitivity to Punishment and Sensitivity to Reward Questionnaire for children; SPT, Spongers Task; RegB_20_1, difference between response times in 0 and 5 cent trials in blocks with a 20% reward frequency; RegB_20_2, difference between response times in 0 and 15 cent trials in blocks with a 20% reward frequency; RegB_80_1, difference between response times in 0 and 5 cent trials in blocks with an 80% reward frequency; RegB_80_2, difference between response times in 0 and 15 cent trials in blocks with an 80% reward frequency; HDT, Hungry Donkey Task; HRV, Heart Rate Variability; AHR, Average Heart Rate.

	7.	8.	9.	10.	11.	12.	13.	14.
	,215	,202	,005	-,027	,032	,038	,047	-,085
	,362	,394	,982	,909	,894	,874	,844	,722
	-,078	,276	,437	,166	-,269	,115	-,084	-,183
	,744	,239	,054	,484	,251	,630	,725	,441
	,189	-,116	,121	,015	,190	,173	,060	,233
	,425	,625	,613	,949	,421	,466	,802	,322
	,131	,169	-,287	-,286	,038	-,027	,043	,029
	,581	,477	,220	,222	,875	,911	,858	,904
	,191	,225	-,101	-,084	,277	-,108	,034	,194
	,419	,340	,673	,724	,238	,652	,886	,412
	,492*	-,029	,195	,289	-,065	,394	**,508***	-,321
	,028	,905	,409	,217	,787	,086	**,022**	,168
	-	-,152	,236	,194	**,538***	,331	**,561***	,158
	-	,522	,316	,413	**,014**	,155	**,010**	,506
		-	-,174	-,131	**-,587****	-,263	-,123	-,135
		-	,463	,582	**,006**	,262	,604	,571
			-	**,770****	,185	**,669****	**,565****	,173
			-	**,000**	,435	**,001**	**,009**	,466
				-	,259	**,674****	**,836****	,068
				-	,271	**,001**	**,000**	,777
					-	,105	,398	,362
					-	,659	,082	,116
						-	**,637****	,132
						-	**,003**	,578
							-	-,099
							-	,679
								-
								-

Chapter 6
Discussion

Summary

Classifying individuals with mental health problems has become an integral part of how we understand mental health. Psychiatric classifications shape how we interpret psychological differences and individual stories. These classifications were developed to standardize mental health care and help mental health professionals communicate better (with one another) about observed problems. Yet, they have come to be used by many different stakeholders in widely varying contexts, including scientific, therapeutic, pedagogical, social and administrative ones (Werkhoven et al., 2022). As such, they have not only influenced the course of psychiatry, but their impact has come to stretch well beyond that of mental health care (Corrigan & Watson, 2002; First et al., 2019; Hacking, 2007).

As classifications have come to play an increasingly important role in our understanding of mental health, both in psychiatry and society, questions have arisen about how we construct and understand these classifications. In the introductory chapter, I outlined the debate surrounding psychiatric classification using five tentacles. These tentacles covered the following questions:

- Tentacle 1: Are classifications 'real'?
- Tentacle 2: How do we define and understand classifications?
- Tentacle 3: Do classifications explain the causes of problematic behaviors?
- Tentacle 4: How do classifications affect the individuals who receive them?
- Tentacle 5: Are classifications clinically useful?

This thesis aims to shed light on these questions and critically evaluate the practice of psychiatric classification in mental health care, focusing on the classification ADHD. Specifically, gaps in knowledge exist on how classifications are communicated about and understood 'in the wild' by the stakeholders who utilize them. Moreover, the varying opinions and findings on the individual consequences and clinical utility of classifications make it difficult to draw definitive conclusions about how we can better utilize our classificatory system. The different chapters in this thesis each covered a topic related to one or more of the five tentacles.

Chapter 2

In chapter 2, we explored how ADHD stakeholders navigate and make sense of the complexity surrounding the ADHD classification. To this purpose, we analyzed stakeholder perspectives from seven focus groups: adults classified with ADHD, adolescents classified with ADHD, parents of children classified with ADHD, clinicians, researchers, teachers, and policymakers. We collected verbatim data of these seven discussions on ADHD and analyzed the responses prompted by the same set of questions using thematic analysis.

We found seven different themes in how stakeholders navigated the classification ADHD. Four themes were common to all or most stakeholder groups, while three themes were unique to a (subset of) focus group(s). However, what stood out most was an overarching discursive pattern: participants expressed highly ambivalent ideas on ADHD but made little or no reference to their ambivalence. We found this ambivalence in the contradictory accounts presented by stakeholders, where they agreed with different sides of a debate sequentially. Notably, participants did not put the conflict between (their own) different perspectives into words.

As such, we hypothesized that their ambivalence was dormant, in the sense that participants were not aware of the conflicting aspects of their accounts. This may arise from tensions between the natural kinds approach and social kinds approach to ADHD. Stakeholders seemed to (implicitly) operate largely from a natural kinds approach, where they believed classifications capture 'true biological entities' that cause problematic behaviours. Yet participants attempted to integrate ideas from the social kinds approach into their rationale, leading to (undetected) conflict.

Chapter 3

In chapter 3, we studied how the classification ADHD is explained and given meaning in psychoeducation. Psychoeducation is an important source of information for shaping parents' and children's understanding of ADHD. Furthermore, it may affect the therapeutic alliance and how we understand psychological differences in society. We therefore analyzed 41 written psychoeducational materials from four different countries, the USA, the UK, the Netherlands, and Hungary. We used discourse analysis to identify patterns in how the materials construct the discourse on ADHD.

The materials contained several internal conflicts in how ADHD was framed and contextualized. Notably, these conflicts remained unaddressed in the documents. Conflicts arose from tension between 1) cause versus consequence, 2) uncertain complexity versus certain simplicity, 3) normality versus abnormality and 4) specificity versus generality. In addition, there was a clear pattern in the materials of emphasizing 5) the necessity of the expert view.

We speculate that these unaddressed, internal conflicts arise from a covert tension within the biopsychosocial model, which we called the primacy of biology. We found that materials often prioritized biology in the information provided, terminology used and ordering of statements. This primacy is illustrated in the notion, found in many materials, that ADHD is caused by neurobiological difficulties in the context of environmental risk factors. The opposite was never considered: could ADHD be caused by environmental difficulties in the context of biological risk factors? This covert primacy of biology may well lead to tension in the biopsychosocial model and in turn lead to inconsistent and incoherent information on ADHD.

Chapter 4

In chapter 4, we studied the impact and stigma associated with classifications. In a large, real-life vignette study (N=1605), we investigated differences in attitude between people who did and did not know the psychiatric classifications of a young adult sharing a short personal story. Participants watched a brief video of the young adult talking about her social interactions, with or without prior knowledge of her classifications. Participants then answered a series of questions about how they felt about, thought about and expected to behave towards her.

We found differences in cognitive and behavioral attitude between people who did and did not know her psychiatric classifications. Participants who knew her classifications were more likely to think the young woman would want medication for her difficulties and they were more likely to think of her as vulnerable. Participants who knew of her classification also had a more negative behavioral attitude towards her than those who did not know of her classifications. This trend was present across all items, but was most prominent in our final behavioral item: participants who knew her classifications, were least likely to want her to babysit their children. Finally, we found that people with direct or indirect personal experience of psychiatric classifications held more positive attitudes towards the young woman.

These results highlighted that classifications guide us in making assumptions about an individual and the problems they experience. For someone dealing with mental illness, the change in attitude caused by knowledge of their classifications may be an important factor in deciding whether or not to share them. Ultimately, open communication about mental health should lead to less social distance, not more.

Chapter 5

In chapter 5, we studied the clinical utility and predictive value of traits associated with ADHD on treatment outcome. We assessed whether individual differences in reward sensitivity could be used to predict which children with ADHD would benefit most from a behavioral intervention that included reinforcement. A 12-week behavioral intervention was offered to 21 children with ADHD and their parents. Reward sensitivity was assessed prior to the intervention using a combination of psychological and physiological measures. ADHD symptoms were assessed pre- and post-treatment, to determine the efficacy of the behavioral intervention.

Children showed improvement overall, as parents rated their children as less inattentive and hyperactive after treatment. These findings support previous research that has shown that behavioral interventions are moderately effective. Children who had low parental ratings of reward sensitivity, specifically on the impulsivity/fun seeking scale of the SPSRQ-C, improved most during treatment. No other measure of reward sensitivity predicted pre/post-treatment change in ADHD symptoms.

In this pilot study, we made a first attempt to connect the extensive neuroscientific literature on reward processing in children with ADHD to clinical practice. We found that pre/post-treatment change was associated with one specific aspect of parent-rated pre-treatment reward sensitivity. This result suggested that children with low impulsive negative behavior to gain reward, may benefit most from a behavioral intervention using reward contingencies. This preliminary finding is promising in that it suggests individual neuropsychological profiles in ADHD may be applicable for predicting the effectiveness of treatments.

General Discussion

Over the course of working on this thesis, the debate surrounding the ADHD-classification has often seemed polarized to me. Albeit slightly oversimplified, it has felt like two sides pinned against each other. One side takes a mostly biomedically oriented approach in favor of our current diagnostic system, largely supports the natural kinds perspective and continues research efforts to uncover the neurobiological mechanisms underlying classifications. The other side takes a largely critical stance towards the ADHD-classification, questioning its utility and value in mental health care and seems to fight to remove psychiatric classifications from our daily clinical practice.

In line with this polarized rationale, the question often posed is: 'Should we be in favor of or opposed to psychiatric classification?'. Based on findings from previous chapters of this thesis, I would conclude that the answer requires much more nuance than either option can provide. Our current classificatory system is valuable in that it has helped standardize mental health care and research, it has advanced our communication and provided recognition and support for those experiencing difficulties. Removing the classificatory system entirely is therefore not a likely solution. Yet, the results from this thesis show that major improvements can be made in how we understand and use our classifications. Specifically, improvements need to be made in how we (as researchers and health care professionals) communicate about and explain classifications. I will discuss the most important findings and conclusions below and place them in the context of five tentacles from chapter 1.

Tentacle 1: Are classifications 'real'?

Tentacle 1 poses the question: 'Are classifications real?'. We note in chapter 1 that if we agree on what classifications mean and how to define them, then we can also agree that they are real and acknowledge that difficulties experienced by individuals with a classification deserve recognition and support. Classifications are real because of our societal agreement on what they mean. However, classifications are not "real" in the sense that they do not refer to a singular underlying biological mechanism (Erlandsson et al., 2016; Pérez-Álvarez, 2017). They are real through the lens of the social kinds approach, but not the natural kinds approach (Beebee & Sabbarton-Leary, 2010; Cooper, 2004; Hacking, 2007).

In subsequent chapters we found that confusion between the social and natural kinds approach has seeped into how different stakeholders discuss ADHD. In chapter 2, stakeholders appeared to (implicitly) operate from a natural kinds approach, by suggesting that ADHD is situated in the brain and referring to it as an entity that causes problematic behaviors. Yet simultaneously, they also attempted to integrate ideas from the social kinds approach by suggesting that ADHD exists because of our societal norms and stating that 'we' decide when individuals do or do not have ADHD. This led to undetected conflicts in how stakeholders discussed ADHD. We concluded that this ambivalence remains dormant (Armitage & Arden, 2007; Priester & Petty, 2001; van Harreveld et al., 2015) in accounts of ADHD. In chapter 3, we found similar conflicts in how psychoeducational materials explained ADHD to parents of children with an ADHD classification. Materials mixed up cause and consequence in explaining ADHD. Moreover, they suggested that we both do not know exactly what mechanisms underlie ADHD, while also suggesting certainty in other sections of the text in what is known about the genetic and neurobiological underpinnings of ADHD.

The conflict between the social and natural kinds accounts may lead to confusion, misrepresentations and decontextualization of ADHD. Ultimately, for those diagnosed with ADHD, and their parents, these conflicts may hamper their ability to understand themselves in the context of their attentional difficulties. Promoting a social kinds perspective, where the descriptive and a-theoretical nature of psychiatric classifications is stressed (Tsou, 2015), may provide a framework for developing more awareness and competency in navigating the complexity of psychiatric classification. Moreover, we should explicate that psychiatric difficulties are real and should be taken seriously, while avoiding the notion that ADHD causes those difficulties.

Tentacle 2: How do we define and understand classifications?

Tentacle 2 poses the question: 'How do we define and understand classifications?' In chapter 1 we stress that classifications are names for commonly occurring symptom-clusters (American Psychiatric Association, 2013; Tsou, 2015; World Health Organization, 2004). How we categorize symptoms and define those categories are therefore decisions that we (as the psychiatric profession) make. Hence, we have control over decisions on when to call experienced difficulties problematic or out of the norm, we define which people are classified as having a psychiatric disorder and we are involved in decisions on when to change or expand our definitions of a classification.

ADHD is a name used to group the behaviors hyperactivity, impulsivity and inattention (American Psychiatric Association, 2013). However, our findings show that this fact often gets lost in the deeper understanding of ADHD. Although ADHD is 'formally' understood through the criteria presented in the DSM (American Psychiatric Association, 2013), we find that definitions of ADHD 'in the wild' differ and often encompass a much broader

set of characteristics or symptoms. Moreover, ADHD seems to become its own entity in how it is understood and discussed. In chapter 2 and chapter 3, we find that ADHD is regularly referred to as an explanation for or a cause of experienced difficulties. Similarly, we found a clear pattern in chapter 3, where ADHD was on the one hand described as a clearly defined disorder. Yet, in subsequent explanations many other behaviors and characteristics were added to the description of the disorder and even said to be caused by it. These findings show a widening of our 'informal understanding' of the disorder, which makes it increasingly difficult to fully comprehend what the disorder entails for different people.

As discussed in chapter 1, individuals with an ADHD classification undeniably have many different characteristics, including many positive ones. However, we need to carefully consider how much of someone's character and identity we are willing to attribute to ADHD. The shift and widening of our informal understanding of ADHD may well impact children's and adolescents' identity formation in ways we cannot (yet) fully comprehend.

Tentacle 3: Do classifications explain the causes of problematic behaviors?

Tentacle 3 poses the question 'Do classifications explain the causes of problematic behaviors?' Although this topic is highly debated in psychiatry, the answer is likely 'no'. We (as of yet) have no evidence for underlying causal mechanisms for classifications, nor do we have any indication that biomarkers exist for any of the classifications in the DSM (Efron, 2015; Frances, 2013, 2016; Salekin et al., 2022; Timimi, 2014, 2015). This lack of evidence is likely related to the changing nature of the definitions of our classifications, as well as the heterogeneity in both symptom clusters and any putative causal mechanisms.

Although we did not aim to study causal mechanisms underlying ADHD in this thesis, we did find clear miscommunications and misunderstandings among stakeholders on this topic. In chapter 2 and chapter 3 we found that knowledge on the 'lack of findings' in biomedical research is limited. The idea that the classification ADHD is caused by abnormalities in the brain is widespread. Similarly, biomedical and genetic causes are often presented with much (unwarranted) certainty and lack of nuance. This became clear from the focus groups in chapter 2, where we found a conflict in how participants discussed ADHD to be situated in the brain as well as in society. Chapter 3 had similar findings: neurobiological information often took precedence over psychosocial information resulting in what we called a 'primacy of biology' (Batstra et al., 2020; Benning, 2015; Bourdaa et al., 2015; Freedman, 2016; Mitchell & Read, 2012; Ponnou & Gonon, 2017). The idea that we have identified clear and specific causes of the classification ADHD was largely supported by the psychoeducational materials we analyzed.

Clear and open communication about what we do and do not know about underlying causal mechanisms of ADHD is a major assignment for mental health researchers, as well as clinical professionals. This will require more nuanced and complex explanations of

ADHD. Without nuance and complexity, misunderstandings about ADHD will continue to lead to decontextualizing and individualizing the classification. Spreading awareness of how biological perspectives on ADHD often take priority over psychosocial perspectives on ADHD, and trying to balance these perspectives would be an important step forward.

Tentacle 4: How do classifications affect the individuals who receive them?

Tentacle 4 poses the question 'How do classifications affect the individuals who carry them?' In chapter 1, we discussed the many different positive and negative consequences classifications may have (Angermeyer & Matschinger, 2003; Corrigan & Watson, 2002; Hinshaw, 2005; Klasen, 2000; Meerman et al., 2017; Thachuk, 2011; Timimi, 2017; van Hulst et al., 2021; Werkhoven et al., 2022). On the one hand, many individuals (initially) feel more understood and accepted because of their classification. On the other hand, classifications have been argued to decontextualize and individualize difficulties and may lead to increased stigma experienced by classified individuals.

The contrast between advantages and disadvantages of classifications is reflected by the ambivalence in the stakeholder accounts on the value of the ADHD classification. In chapter 2, we found the internally conflicting themes 'ADHD says both nothing and a lot', 'the impact of the classification ADHD is both positive and negative', and 'considering ADHD to be a category is both helpful and harmful'. Each of these themes highlights different aspects of the conflict that exists in how an ADHD-classification affects an individual. Ultimately, many of these accounts amount to individuals with a classification wanting to be recognized for their experienced difficulties, but not wanting to be reduced to them. Finding a balance between how a classification can provide recognition, without reducing an individual to it, is of paramount importance for improving our classificatory system.

One apparent way in which individuals can be reduced to their classification is through stigma (Corrigan & Watson, 2002; Hinshaw, 2005). We studied the stigma associated with and attitude changes caused by knowledge of psychiatric classifications in chapter 4. We found small, but relevant, differences in the cognitions about and behaviors towards a young adult associated with knowledge of her classifications. These findings highlight how classifications can lead to someone being viewed or perceived differently. They are (partially) reduced to their classification. Ultimately, everyone should be able to communicate openly about their mental health and any mental health classifications. Yet to reach that goal, open communication about psychiatric difficulties needs to lead to less, not more, stigma. Promoting contact between those with and without a lived experience of mental illness and psychiatric classification may help combat these negative effects.

Tentacle 5: Are classifications clinically useful?

Tentacle 5 poses the question 'Are classifications clinically useful?' We noted in chapter 1

that the goal of mental health care, and by extension our classificatory system, is to provide support, help and appropriate treatment options for people experiencing mental health difficulties. To this end, classifications have guided and stimulated research practices and helped to standardize and communicate about experienced difficulties (Frances, 2013, 2016; Jablensky, 2016; Maj, 2018). At the individual level, classifications can help validate patients' experiences, and encourage and guide them in seeking the necessary help and support (Werkhoven et al., 2022).

Again, we did not aim to directly study the clinical utility of classifications in this thesis, but we did evaluate the opinions of various stakeholders on how classifications are clinically useful to them. We found that stakeholders provide mixed evaluations of that clinical utility and that conflicts exist in their perspectives. Psychoeducational materials in chapter 3 noted that classifications provide shortcuts and tools to ensure better support for children with a classification. Materials mentioned that classifications inform us on how to better manage, support and raise a child with ADHD. The stakeholders we spoke to in chapter 2 made similar statements. Classifications were said to provide shortcuts to understanding children, adolescents and young adults better. Moreover, classifications open doors to necessary treatment and support, both in and outside of the school-context. However, despite these positives, we discovered a number of dilemmas in the clinical utility as described by stakeholders. For example, participants in chapter 2 also stated that we should not be using classifications as shortcuts, but that we need to look beyond the classification to individual needs. According to various stakeholders, classifications seem to suggest that we know exactly what is going on, while in fact we do not. Similarly, stakeholders noted that classifications often close doors and limit children and adolescents in the opportunities for unnormed development they might otherwise get. One sentiment that resonated across all groups was that classifications should indicate that we need to put in more work to understand and help the individual, not less. In line with the conclusions from previous paragraphs, classifications only indicate that an individual struggles with a certain cluster of symptoms. They do not provide any information on what has caused those symptoms, and limited information on how they can be adequately dealt with. Those questions can only be answered on a case-to-case basis.

One way to take a more individualized approach to ADHD in clinical practice is exemplified in chapter 5. We looked at the predictive value of reward sensitivity, an underlying psychological construct commonly associated with the ADHD classification, on treatment outcome. In this study, we found preliminary evidence that individual neuropsychological profiles might be helpful to predict which treatment may be most beneficial to an individual. Moreover, we found that behavioral traits, rather than classifications themselves, may be useful for determining which treatments could be recommended.

Recommendations for mental health care

If we had the opportunity to redesign the classificatory system completely from scratch, we might make very different (and potentially better) decisions on how to conceptualize and categorize psychiatric suffering. Yet our current classifications were developed over the last 60 years and have become deeply embedded in our mental health care system, as is described in this thesis. Specifically, they have become a central component in how individuals with mental health problems understand and contextualize their difficulties. Changing the classificatory system would therefore not just entail a paradigm shift for mental health research and care, it would also require a shift for individuals carrying psychiatric classifications. A shift in their understanding of the difficulties they experience. The fact that so many people with a classification, specifically those with ADHD, greatly value and identify with their classification and even consider it to be an integral part of who they are, needs to be part of any decisions on how to change or adapt our classifications.

All ADHD stakeholders should therefore be involved in decisions on how to (re-)define and understand the classification. These are complex decisions to make and they require continued communication between research, clinical practice, and society at large. We have formulated five recommendations that follow directly from this thesis and that are worthy of our attention in our discussion of and communication about ADHD:

1. We need to promote a social kinds approach to ADHD, in which we stress that classifications are purely descriptive, but very real through their consequences and our societal agreement on what they mean.
2. We should carefully consider what characteristics and behaviours we want to attribute to ADHD (formally, but especially informally).
3. We should communicate clearly and openly about what we do not know about underlying causal mechanisms of ADHD. We should be explicit in referring to ADHD only as a name for experienced difficulties and not as a cause of those difficulties.
4. We need to ensure that individuals carrying a classification feel recognized for their difficulties, but do not feel reduced to them. Continuing to educate the public about what classifications do and do not mean will help combat stigma and ensure that we see the individual as a whole, and not just their classification.
5. We should remember that classifications indicate that we need to invest and work more to understand individuals as opposed to suggesting that – with this classification - we already found out how to understand them.

Future directions for research

In addition to recommendations for mental health care and clinical practice, we would also like to formulate a number of future directions for research. Directly following from the

research discussed in this dissertation, it would be informative to study if stakeholders are aware of their own ambivalence on the ADHD classification and if so, how they interpret it. By asking them specifically about the conflicts in their accounts, we may gain a better understanding of what they have learned about, and how they have come to understand ADHD. For example, we could ask them about how they understand ADHD as both a definition and cause of behaviors; we could ask how the advantages and disadvantages directly opposing one another compare; and we could ask how a classification can both guide our understanding of the individual, while simultaneously not saying much about the individual. Setting up subsequent focus groups or individual interviews could provide answers to such questions.

Following our findings in chapter 3, on the written psychoeducational materials, it would be of interest to study how ADHD is communicated about by health care professionals. Direct communication about ADHD by health care professionals is one of the first avenues through which parents and children receive information on ADHD. It is therefore likely a major factor in determining how the ADHD classification is interpreted by children and parents. We could collect data on psychoeducational conversations between professionals and their clients, and analyze them as we did the psychoeducational materials. Moreover, collecting data through interviews and questionnaires on how psychoeducation is in turn understood by children and parents, may inform us on how to better navigate communication about ADHD with clients.

In our real-life vignette study from chapter 4, we noted the importance of informing the general public about classifications and stimulating direct contact between the public and individuals with psychiatric classifications. Direct and indirect exposure to individuals with classifications has previously been found to reduce stigma and to stimulate understanding of and empathy for others (Blascovich et al., 2001; Corrigan, 2000; Corrigan et al., 2012; Couture & Penn, 2003; Pettigrew & Tropp, 2008; Stuart et al., 2011; Ungar et al., 2016). We should therefore continue outreach activities and design studies to explore how we can facilitate open and honest communication about psychiatric classifications.

Conclusion

In this thesis, we showed that our understanding of the psychiatric classification ADHD is marked by conflict and ambivalence. Not so much between different parties, but within individuals and within the overarching professional perspective on ADHD. These conflicts are caused by subtle but relevant misunderstandings in how we discuss and communicate about ADHD. This thesis therefore highlights the importance of clear communication about what we do and do not know about psychiatric classifications and what they do and do not mean. Specifically, knowledge of our psychiatric classifications should extend beyond the research community. It should be shared, discussed and, most importantly, be interpreted with all stakeholders involved. If we work towards clear communication,

we can (1) ensure that there is less misunderstanding and conflict on what ADHD encompasses, (2) work towards a focus on the individual and their specific needs, and (3) improve how those with classifications are understood by themselves and others in the context of their difficulties.

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Nederlandse samenvatting

Introductie

Psychiatrische classificaties zijn namen die wij geven aan clusters van symptomen. We hebben deze classificaties ontwikkeld om de geestelijke gezondheidszorg (GGZ) te standaardiseren. De impact van onze classificaties reikt echter veel verder dan alleen de GGZ. Classificaties geven vorm aan de manier waarop we psychische verschillen tussen mensen begrijpen. Dit gebeurt in de GGZ, maar vooral ook in onze maatschappij. Mensen met vergelijkbare ervaringen worden gegroepeerd op basis van classificaties. De manier waarop we die classificaties interpreteren en bespreken heeft impact op hoe we hun individuele verhalen begrijpen. In de loop van de tijd, is de GGZ steeds meer gaan leunen op classificaties, hetgeen heeft geleid tot een verhit debat. Dit verhitte debat gaat vaak over classificaties die veelal aan kinderen worden gegeven, zoals ADHD en autisme.

Ons gebruik van psychiatrische classificaties en het debat daarover is ontzettend complex. In dit proefschrift beschrijf ik dit onderwerp als een verborgen schepsel, waarvan de verschillende tentakels regelmatig naar de oppervlakte komen in de levens van kinderen, jongeren en jongvolwassenen. Wellicht is het wat te simpel, maar ik beschrijf hier vijf tentakels van psychiatrische classificaties. Deze tentakels geven structuur aan mijn inleiding en discussie over dit onderwerp. De tentakels zijn:

- Tentakel 1: Zijn classificaties 'echt'?
- Tentakel 2: Hoe definiëren en begrijpen we classificaties?
- Tentakel 3: Verklaren classificaties psychische problemen?
- Tentakel 4: Hoe beïnvloeden classificaties de individuen die ze dragen?
- Tentakel 5: Hebben classificaties klinisch nut?

Voordat ik verder in ga op de tentakels, moet ik nog twee dingen benoemen.

1. ADHD is de classificatie waar ik het meeste onderzoek naar heb gedaan, en staat daarom centraal in dit proefschrift. Veel van wat ik hieronder schrijf is echter ook toepasbaar op andere psychiatrische classificaties, en daarom trek ik mijn verhaal soms breder.
2. In ons dagelijkse taalgebruik, gebruiken we de termen 'diagnose', 'classificatie' en 'label' vaak door elkaar. In de klinische praktijk zijn deze echter niet hetzelfde. Een diagnose refereert naar een uitgebreid klinisch proces, waarbij problemen van een individu worden beschreven, uitgelegd en in context geplaatst. Dit gebeurt vaak aan het einde van een klinisch verslag in de vorm van een (aantal) alinea(s). Een diagnose kan voldoen aan de criteria van een psychiatrische classificatie, zoals beschreven in het psychiatrische handboek, de DSM. Deze classificatie wordt in ons dagelijks taalgebruik ook wel een label genoemd. Om duidelijk te zijn; ADHD en autisme zijn dus

classificaties, en geen diagnoses. Dit benoem ik hier specifiek omdat dit proefschrift gaat over psychiatrische classificaties, en niet over het bredere diagnostische proces.

De vijf tentakels

Tentakel 1: Zijn classificaties 'echt'?

Een centrale vraag in het debat over psychiatrische classificaties, is of ze 'echt' zijn. Deze vraag kan worden gekoppeld aan een discussie over of classificaties een 'natuurlijke soort' of een 'sociale soort' zijn. Het natuurlijke soorten perspectief gaat ervan uit dat classificaties natuurlijke categorieën vertegenwoordigen. Hierin schuilen de implicaties dat biologische mechanismen onderliggend zijn aan classificaties, dat classificaties vastliggen in een individu, en dat onderzoekers de oorzaken van classificaties kunnen vinden door simpelweg beter hun best te doen deze op te sporen. Het sociale soorten perspectief gaat ervan uit dat classificaties sociale constructen zijn. Wij als maatschappij hebben ze bedacht en omarmd. Hierin schuilt de implicatie dat wij, als geestelijke gezondheidszorg en maatschappij in bredere zin, keuzes maken in hoe en wanneer we psychische problemen van mensen classificeren.

Hoewel er nog altijd debat is over deze perspectieven, gaan we in dit proefschrift uit van het sociale soorten perspectief. Classificaties zijn namelijk beschrijvend (tentakel 2) en na jarenlang onderzoek is er nog altijd geen bewijs dat biologische mechanismen ten grondslag liggen aan deze classificaties (tentakel 3). We maken echter nog vaak een denkfout in de manier waarop we over classificaties communiceren, die voorkomt uit het natuurlijke soorten perspectief. Classificaties zijn slechts namen voor clusters van gedrag. In ons taalgebruik suggereren we echter vaak dat classificaties datzelfde gedrag veroorzaken. Classificaties worden hierdoor gezien als een entiteit (een natuurlijke soort) die de problemen veroorzaakt. Als een kind bijvoorbeeld druk is, kunnen we dat classificeren als ADHD. We zeggen dan vervolgens vaak, 'hij is druk, omdat hij ADHD heeft'. Dat klopt niet. Wat we eigenlijk zouden moeten zeggen is; 'hij is druk, waarom weten we niet precies, maar we kiezen ervoor om dat ADHD te noemen'. Deze denkfout wordt ook wel 'reïficatie' genoemd, letterlijk het 'tot ding maken' van onze definities.

Ik moet hier benadrukken dat de sociale soorten benadering de echtheid van psychische klachten en het lijden eronder niet in twijfel trekt. Classificaties zijn echt omdat we met elkaar afspreken wat ze inhouden. Daarmee erkennen we ook dat de problemen die mensen ervaren echt zijn, en dus moeten worden erkend. Drukte is een realiteit die door sommige kinderen wordt ervaren, ook als die drukte niet door 'de ADHD' wordt veroorzaakt. Als we deze denkfout wel maken, heeft dit veel consequenties voor hoe het individu en de omgeving de ervaren problemen begrijpen. Deze consequenties worden in de volgende tentakels verder uitgelegd.

Tentakel 2: Hoe definiëren en begrijpen we classificaties?

Classificaties zijn, per definitie, beschrijvend. Het zijn namen die wij geven aan clusters van (probleem)gedrag of symptomen die vaak samen voorkomen. Zo kiezen wij ervoor om hyperactiviteit, een tekort aan aandacht en impulsiviteit samen te clusteren en ADHD te noemen.

Wij kiezen hoe we symptomen groeperen en definiëren en dus is er ruimte voor debat over deze keuzes. Dit debat is de afgelopen decennia gevoed door een toename van ons formeel en informeel gebruik van de classificatie. Deze stijging kan worden toegewezen aan veranderingen van onze definities. Zo worden er met enige regelmaat wijzingen aangebracht in de beschrijving van ADHD in de DSM. Bij de ontwikkeling van de recentste editie van de DSM (DSM 5) is bijvoorbeeld gekozen om de leeftijdscriteria van ADHD op te rekken. We mogen nu ook ADHD classificeren als de symptomen voorkomen voor 12 jaar, terwijl dit eerder alleen voor 7 jaar mocht. Deze verandering betekent dat meer mensen nu een ADHD-classificatie kunnen krijgen. Deze verandering betekent echter niet dat deze mensen nu ook andere problemen ervaren, alleen dat we er een andere naam aan mogen geven.

Ook in ons informele gebruik van classificaties vinden veranderingen plaats. Een voorbeeld daarvan zijn de 'verborgen ontwikkelingsstoornissen' bij vrouwen, die de laatste jaren veel belicht zijn. Het idee hierachter is dat ADHD of autisme anders tot uiting zouden komen bij vrouwen dan bij mannen. Kort door de bocht, zorgt ADHD er dan bij jongetjes bijvoorbeeld voor dat ze door de klas stuiteren en bij meisjes dat ze stil in een hoekje zitten weg te dromen. De uitdrukking dat ADHD of autisme 'anders tot uiting komen', is echter een goed voorbeeld van de hierboven beschreven denkfout. Dit suggereert dat deze classificaties een entiteit zijn die verschillende symptomen kunnen veroorzaken. Dat klopt dus niet. De conclusie kan niet zijn dat ADHD anders tot uiting komt bij vrouwen, maar dat wij de keuze maken een steeds grotere groep symptomen te classificeren als ADHD. We kiezen ervoor nu niet alleen drukke jongetjes te classificeren met ADHD, maar om ook dromerige meisjes in dezelfde categorie te scharen.

Hoe we besluiten om gedrag te groeperen en te benoemen beïnvloedt hoe we de problemen van mensen begrijpen. We moeten hierbij in gedachten houden dat onze definities niets veranderen aan de problemen die worden ervaren, en dat we ook niets meer of minder te weten komen over de oorzaken daarvan. Dat een 11-jarig dromerig meisje nu een ADHD classificatie kan krijgen, verandert niets aan haar aandachtstekort en ook niet aan de oorzaak van dat aandachtstekort. We geven het nu simpelweg een (andere) naam. We moeten ons als maatschappij blijven realiseren dat we daarin keuzes maken en ons vooral ook blijven afvragen welk gedrag we willen classificeren als een psychiatrische stoornis.

Tentakel 3: Verklaren classificaties de oorzaak van psychische problemen?

Wetenschappelijk onderzoek naar classificaties is veelal gericht geweest op het achterhalen van de oorzaken. Dit onderzoek kan grofweg worden opgedeeld in biomedisch en psychosociaal onderzoek. Biomedisch onderzoek zoekt naar oorzaken in de (neuro)biologie van het individu. De psychosociale benadering zoekt naar oorzaken in de interactie tussen het individu en hun omgeving. Hoewel beide benaderingen worden gevolgd binnen de wetenschap, heeft de biomedische benadering de afgelopen decennia de overhand gehad.

Een overzicht van het biomedische onderzoek naar ADHD valt ver buiten de strekking van dit proefschrift, maar is een onderwerp waar nog altijd hevig over wordt gediscussieerd. Er is bijvoorbeeld gevonden dat een aantal hersengebieden van kinderen met ADHD gemiddeld net iets kleiner zijn dan bij kinderen zonder ADHD. Deze verschillen worden echter alleen gevonden op groepsniveau met hele kleine effectgroottes. We kunnen dus op basis van dit onderzoek niet concluderen dat individuele kinderen met ADHD echt neurobiologisch verschillen van individuele kinderen zonder ADHD. Er bestaat dan ook geen enkele biomarker die kan worden gebruikt om ADHD (of welke andere classificatie dan ook) vast te stellen. Ditzelfde gebrek aan oorzakelijke bevindingen geldt trouwens ook voor psychosociaal onderzoek. De oorzaken van de symptomen die we ADHD noemen zijn complex, multivariaat en verschillen per individu. Daar bovenop komt ook nog dat onze definitie van ADHD met enige regelmatig verandert, zoals beschreven in tentakel 2. De variatie binnen de groep van mensen met een ADHD classificatie overschaduwd daarom de variatie tussen de groepen mensen met en zonder ADHD.

Hoewel de verklarende waarde van classificaties op wetenschappelijk niveau dus ter discussie kan worden gesteld, kunnen ze op individueel niveau wel van waarde zijn. In de ervaring van een individu kan een classificatie voelen als een verklaring voor de ervaren problemen, zelfs als deze geen informatie geeft over een onderliggende oorzaak. Classificaties kunnen op die manier leiden tot opluchting, meer acceptatie en het gevoel van schuld verlichten voor individuen die niet volledig voldoen aan maatschappelijke normen.

Tentakel 4: Hoe beïnvloeden classificaties de individuen die ze dragen?

Hoe classificaties precies het individu en hun ontwikkeling beïnvloeden is iets waar we weinig over weten. Er is weinig onderzoek naar hoe het wel of niet krijgen van een classificatie invloed heeft op iemands levensloop. Wat we wel weten over de impact van classificaties, komt van observaties, zelfreflectie en vignette studies.

Aan de ene kant worden vaak positieve effecten benoemd. Zo leiden classificaties tot meer begrip voor en normalisatie van ervaren problemen. Mensen voelen zich erkend en begrepen door het krijgen van een classificatie. Classificaties halen schuld weg bij het individu. Ze kunnen op individueel niveau als een verklaring voelen voor waarom

het niet lukt om te voldoen aan maatschappelijke normen. Aan de andere kant zijn ook meerdere nadelen benoemd. Zo individualiseren en de-contextualiseren classificaties de ervaren problemen. Een classificatie wordt namelijk toegewezen aan het individu, en niet aan de omgeving, school of familie. Hierdoor kan de context waarin problemen ontstaan over het hoofd worden gezien. Een voorbeeld hiervan is het relatieve leeftijdseffect. Jongere kinderen in de klas krijgen namelijk vaker een ADHD classificatie dan hun oudere klasgenoten. Het 'jongere' gedrag van deze kinderen wordt niet als zodanig herkend, maar wordt toegeschreven aan de classificatie ADHD.

Een ander nadeel van classificaties is het mogelijke stigma dat ze met zich meedragen, al is ook het onderzoek naar stigma bij classificaties tegenstrijdig. Sommige studies suggereren dat classificaties inderdaad leiden tot een negatief stigma. Andere studies suggereren juist dat het negatieve stigma verbonden is aan het gedrag en dat classificaties helpen bij het accepteren van dat gedrag. Op basis van de huidige kennis kunnen we dus nog weinig zeggen over de daadwerkelijke impact van classificaties. Classificaties lijken voor- en nadelen te hebben, die van de context afhangen en bovendien vaak met elkaar in wisselwerking zijn.

Tentakel 5: Hebben classificaties klinisch nut?

Classificaties zijn ontwikkeld om geestelijke gezondheidszorg te verbeteren en de klinische praktijk te informeren over welke behandelingen kunnen worden ingezet. Classificaties zijn daarin ontwikkeld om overeenkomstig te zijn met andere medische categorieën: ze moesten wijzen op specifieke behandelingen gekoppeld op onderliggende causale mechanismen. Door het gebrek aan bevindingen over deze causale mechanismen, en dus de daarop gerichte behandelingen, zijn de verwachtingen echter bijgesteld. In brede zin geven classificaties nu op twee manieren richting aan de klinische praktijk. 1) Bij het opstellen van een behandelplan (op basis van richtlijnen die zijn opgesteld aan de hand van onderzoek naar groepsgemiddelden). 2) Bij het geven van informatie over gemiddelde prognoses. Bovendien zorgen classificaties voor gestandaardiseerde taal die het makkelijker maakt om over problemen en behandeling te communiceren.

Mede door de grote individuele verschillen en de lage voorspellende waarde van classificaties, wordt het klinische nut van classificaties echter ook veel bekritiseerd. Non-specifieke factoren lijken vaak een veel grotere rol te spelen in behandelsucces dan specifieke factoren of de classificaties zelf. Zo blijkt de therapeutische relatie, de band met de therapeut, verreweg de beste voorspeller voor behandelsucces te zijn. Ook voor medicatie geldt dat de effecten vaak a-specifiek zijn. Een voorbeeld daarvan zijn de bevindingen over het sterke placebo-effect bij psychiatrische medicatie. Medicatie heeft effect onafhankelijk van de toegewezen classificaties en lijkt bovendien meestal niet gericht op een specifieke biochemische disbalans (terwijl dat wel vaak zo wordt gecommuniceerd aan mensen met een classificatie).

Het onderzoek in dit proefschrift

De hoofdstukken van dit proefschrift gaan over vragen die samenhangen met de vijf hiervoor beschreven tentakels. Het doel is om vragen uit de tentakels te beantwoorden en zo de impact van classificaties beter te begrijpen. In hoofdstuk 2 en hoofdstuk 3 kijken we naar hoe ADHD wordt begrepen door belanghebbenden en in psychoeducatieve materialen. In hoofdstuk 4 verkennen we hoe psychiatrische classificaties impact hebben op onze perceptie van een jongvolwassene. In hoofdstuk 5 kijken we naar de klinische waarde van beloningsgevoeligheid als voorspeller van behandeluitkomst bij ADHD.

Hoofdstuk 2

In hoofdstuk 2 hebben we onderzocht hoe belanghebbenden bij ADHD de complexiteit van de classificatie ADHD begrijpen. Hiervoor hebben we perspectieven van zeven groepen belanghebbenden verzameld. Deze groepen waren: volwassenen met ADHD, jongeren met ADHD, ouders van kinderen met ADHD, clinici, onderzoekers, docenten en beleidsmakers. In focusgroepen verzamelden we de reacties van de verschillende belanghebbenden op dezelfde set vragen. We hebben deze data vervolgens aan de hand van thematische analyse bestudeerd.

In de data vonden we zeven verschillende thema's in hoe ADHD begrepen werd door de belanghebbenden. Vier thema's kwamen voor in alle focusgroepen, terwijl drie van de thema's specifiek waren voor een (subset van) focusgroep(en). Wat echter het meeste opviel was een overkoepelend patroon: deelnemers uitten tegenstrijdige ideeën over ADHD, maar benoemden hun ambivalentie niet. Zo zegt ADHD volgens de belanghebbenden niets en heel veel over een persoon, is het groeperen van mensen aan de hand van de classificaties behulpzaam en belemmerend, en komt ADHD voort uit het brein en uit de maatschappij. Opmerkelijk was vooral dat deelnemers de conflicten in hun eigen perspectieven niet benoemden.

In dit hoofdstuk hypothetiseren we daarom dat de ambivalentie van de belanghebbenden 'slapend' is ('dormant' in het Engels). Deelnemers lijken zich niet bewust van de conflicterende aspecten van hun uitspraken. Deze 'slapende ambivalentie' komt mogelijk voort uit spanning tussen de natuurlijke soorten en sociale soorten benaderingen van ADHD. Deelnemers lijken (impliciet) grotendeels te spreken vanuit een natuurlijke soorten benadering: ze gaan ervan uit dat classificaties echte 'onderliggende' biologische entiteiten vertegenwoordigen die psychiatrische problemen vooroorzaken. Tegelijkertijd proberen ze ook ideeën vanuit de sociale soorten benadering te verwerken in hun uitspraken. In de sociale soorten benadering zit juist de tegenoverstelde aanname dat psychiatrische classificaties bestaan op basis van sociale en maatschappelijke keuzes, en afspraken die we daarover maken. Doordat de deelnemers beide benaderingen lijken te omarmen, zonder zich bewust te zijn van het verschil, sijpelt er ambivalentie in hun perspectieven.

Hoofdstuk 3

In hoofdstuk 3 bestudeerden we hoe de classificatie ADHD wordt uitgelegd en betekenis krijgt in psychoeducatie. Psychoeducatie speelt een belangrijke rol in hoe mensen hun eigen psychiatrische classificatie begrijpen. Omdat kinderen en ouders in psychoeducatie een afspiegeling zien van hoe de therapeut hun verhaal begrijpt, beïnvloedt het ook de therapeutische relatie. Bovendien beïnvloeden psychiatrische classificaties en bijbehorende psychoeducatie indirect de maatschappelijke visie op psychologische variatie in het algemeen. Wij onderzochten hoe in psychoeducatie betekenis wordt gegeven aan de classificatie ADHD. Hiertoe analyseerden wij het discours (de manier van praten over een onderwerp) van 41 psychoeducatieve materialen uit vier verschillende landen (de VS, het VK, Nederland en Hongarije).

In de psychoeducatieve materialen, vonden wij een aantal interne conflicten in hoe ADHD werd uitgelegd en binnen een context werd geplaatst. Opvallend was dat deze conflicterende uitleg van ADHD gevonden werd binnen één overkoepelende visie op ADHD, en niet tussen verschillende kampen, en dat de conflicten niet werden besproken in de psychoeducatieve materialen. De conflicten kwamen voort vanuit spanning tussen (1) oorzaak versus gevolg, (2) onzekere complexiteit versus zekere simpliciteit, (3) normaal versus abnormaal, en (4) specificiteit versus algemeenheid. Daarnaast werd in het laatste patroon (5) de noodzaak van expertise benadrukt.

We speculeren dat deze onbenoemde interne conflicten voortkomen vanuit een verborgen spanning in het biopsychosociale model. Dit noemen we het 'primaat van de biologie'. We vonden dat in de psychoeducatieve materialen vaak prioriteit werd gegeven aan de biologische benadering, bijvoorbeeld in hoe de informatie werd gepresenteerd, in de terminologie en in de volgorde van uitspraken. Het primaat van de biologie komt bijvoorbeeld naar voren in het perspectief (dat we vonden in veel van de materialen), dat ADHD wordt veroorzaakt door neurobiologische afwijkingen in de context van omgevingsfactoren. Het tegenovergestelde wordt zelden overwogen, namelijk dat ADHD wordt veroorzaakt door afwijkingen van de omgeving in de context van neurobiologische risicofactoren. Het primaat van de biologie veroorzaakt spanning in het biopsychosociale model en leidt daarom tot inconsistente en incoherente informatie over ADHD.

Hoofdstuk 4

In hoofdstuk 4, bestudeerden we het stigma van psychiatrische classificaties. In een grote vignet-studie met 1605 deelnemers, keken we naar verschillen in attitude tussen mensen die wel of geen weet hadden van de psychiatrische classificaties van een jongvolwassene. Deelnemers bekeken een korte video van een jonge vrouw die vertelde over haar sociale interacties. Hierbij hadden deelnemers wel of geen voorafgaande informatie over haar classificaties. Deelnemers beantwoordden na de video een serie vragen over hun gevoelens, gedachten en verwachte gedrag naar deze jonge vrouw.

We vonden verschillen in de gedachten en het gedrag tussen mensen die wel en niet van de classificaties van de jonge vrouw afwisten. Deelnemers die haar classificaties kenden waren meer geneigd om te denken dat de jonge vrouw medicatie zou willen gebruiken en waren meer geneigd om haar als kwetsbaar te zien. Deelnemers met kennis van haar classificaties verwachtten zich ook negatiever tegenover haar te gedragen. Deze trend was aanwezig in alle items, maar was het sterkst voor één item: mensen die haar classificaties kenden wilden minder graag dat de jonge vrouw op hun kinderen zou passen. Als laatste vonden we dat mensen met eigen ervaringen met classificaties positievere attitudes hadden naar de jonge vrouw.

Deze resultaten laten zien dat classificaties impact hebben op onze aannames over een persoon. Voor iemand met psychische kwetsbaarheid, spelen deze aannames een belangrijke factor in hun keuze of ze hun classificatie wel of niet delen met hun omgeving. Uiteindelijk zou open communicatie over mentale gezondheid moeten leiden tot minder sociale afstand en niet meer.

Hoofdstuk 5

In hoofdstuk 5 bestudeerden we de klinische bruikbaarheid en voorspellende waarde van eigenschappen geassocieerd met ADHD op behandeluitkomst. We onderzochten of individuele verschillen in beloningsgevoeligheid konden worden gebruikt om te voorspellen welke kinderen met ADHD baat zouden hebben bij een gedragsinterventie. 21 kinderen met ADHD en hun ouders namen deel aan de gedragsinterventie. We maten beloningsgevoeligheid met psychologische en fysiologische instrumenten voorafgaande aan de interventie. We maten ADHD symptomen voor én na de interventie. Het verschil in ADHD symptomen gebruikten we om de effectiviteit van de gedragsinterventie te bepalen.

Kinderen boekten over het algemeen vooruitgang; ouders beoordeelden hun kinderen als minder onoplettend en minder hyperactief na de interventie. Deze bevindingen bevestigen eerder onderzoek dat heeft laten zien dat gedragsinterventies gematigd effectief zijn bij ADHD. Kinderen die lage scores hadden op beloningsgevoeligheid verbeterden op de 'impulsivity/fun seeking' schaal van de SPSRQ-C, het meest tijdens de behandeling. Geen van de andere maten van beloningsgevoeligheid voorspelden veranderingen in gerapporteerde symptomen.

In deze pilot studie, hebben we een eerste poging gedaan om de uitgebreide neurowetenschappelijke kennis over beloningsgevoeligheid bij kinderen met ADHD te betrekken in de klinische praktijk. We vonden dat gedragsveranderingen door de interventie waren gerelateerd aan een specifiek aspect van beloningsgevoeligheid gerapporteerd door de ouders. Dit resultaat suggereert dat kinderen die niet geneigd zijn om zich impulsief en negatief te gedragen voor een beloning, mogelijk het meeste baat hebben bij een gedragsinterventie die gebruik maakt van beloning. Deze eerste

bevindingen zijn veelbelovend. Ze suggereren dat individuele neuropsychologische profielen zouden kunnen worden gebruikt voor het voorspellen van effectiviteit van behandeling.

Conclusie

In dit proefschrift, laten we zien dat de psychiatrische classificatie ADHD wordt gekenmerkt door conflict en ambivalentie. Opvallend is dat dit niet ontstaat tussen verschillende partijen, maar binnen individuen en binnen de overkoepelende professionele blik op ADHD. Deze conflicten worden veroorzaakt door subtiele, maar relevante misverstanden over hoe we ADHD begrijpen en bespreken. Dit proefschrift benadrukt daarom het belang van duidelijke communicatie over wat we wel en wat we niet weten over psychiatrische classificaties, en over wat psychiatrische classificaties wel en niet betekenen. We moeten onze kennis over ADHD zo duidelijk en precies mogelijk delen met het bredere publiek. Zo kunnen we de classificatie ADHD bespreken en interpreteren met alle belanghebbenden samen. Als we samen toewerken naar duidelijke communicatie kunnen we 1) ervoor zorgen dat er minder misverstanden en conflicten bestaan over wat ADHD is, 2) toewerken naar het zo goed mogelijk begrijpen van het individu en hun specifieke behoeftes en 3) verbeteren hoe mensen met classificaties door zichzelf en door anderen worden begrepen in de volledige context van hun problemen.

Hiertoe formuleren we een aantal aanbevelingen:

1. We moeten de waarde van een sociale soorten benadering bij ADHD benadrukken. Hieruit wordt duidelijk dat classificaties puur beschrijvend zijn, maar ook 'echt' door onze maatschappelijke afspraken over wat ze betekenen.
2. We moeten goed overwegen welke eigenschappen en gedragingen we willen toeschrijven aan ADHD. Dit moeten we doen in zowel ons formele als in ons informele begrip van ADHD.
3. We moeten duidelijk en open communiceren over wat we wel en met name wat we niet weten over de causale mechanismen van ADHD. Hierbij moeten we benadrukken dat ADHD een naam is voor ervaren problemen, en niet een oorzaak daarvan.
4. We moeten ervoor zorgen dat de problemen van individuen met classificaties worden erkend, zonder dat we hen tot hun classificatie reduceren. Daartoe moeten we doorgaan met het delen van informatie over hoe we classificaties begrijpen met het bredere publiek. Dit helpt om stigma te bestrijden en zal ertoe leiden dat we het individu in zijn geheel kunnen zien, en niet alleen hun classificatie.
5. In ons huidige gebruik van classificaties schuilt de aanname dat die classificatie ons al vertelt hoe het individu in elkaar steekt. We moeten echter uitdragen dat het stellen van een classificatie juist aangeeft dat we meer tijd en energie moeten investeren in het begrijpen van het individu.

Dankwoord

Dankwoord

Jaja, daar is-ie dan! Het leukste hoofdstuk! En je zou verwachten dat ik na vier jaar promotieonderzoek kort en beknopt heb leren schrijven. Dit dankwoord bewijst het tegendeel. Sorry, not sorry!

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Sophie, mijn oudste, (en onderhand ook wel meest volwassen!) vriendinnetje. We zijn ooit

na een volleybaltraining in de kleedkamers van de Diamantstraat blijven plakken en op het gespreksonderwerp 'vriendschap' uitgekomen. Ik kan me totaal niet herinneren waar dat gesprek precies over ging, maar wel dat we toen hebben afgesproken altijd vrienden te blijven. Zo'n 15 jaar later kan ik toch wel stellen dat dat is gelukt! We zijn onderhand zo'n beetje de hele wereld over gestuiterd, maar ik ben heel blij dat we nu op fietsafstand van elkaar zijn geland. Bedankt voor al je rust, onuitputtelijke interesse, gezelligheid, relativeringsvermogen en vooral je humor. Knuffel aan **Malou**!

Aan **Soof's Fuckbois+**. Jahoor **Anton**, zie je die 'plus'? Je hoort er ook bij! Samen met iedereen uit de **UCU-gang** natuurlijk. Hoe bizar is het dat we 12 jaar geleden begonnen met studeren? We zijn echt snel oud geworden. Bedankt voor alle spelletjesavonden, etentjes en (nieuwjaars)feestjes die we afgelopen jaren hebben gehad! To **Zach**, **Daisy**, **Eddie**, **Ramya** and **Audrey**, even though we don't talk to each other half as much as we should, it feels so good to know that I can escape to just about anywhere in the world and have a place to stay! Dan de **Skiwi's** (waar die titel vandaan komt weet ik niet, maar in mijn hoofd is dit nog steeds onze groepsnaam). Hoe tof dat we elkaar hebben gevonden in onze liefde voor de sneeuw… en biertjes, en wijntjes, en veel te veel eten bij het UCPA-buffet. Op naar nog veel meer zonnige skivakanties, het hoarden van beurre demi-sel, flying-jesussen en face-firsts in la poudre en schattige 80-jarige ski-docenten. Er zijn maar weinig mensen met wie ik zoveel 'insider-references' heb. Alors on y va! En een speciale shout-out aan **Lyanne** voor de introductie van mijn nieuwe obsessie. Dit boek was zo'n 3 maanden eerder af geweest als ik niet was begonnen met breien (Hoi **Bier&Brei-Crew!**). **Vivek**, thanks for being up for anything anytime! I'm happy we share so many similar interests and can always find something new to get up to! Up next; getting our respective houses decorated! **Nha-Lan**, hoe cool dat het na al die jaren (onderhand al bijna 20!) nog steeds hetzelfde voelt. Met die gesigneerde hardcopy zit het wel goed, maar alleen in ruil voor een uitnodiging om op kraamvisite te komen in je Zwitserse paradijsje! Dat lijkt me toch een eerlijke deal. Then, very importantly: **The Dutch Girls**! It's easy to look back at pictures of the PCT and remember all the beautiful places we hiked. But what stands out most to me is how truly happy we look in those pictures, how insanely much fun we had, and how at ease I felt hiking with you all. Not a day has gone by in the last two years being crouched behind my computer working on this book that I haven't wished I was sunbathing and skinny dipping in Thousand Island Lakes after failing miserably to climb Banner Peak. Thank you guys for making such a beautiful trip an absolutely unforgettable one! And **Greg**, thanks for wanting to be our fifth Dutch Girl!

Aan de mensen uit het **Einde van het Westen**, hoe tof om zo'n relaxte en betrokken familie te hebben! Jullie staan klaar als er iets is, en zijn verder vooral in voor veel gezelligheid. Hoewel ik mezelf niet als Zeeuw zou durven bestempelen, voelt ik me toch altijd een tikkeltje Zeeuws als ik jullie met een (gedurende de avond progressief sterker wordend) accent hoor kwebbelen over van alles en nog wat.

Lieve **Pap** en **Mam**! Nu is de grote vraag natuurlijk, waar begin je met het bedanken van je ouders? Bedankt voor alles! Dat klinkt stom, maar is toch waar. Bedankt dat jullie er altijd zijn om alle mooie momenten uitgebreid te vieren en dat jullie direct klaarstaan als het even niet zo lekker gaat. Jullie zijn de definitie van een veilige haven. Bedankt dat jullie alle hoofdstukken van dit boekje doorgespit hebben. Zelfs als jullie van de onderwerpen geen chocola konden maken, hadden jullie altijd feedback op mijn (gebrekkige) taalgebruik, vooral in het Nederlands. Dat er zoveel fouten in dit dankwoord staan, is alleen omdat jullie kritische blik er niet overheen is gegaan. En bovendien bedankt dat jullie altijd een harig monster in huis hebben om uitgebreid mee te knuffelen. Ik zie uit naar het moment waarop dit allemaal is afgerond, en ik weer 100% aanwezig ben als we elkaar zien! Op naar alle mooie momenten die nog komen gaan!

En als allerlaatste, en daarmee heb je het bijzonderste plekje in dit dankwoord! **Kiri**, het is kort en krachtig. Wat ben ik trots dat ik jouw zusje mag zijn!!!

Miri

Publications

Peer Reviewed Publications

van Langen, M.J.M., van Hulst, B.M., Bos, D.J. & Durston, S. (2023) Should I share my diagnosis? How our attitude towards other people is colored by knowledge of their psychiatric classifications. Submitted.

van Langen, M.J.M., van Hulst, B.M. & Durston, S. (2023). Hidden in plain sight: how individual ADHD stakeholders have conflicting ideas about ADHD but do not address their own ambivalence. European Child and Adolescent Psychiatry, 1-13.

van Langen, M.J.M., Szőke, R., Rijkelijkhuizen, D.N.J., Durston, S., & van Hulst, B.M. (2023). Tegenstrijdigheden in psycho-educatie voor ouders van kinderen met ADHD: een discoursanalyse. Tijdschrift voor Psychiatrie, 158-162.

van Langen, M.J.M., Szőke, R., Rijkelijkhuizen, D.N., Durston, S., & van Hulst, B.M. (2022). Lost in explanation: internal conflicts in the discourse of ADHD psychoeducation. BMC psychiatry, 22(1), 1-9.

van Langen, M.J.M., van Hulst, B.M., Douma, M., Steffers, M., van de Wiel, N.M., van den Ban, E., Durston, S. & de Zeeuw, P. (2021). Which child will benefit from a behavioral intervention for ADHD? A pilot study to predict intervention efficacy from individual reward sensitivity. Journal of Attention Disorders, 25(12), 1754-1764.

Other Publications

van Langen, M.J.M, Oranje, B., Sips, A. & Durston, S. (2021). Feasibility and effectiveness of a yoga intervention for severely affected children and young adults with non-internalizing psychiatric symptoms: a pilot study. Online Preprint.

van Langen, M.J.M., van Hulst, B.M., Bos, D.J. & Durston, S. (2022) Disorders in context: how our language shapes our understanding of psychiatric illness. Myrte van Langen. Opinion Piece in Journal of Neuroscience and Cognition (Published by N&C-master program of Utrecht University).

van Langen, M.J.M. (2019) Label of diagnose? Over de impact van woordkeuze bij ADHD. Opinion Piece in Balans Magazine.

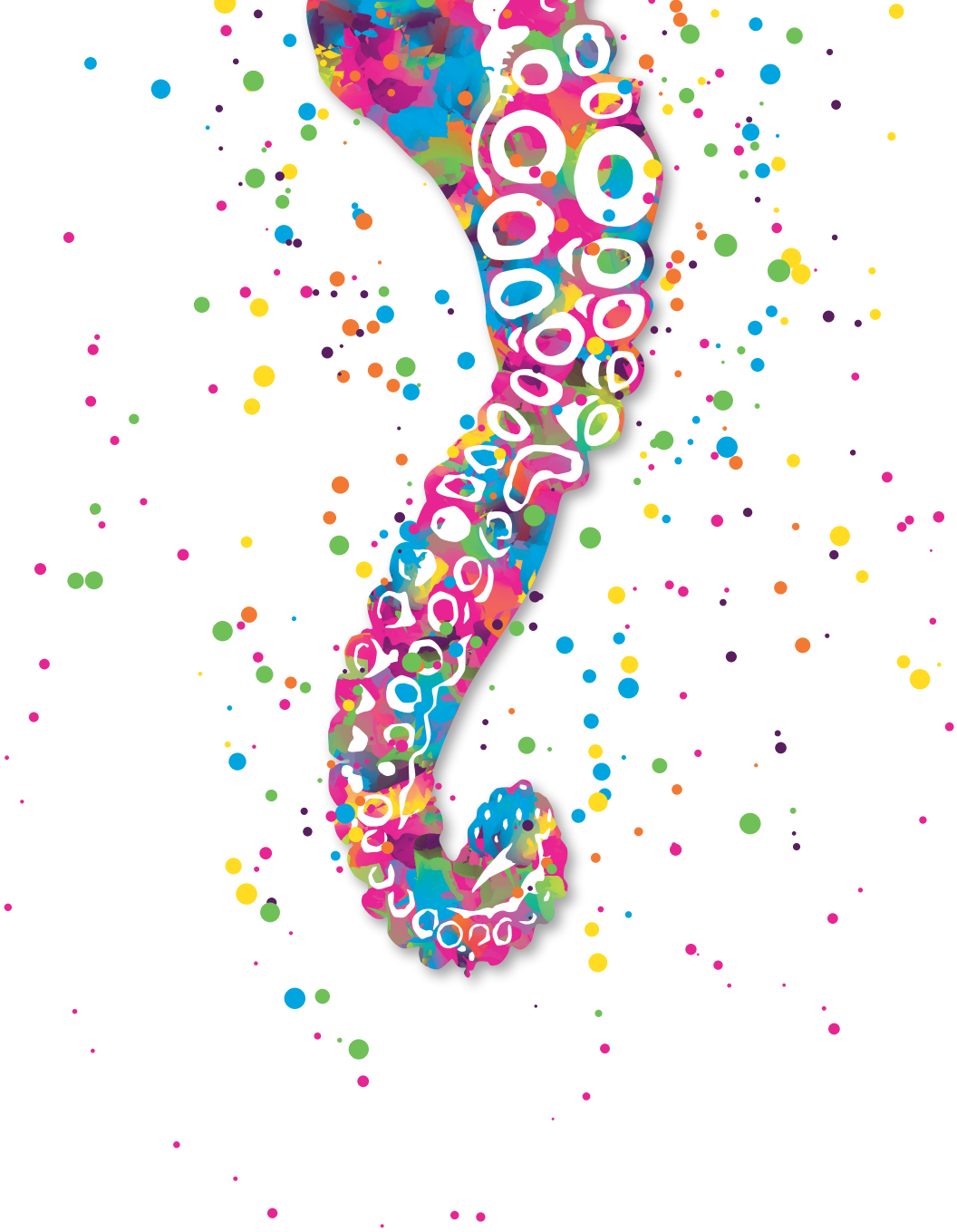
Curriculum Vitae

Curriculum Vitae

Myrte van Langen was born on May 20th 1993 in Alphen aan den Rijn. She obtained her bilingual VWO diploma at Scala College in Alphen aan den Rijn in 2011 and then started her bachelor's degree in the liberal arts and sciences program of University College Utrecht. She majored in neuroscience and psychology and completed a minor in linguistics. She also spent a semester studying at the University of Auckland in New Zealand. In 2014 she completed her bachelor's degree cum laude. She then started her research master's degree called 'Developmental Psychopathology in Education and Child studies', at the Department of Pedagogy at Leiden University. Here she was able to combine clinical and scientific training. She wrote her master's thesis on differences between men and women with an autism classification. In May 2017 she completed her master's degree cum laude. In November 2017 she started a position as research assistant in the NICHE-lab of the department of psychiatry at the University Medical Centre in Utrecht, which was extended into a PhD-position in September 2018. In addition to her work on the projects in this thesis, she was involved in the coordination of a bachelor's course on the science, ethics and experiences of diagnostic labels in mental health care. In 2021 she took 6 months leave to complete a thru-hike of the Pacific Crest Trail through the United States from Canada to Mexico. In the spring of 2023, she completed her PhD. Myrte currently works as a researcher at the Ben Sajet Centrum in Amsterdam where she studies long term care for people with intellectual disabilities.

Myrte van Langen werd op 20 mei 1993 geboren te Alphen aan den Rijn. In 2011 behaalde ze haar eindexamen tweetalig VWO aan het Scala College te Alphen aan den Rijn en begon ze aan haar bacheloropleiding 'Liberal Arts and Sciences' bij University College Utrecht. Ze richtte zich hier op vakken in de neurowetenschappen en psychologie en rondde een minor in taalkunde af. Ook studeerde ze een semester in het buitenland bij de University of Auckland in Nieuw-Zeeland. In 2014 behaalde ze haar bachelordiploma cum laude. Daaropvolgend begon ze aan de onderzoeksmaster 'Developmental Psychopathology in Education and Child Studies' van de afdeling pedagogiek van de Universiteit Leiden. Hier combineerde ze een klinisch traject tot basis-orthopedagoog met een wetenschappelijke opleiding. Ze schreef haar masterscriptie over verschillen tussen mannen en vrouwen met een autisme classificatie. In mei 2017 behaalde ze haar masterdiploma cum laude. In november 2017 begon ze als onderzoeksassistent bij het NICHE-lab op de afdeling psychiatrie van het UMC Utrecht. Haar aanstelling als onderzoeksassistent werd in september 2018 omgezet in een PhD-traject. Naast haar werkzaamheden aan dit proefschrift over psychiatrische classificatie en ADHD, was ze betrokken bij de coördinatie van het bachelorvak: 'De wetenschap, ethiek en ervaring van diagnostische labels in

geestelijke gezondheidszorg'. In 2021 nam Myrte een half jaar verlof om door de Verenigde Staten van Canada naar Mexico te wandelen over de Pacific Crest Trail. In het voorjaar van 2023 rondde ze haar PhD-traject af. Myrte werkt momenteel als onderzoeker bij het Ben Sajet Centrum in Amsterdam en richt zich op onderzoek naar langdurige zorg voor mensen met een verstandelijke beperking.



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