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# Patterns of Coping: How Children with ADHD and Their Parents Perceive and Cope with the Disorder

Noam Ringer

Doctoral Thesis in Education at Stockholm University, Sweden 2020

# Patterns of Coping: How Children with ADHD and Their Parents Perceive and Cope with the Disorder


## Noam Ringer


Academic dissertation for the Degree of Doctor of Philosophy in Education at Stockholm University to be publicly defended on Monday 14 September 2020 at 10.00. The defence will be held via Zoom.


### Abstract

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental diagnosis characterized by symptoms of excessive motor activity, impulsivity, and inattention. Previous research indicates that ADHD has negative implications on the psychosocial functioning of children with ADHD and their parents. In order to fully understand the implications of ADHD we need to understand how children and parents perceive and cope with its symptoms. The aims of this thesis were to (1) identify perceptions of the symptoms among children with the disorder and their parents; (2) identify strategies that children and parents apply in order to cope with the symptoms; and (3) explore patterns between perceptions and coping strategies. The methods used in this thesis are qualitative and include a systematic review of qualitative studies and the analysis of semi-structured interviews with children and parents.

The results show a variation among children with ADHD as regards their perceptions and coping strategies. With reference to perceptions, five themes were identified among the children: (1) the causes of their symptoms ("there is something wrong with me", "there is something wrong with my environment", "this is my personality, a part of who I am"); (2) the implications of the symptoms for their life; (3) symptom timelines; (4) the ability to control the symptoms; and (5) the uniqueness of the symptoms (perceiving the symptoms as either a spectrum or a dichotomy). The study also identified three types of coping strategies that the children applied to manage their symptoms: (1) controlling oneself; (2) making changes in the environment; and (3) following the symptoms and satisfying immediate needs.

This study found three observable patterns between how children perceive their ADHD and how these children cope with its symptoms. Children who perceive their symptoms as a result of a deficiency within themselves engaged with attempts at self-control, while those children who perceive their symptoms as a result of a problematic environment attempt to change their environment. Also, children who perceive their ADHD as a part of their personality express a tendency to "follow the symptoms." Additionally, patterns were observed between the perceived uniqueness of ADHD and applied coping strategies. That is, children who perceived ADHD as a spectrum engaged in controlling themselves, whereas those who perceived ADHD as a unique and dichotomous characteristic engaged in making changes in their environment.

As regards the parents of children with ADHD, this study found that parents perceive their child's symptoms as a source of difficulties for the parent and as a result of a biological dysfunction. Parents cope with their child's symptoms by: (1) adjusting their behaviors towards the child; (2) searching for knowledge and becoming experts; (3) regulating negative emotions in relation to the child and others; and (4) negotiating between ADHD and everyday demands, personal wishes and values. In particular, patterns were observed between the perceptions parents have of their child's behaviors being the result of biological dysfunctions and the coping strategies that these parents employ as a result.

This thesis highlights the importance of giving attention to the perceptions that children and parents have of ADHD symptoms and how they cope with them in order to inform and contribute to future research and clinical work.



**Keywords:** *ADHD, Children, Parents, Lived-experience, Meaning-making, Parenting stress, Coping, Perceptions, Self-management, Illness-representations, Transactional theory, Leventhal's Common Sense Model, First-hand perspective, Qualitative methods, Interviews.*

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In memory of Ido Pesso, whose best way of coping was his smile

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# List of Papers

This thesis is based on the following papers, each of which is the product of the study referred to in the text with the corresponding Roman numeral:

Paper I
Ringer, N. (2019): Living with ADHD: A Meta-Synthesis Review of Qualitative Research on Children's Experiences and Understanding of Their ADHD, *International Journal of Disability, Development and Education*, DOI: 10.1080/1034912X.2019.1596226

Paper II
Ringer, N. (2019). Young people's perceptions of and coping with their ADHD symptoms: A qualitative study. *Cogent Psychology, 6*(1), 1608032. https://doi.org/10.1080/23311908.2019.1608032

Paper III
Ringer, N. (2020) Utilizing the Common-Sense Model of illness representations to explore children's perceptions of, and coping with ADHD. *Journal of Mental Health*, DOI: 10.1080/09638237.2020.1714010

Paper IV
Ringer, N., Wilder, J., Scheja, M., & Gustavsson, A. (2019) Managing children with challenging behaviours. Parents' meaning-making processes in relation to their children's ADHD diagnosis. *International Journal of Disability, Development and Education*, DOI: 10.1080/1034912X.2019.1596228

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# Preface

This research project is about how children with Attention Deficit Hyperactivity Disorder (ADHD) and their parents perceive and cope with the child's ADHD. My aim has been to contribute to the theoretical understanding of how ADHD is perceived and managed, based on the first-hand perceptions of those who live with the condition.

The core symptoms of ADHD are inattention, impulsivity, and hyperactivity (American Psychiatric Association, 2013). For many children, living with ADHD means negative consequences for their psychosocial functioning. For example, ADHD in children is related to problems in social relationships with their peers (Hoza, 2007; McQuade & Hoza, 2008), parents (Chang & Gau, 2017), and siblings (Mikami & Pfiffner, 2008). Children with ADHD also have academic difficulties (Arnold, Hodgkins, Kahle, Madhoo & Kewley, 2020) and behavioral problems in the classroom (Junod, DuPaul, Jitendra, Volpe & Cleary, 2006). In addition, ADHD is related to lower perceived well-being (Ahlstrom & Wentz, 2014) and mental illness in children (Biederman, Newcorn & Sprich, 1991). Additionally, parents of these children experience high levels of parenting stress and emotional burden (Theule, Wiener, Rogers, Marton, 2011; Corcoran, Schildt, Hochbrueckner, & Abell, 2017).

Considering the implications of ADHD on the lives of children and their parents, it is not surprising that this is one of the most common reasons for seeking help from child and adolescent outpatient clinics in Sweden (Kopp & Gillberg, 2003).

My interest in children's and parents' first-hand perspectives of ADHD and their coping with it in their daily life has its origin in the difficulties I experienced in my clinical work as a psychologist at the Child and Adolescent Psychiatry clinic for the Stockholm Region'. My motivation as a practitioner has been to offer long-lasting, effective psychosocial interventions for children and youth with ADHD and their families. In my work, I realized that even though I suggested many evidence-based and approved techniques for managing ADHD, most children and parents did not use these techniques.

Obviously, there are many reasons why patients do not follow a clinician's recommendations. One might be that the individual's thoughts, beliefs, and understandings of ADHD, as well as what they themselves do to manage it, were not taken into consideration when planning and implementing the sug-

gested interventions. I hope this research project will illuminate important aspects related to individual first-hand perspectives of, and coping with, ADHD so that these can be used in clinical work.

My point of departure for this project is that ADHD is a complex phenomenon that should be understood based on biological, psychological, and social factors in the individual's life. However, even with my acknowledgment of the importance of biological and social elements, the focus of this project is on processes within the individual; that is, the perspectives of the individuals who themselves live with ADHD.

This dissertation is within the subdiscipline of Health Education. Having an educational perspective means that I view individuals' coping with their symptoms, as well as everyday ADHD-related problematic situations, as a learning process. In this dynamic process, when interacting with their social environment, individuals learn about their health condition, build personal meanings related to it, and evaluate these meanings. This type of learning is informal, occurring in the personal arena of everyday life outside the medical arena. Studies on representations of health and illness have been a long tradition at the Department of Education at Stockholm University, and include studies on laypeople's representations of conditions such as disability (Tham, Borell & Gustavsson, 2000; Gustavsson, 2001), psychiatric illness (Ohlsson, 2009), allergies (Lauritzen, 2004), and childhood obesity (Roll Bennet & Bergström, 2015).

Four studies make up this project, the planning and design of which are the result of my gradual analyses of earlier research and each of these studies. In the first stage, I wanted to examine what research tells us about children's own perceptions of their life with ADHD. This need led me to conduct a meta-synthesis of qualitative studies on the subject. In turn, the results of the synthesis led me to my special focus on children's perceptions of, and coping with, the symptoms. This is also when my interest in the possible patterns between how the symptoms are perceived and how they are managed developed.

My interest in parents has been there from the beginning. As a parent myself as well as a clinician, I was interested in learning how parents cope with their child's behaviors in everyday life. I was also interested in investigating the role parents' perceptions of ADHD play in how they manage their child's behaviors.

Since my ambition was to contribute to the knowledge of individuals' first-hand perspectives, I chose to base my empirical studies on interviews. In the beginning, my intention was to approach the interviews as exploratively as possible, looking for themes and patterns within the empirical data in order to develop abstract conceptualizations. However, while conducting my research I used existing theoretical models of coping in order to make sense of the results and to further explore the data.

The structure of this text is rather traditional, comprising four chapters: *Background*, *Methodology*, *Results*, and *Discussion*. My intentions in writing this text were not merely to describe my empirical studies and discuss their results, as I have already done this in the published articles. With this text, I intended to integrate the results of the four studies and to explore the knowledge my research added to the field of science, while also reflecting in a more personalized way on the process of conducting the studies.

# Background

In this chapter I will describe background information, based on existing research, which I believe is important in order to understand the project and the choices I have made. I will start with an overview of the literature on the ADHD diagnosis, its prevalence and manifestation, and the diagnostic procedure. In this overview I will particularly highlight the great variation we can find in the manifestation of ADHD and its complexity, considering biological, socioeconomic, and cultural aspects related to it. Later in the chapter, I will describe the psychosocial aspects related to being a child with ADHD, or being the parent of such a child, showing that ADHD means everyday challenges for the children and parents who live with it. Subsequently, I will outline common ADHD interventions and discuss the problems involved with applying them. Finally, the chapter ends with a concluding summary and the rationale for the research project, in which I explain the need to study individuals' perceptions of, and coping with, ADHD in order to understand the psychosocial implications of ADHD, including while applying an intervention.

## The ADHD Diagnosis

### Behavioral Manifestation

The core symptoms of the ADHD diagnosis represent behavioral manifestations of inattention, hyperactivity, and impulsivity (American Psychiatric Association, 2013). The *inattention* component refers to difficulty sustaining focus, and can be manifested in careless mistakes in schoolwork, difficulty remaining focused during lectures, difficulty keeping one's materials and belongings in order, and forgetfulness in daily activities (American Psychiatric Association, 2013). The *hyperactivity* component refers to excessive motor activity, and is manifested in behaviors such as fidgeting, leaving one's seat, climbing or running around even in situations when one is expected to remain in place, talking excessively, and having difficulty waiting one's turn (American Psychiatric Association, 2013). The *impulsivity* component refers to rushed actions, such as taking others' things without asking permission, interrupting or intruding on others, or behaving in a risky way without thinking

about the consequences (American Psychiatric Association, 2013). Acknowledging that most children manifest these behaviors during some part of their development, they are categorized as a developmental disorder when they are persistent, manifested in multiple contexts, and have a negative effect on the child's functioning and development (American Psychiatric Association, 2013).

The manifestation of ADHD in children is highly heterogeneous (Biederman, 2004). Recognizing the great diversity in its manifestation, the diagnosis is divided into three subcategories: ADHD with a dominant component of attention deficit, ADHD with dominant components of hyperactivity/impulsivity, and ADHD that combines all three components equally (American Psychiatric Association, 2013). In addition, the diagnosis designates the severity of ADHD as "mild," "moderate", or "severe" (American Psychiatric Association, 2013).

In addition to the manifestation of the core symptoms of ADHD, individuals with the disorder have a higher risk of developing mental health problems such as depression (Biederman et al., 1991), anxiety (Schatz & Rostain, 2006), or oppositional defiant disorder (Harada, Yamazaki, & Saitoh, 2002). This risk of developing additional mental health problems contributes to the heterogeneity of the ADHD symptoms.

The manifestation of ADHD has been reported differently in girls and boys. For example, a study found that boys report more behaviors related to hyperactivity, inattention, impulsivity, and externalizing problems, while girls report greater intellectual impairments and more internalizing problems (Gershon, 2002).

Furthermore, the manifestation of the symptoms changes with the child's age. Studies on the developmental course of ADHD have shown that its symptoms decrease over time: while younger children show more symptoms of hyperactivity and difficulty controlling their impulses, older children report more symptoms of inattention (Lapalme, Déry, Dubé, & Lemieux, 2018; Willoughby, 2003). However, despite such differences, a high proportion of preschool-aged children who show symptoms at this age continue to have them into adolescence (Lee, Lahey, Owens, & Hinshaw, 2008; Owens, Hinshaw, Lee, & Lahey, 2009).

The subcategorization of the diagnosis along with the risk of developing additional mental problems, as well as the differences between boys and girls and between ages, indicate that there is great variation among children within ADHD with regard to their symptoms.

The diagnostic procedure regarding ADHD differs between countries (Setyawan et al., 2018). In the Swedish context, the National Board of Health and Welfare has formulated guidelines for what should be included in the process (Socialstyrelsen, 2014). According to these, the aim of the diagnostic process is to gain knowledge about the child's developmental history as well as their functioning in daily life in different contexts. This knowledge is obtained

via interviews with parents and teachers and observations of the child's behaviors, as well as via parent- and teacher-directed questionnaires. If possible, an interview with the child is also conducted (Socialstyrelsen, 2014).

## Biological, Socioeconomic, and Cultural Aspects

ADHD is a complex diagnosis, and numerous studies have shown that its prevalence and behavioral manifestation are related to biological, socioeconomic, and cultural aspects.

Studies investigating neurobiological aspects related to ADHD have focused on three levels of dissimilarities between children with ADHD and typically developed children: dissimilarities in *brain structures*, dissimilarities in *brain functioning*, and the role of *neurotransmitters* (Biederman & Faraone, 2002). Regarding dissimilarities in brain structures, studies have shown that children with ADHD have significantly reduced regional gray matter (Valera, Faraone, Murray, & Seidman, 2007). Differences in cortical thickness become smaller over the course of a child's development, however, and maturation and can even reach normal levels in adolescents who have significant decreases in the manifestation of symptoms (Shaw et al., 2006).

Dissimilarities in brain functioning and neural connectivity in individuals with ADHD have also been observed (Cortese et al., 2012). For example, studies have shown that children with ADHD have lower brain activity in systems involved in executive functions, cognitive control, and attention (Cortese et al., 2012). In the motor-related networks and in their connectivity with the amygdala, on the other hand, a higher level of brain activity was observed (Posner et al., 2011). In addition, dysregulation in the two neurotransmitters dopamine and noradrenaline was observed in children with ADHD (del Campo, Chamberlain, Sahakian, & Robbins, 2011).

Studies investigating the genetic component of ADHD have shown that heredity explains the manifestation of ADHD to a certain degree, but that this underlying genetic component interacts with psychosocial and environmental factors (Larsson, Chang, D'Onofrio, & Lichtenstein, 2014).

With regard to socioeconomic aspects related to ADHD, research has shown that the prevalence of children with ADHD is significantly higher in families with low socioeconomic status than in families from high socioeconomic backgrounds, and that this association is manifested across different continents (Russell, Ford, Williams, & Russell, 2016). Some scholars have suggested that the higher prevalence in disadvantaged families is a result of false-positive diagnostics, suggesting that the behavior of children from disadvantaged socioeconomic backgrounds is mistakenly being categorized as ADHD (Morley, 2010).

Some studies have aimed to understand the nature of the relationship between the prevalence of an ADHD diagnosis and family socioeconomic status. While some explanations focus on environmental effects during pregnancy,

such as mothers' smoking (Biederman, Martelon, Woodworth, Spencer, & Faraone, 2017) and maternal psychosocial stress (Okano, Ji, Riley, & Wang, 2019), other studies have tried to identify environmental effects on children after birth, such as parental stress and parental mental illness (Larsson, Sariaslan, Långström, D'Onofrio, & Lichtenstein, 2014).

In addition, family structure has also been shown to be strongly related to ADHD, and children living with a single parent are almost twice as likely to have ADHD than their peers who live in a family with two parents (Russell et al., 2016). This relationship is demonstrated even when the data is adjusted for other socioeconomic and demographic variables (Russell et al., 2016).

Regarding cultural aspects related to ADHD, studies indicate that culture plays a role in the diagnostics, manifestation, and management of ADHD (Singh, 2002, 2008). Schmitz and Velez (2003), for example, have found that mothers in different ethnic groups in the US evaluate their child's behaviors as being impairing to different degrees. These differences are particularly demonstrated with regard to behaviors related to hyperactivity and impulsivity (Gerdes, Lawton, Haack, & Hurtado, 2013). In addition, it has been found that Latinx parents do not perceive ADHD-characteristic behaviors to be the result of a biological mechanism but rather of bad upbringing (Gerdes et al., 2013). In a Chinese study it was demonstrated that Chinese parents of children with ADHD tend to underestimate behaviors related to impulsivity, suggesting that these behaviors are less likely to be manifested in single-child families (Huang et al., 2017).

Other studies have been interested in differences between ethnic groups in terms of the prevalence of the diagnosis. For example, based on population medical and insurance records it was found that white American children were more likely to be diagnosed with ADHD compared to their African-American and Hispanic-American peers (Stevens, Harman, & Kelleher, 2005).

Other studies have looked at regional differences in the prevalence of ADHD diagnoses. Internationally, the prevalence of ADHD varies between countries (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007). However, comprehensive systematic reviews have shown that differences in prevalence may be explained by the diagnostic procedure rather than the geographical location (Polanczyk, Willcutt, Salum, Kieling, & Rohde, 2014). Taking into consideration the differences in diagnostic procedures, the worldwide prevalence of ADHD is assessed to be approximately 5.3% of children and adolescents (Polanczyk et al., 2007).

Additionally, the difference between boys and girls with regard to the prevalence of the diagnosis, with boys being twice as likely as girls to receive the diagnosis (Polanczyk & Rohde, 2007), has been explained by some researchers as a result of cultural expectations (Nussbaum, 2012). This argumentation suggests that the diagnostic criteria are based on how boys manifest the symptoms, which results in girls being underdiagnosed (Nussbaum, 2012). However, a biological argumentation for this sex difference is that boys have a

greater genetic predisposition to ADHD than girls, who are more genetically protected (Martin et al., 2018).

# Psychosocial Functioning of Children with ADHD

## Problems in Everyday Life

Being a child with ADHD has shown to be correlated with problems in several psychosocial domains of life. In the context of peer relationships, children with ADHD are at greater risk of having no friends at all or of not being able to develop stable peer relationships (Kok, Groen, Fuermaier, & Tucha, 2016). In addition, children with ADHD more often feel they are being rejected, left out, or stigmatized in comparison to their peers without ADHD (Hoza, 2007). Furthermore, the peers of children with ADHD often perceive these children to be more disturbing, irritating, and unpredictable than typically developed children (McQuade & Hoza, 2008).

Also, in the context of relationships within the family, children with ADHD more often experience relational problems, negative emotions, destructive communication, and conflicts with their parents (Chang & Gau, 2017; Edwards, Barkley, Laneri, Fletcher, & Metevia, 2001) and siblings (Chang & Gau, 2017; Mikami & Pfiffner, 2008).

In the context of school performance, studies have shown that there is a relationship between ADHD and lower academic achievement (Arnold et al., 2020). This relationship has been demonstrated for preschool, elementary school, and high school pupils (Arnold et al., 2020). In addition, children with ADHD are at significant risk for chronic school absenteeism, in comparison both to typically developed children and to children with other types of neurodevelopmental disorders (Black & Zablotsky, 2018).

Acknowledging the everyday challenges children with ADHD face underlines the importance of understanding the mechanisms behind them.

## Understanding the Mechanisms behind the Challenges

Several studies have attempted to understand the mechanisms behind the relationships between ADHD and low psychosocial functioning in children.

Some studies have focused specifically on the *direct* effect of the ADHD symptoms on these children's performance. For example, regarding the symptoms of hyperactivity/impulsivity, studies have shown a relationship between disruptive classroom behaviors in children with ADHD – such as restlessness, leaving one's seat, and explosive behavior – and a teacher's negative academic evaluation (Conners, Sitarenios, Parker, & Epstein, 1998).

With regard to children's difficulty developing good peer relationships and friendships, Hoza (2007), for example, suggests that the nature of the core symptoms of ADHD may be the explanation. According to this perspective, children with ADHD might have difficulty acquiring social skills and attending to social cues due to the inattention component (Hoza, 2007). In turn, the hyperactivity/impulsivity component leads to the children's unrestrained and overbearing social behaviors, which are likely to be aversive to peers (Hoza, 2007).

A possible direct negative effect of the inattention component of ADHD on academic performance has also been demonstrated (Gray, Dueck, Rogers, & Tannock, 2017). Gray and her colleagues (Gray et al., 2017) compared the academic performance of children with both attention deficit and hyperactivity to children with "only" attention deficit, and found that the symptoms of inattention alone were "enough" to explain the children's performance. However, researchers suggest that "the variation in outcomes indicates that there are a number of other factors within the child, classroom and larger environment that could be accounting for or moderating the relationship between inattention and academic achievement" (Gray et al., 2017, p. 31). This important conclusion proposes that while the symptoms themselves may constitute part of the explanation for the children's psychosocial problems, other moderating factors, such as school environment and characteristics within the child, may also play a significant role.

Recently, several researchers proposed that the way individuals perceive and cope with their symptoms may have an effect on the relationship between ADHD and the psychosocial impairment associated with it (Emilsson, Gustafsson, Öhnström, & Marteinsdottir, 2017; Wong, Hawes, Clarke, Kohn, & Dar-Nimrod, 2018; Wong, Hawes, & Dar-Nimrod, 2019).

Studies investigating children's coping are unfortunately rare (Hampel, Manhal, Roos, & Desman, 2008; Wong et al., 2018). One study examined differences between boys with and without ADHD regarding adaptive and maladaptive coping strategies in the context of interpersonal interactions. The researchers identified nine types of coping strategies: (1) minimization of the problem (e.g., "I say to myself: It isn't serious"); (2) distraction/recreation (e.g., "I'm reading something fun"); (3) increasing control over the situation (e.g., "I try to figure out what the problem is"); (4) encouraging oneself (e.g., "I say to myself: I can make it"); (5) social support (e.g., "I ask somebody's advice"); (6) passive avoidance (e.g., "I'd like to stay in bed"); (7) rumination (e.g., "The situation rushes into my mind over and over again"); (8) resignation (e.g., "I want to give up"); and (9) acting aggressively (e.g., "I'm getting a bad temper"). The results of this study have shown that boys with ADHD used significantly more resignation and passive avoidance in problematic social situations than did boys without ADHD (Hampel et al., 2008).

As opposed to the limited number of studies on children's coping, studies on children's perceptions are more available. Wong and colleagues (Wong et

al., 2018) conducted a systematic review of quantitative and qualitative studies on children's perceptions of their ADHD, and found that there is variation in how children perceive the causes of their ADHD. Some perceive the causes of their symptoms as biological, others as environmental, and still others as part of their identity or as a way of thinking. The review also found that there are mixed perceptions regarding the duration of ADHD. Some children perceive ADHD as a stable condition that will last into the future, while others perceive it as a temporary condition. On the other hand, the review showed that there is homogeneity among children with regard to the perceived consequences of ADHD on their lives and the perceived control they have over it. Regarding the perceived consequences, they perceive that ADHD has adverse consequences on their social relationships and academic performance. With regard to control, the studies included in the overview showed that children believe they have some control over their symptoms (Wong et al., 2018).

The possible relationships between certain perceptions related to ADHD and coping with the symptoms have been the focus of some studies. In a correlation study, Wong and her colleagues (2019) aimed to investigate the relationships between perceptions of ADHD, strategies for managing the symptoms, perceived quality of life, and treatment adherence among youngsters with the diagnosis. This study reports two interesting findings: (1) beliefs that ADHD is caused by biological mechanisms and beliefs that psychological and environmental factors are *not* the causes of ADHD were related to attempts to control or minimize the symptoms as well as to higher perceived quality of life; and (2) beliefs that ADHD had a high impact on life, and that there is little one can do to control it were associated with management of the symptoms through avoidance and with lower perceived quality of life (Wong et al., 2019). With regard to adherence to medication, no relationships were found between adherence and beliefs (Wong et al., 2019).

In another study on the association between youngsters' beliefs and their adherence to ADHD medication, it was found that beliefs that ADHD is the result of a biological dysfunction, beliefs that ADHD has significant effects on life, and beliefs that ADHD will last over a lifetime were significant predictors of medication adherence (Emilsson et al., 2017).

However, as the lack of studies on the possible relationships between perceptions of ADHD and coping with its symptoms makes it difficult to draw any conclusions as to this possible relationship, further studies are needed (Wong et al., 2018).

## Parenting Stress among Parents of Children with ADHD

Several studies have shown that being the parent of a child with ADHD is a demanding and challenging role, and compared to parents of children without

ADHD, parents of children with ADHD experience significantly more stress (Theule, Wiener, Tannock & Jenkins, 2013).

In a review and synthesis of 73 qualitative studies on the lived experience of parents of a child with ADHD, the researchers found that a major component of this experience was the emotional burden related to the management of the ADHD symptoms (Corcoran et al., 2017). This emotional burden took the form of feelings of exhaustion, isolation, anxiety, irritation, desperation, frustration, anger, powerlessness, and helplessness. In addition, the review identified two types of challenges parents experienced: (1) difficulty managing typical family routines, such as getting up in the morning, getting ready for school, and doing homework; and (2) a lack of effective techniques for managing the child's behaviors. These parental challenges affected other areas of the parents' lives such as their marital relationship, health, and working opportunities (Corcoran et al., 2017).

Some studies aimed to identify factors related to the association between parenting stress and having a child with ADHD, as well as to understand the mechanisms behind this relationship (Theule et al., 2011). Theule and her colleagues (Theule et al., 2013) found that parents' stress increased as the severity of the ADHD symptoms increased. In addition, they found that parenting stress was significantly higher among single parents and parents who perceived that they had low social support (Theule et al., 2011). Child sex, parent age, and parent education, on the other hand, were not correlated with stress in the parents (Theule et al., 2011).

Some scholars suggest that parents' perceptions of their child's behaviors may be related to their own stress (Harrison & Sofronoff, 2002). For example, it was found that parents who perceive their child's behaviors in terms of "wanting to get attention," "the child's nature," and "laziness," as opposed to parents who perceive the behaviors as the result of biological factors, reported higher levels of parenting stress. In addition, perceiving the child's ability to control their behaviors as a function of the child's motivation or will was related to higher parenting stress (Harrison & Sofronoff, 2002).

Some researchers suggest that parents' coping may play a moderating role in the relationship between the child's ADHD and the parents' stress (Podolski & Nigg, 2001; Williams, Harries, & Williams, 2014). In a study based on interviews with parents of children with ADHD, the researchers identified patterns between how the parents managed their child's problematic behaviors and their emotional burden and stress (Williams et al., 2014). Firstly, the study revealed two main challenges parents face: direct challenges, in which the child's behaviors constitute direct problems for the parent; and indirect challenges, in which the child's behaviors constitute problems for someone else but the parent is the one who has to solve them. In addition, the study identified three types of resources that affected a parent's ability to manage their child's behaviors: emotional resources (negative/positive emotions regarding

the child), physical resources (their energy level), and knowledge resources (skills and information for knowing what to do) (Williams et al., 2014).

Furthermore, the researchers highlighted two types of coping pathways: cognitive and emotional. The cognitive pathway was characterized by rational problem-solving. In this pathway, the parent stayed a step ahead of the child and focused on anticipating problem behaviors. The child's behaviors were thus managed by forming an adjusted environment for the child to operate in. In the emotional pathway, on the other hand, parents reacted to the child's problematic behaviors based on their negative emotions, by forcing control or through avoidance. Parents who applied coping strategies related to the cognitive pathway experienced less stress and more control in comparison to those who applied coping strategies related to the emotional one (Williams et al., 2014).

Another study, this time a quantitative one, by Podolski and Nigg (2001) aimed to examine the relationships between parents' strategies for coping with their child's ADHD-related behaviors and parenting distress. Four types of coping strategies were examined. The first, *acquiring social support*, entailed parents using social support from relatives, friends, and neighbors for practical and emotional support. The second type of coping, *reframing*, entailed a parent's cognitive reframing or redefining of stressful events to make them more manageable. The third type, *seeking spiritual support*, entailed parents acquiring support through religious faith. The fourth strategy involved *seeking support from community resources*, such as healthcare providers or the school. In general, frequent use of all coping strategies was associated with less stress. However, the results showed that positive reframing was the strategy that contributed the most to reducing stress and increasing parenting satisfaction, for both mothers and fathers. For mothers, seeking spiritual support was also strongly related to reducing parenting stress (Podolski & Nigg, 2001).

These studies by Podolski and Nigg (2001) and Williams et al. (2014) indicate that parents' perceptions of their child's ADHD-related behaviors and their coping strategies may play an important role in the parents' experience of stress. However, studies on the role of these aspects are limited, and further research is needed in order to understand the mechanisms behind the relationship between parents' perceptions and management of their child's ADHD (Wong et al., 2018).

## ADHD Interventions

There are many types of interventions aiming to help children with ADHD and their parents in managing ADHD. The most common ones can be categorized into pharmacological, behavioral, and educational interventions (Purdie, Hattie, & Carroll, 2002). Pharmacological treatments aim to directly target

neuropsychological mechanisms in the brain in order to decrease the manifestation of the symptoms (Pliszka, 2007). In Sweden, the most common medical treatment of ADHD in children is the use of stimulant drugs (Socialstyrelsen, 2014), which effect mechanisms related to norepinephrine and dopamine levels in the brain and directly target hyperactivity and attention deficits (Pliszka, 2007). Approximately 25% to 30% of children do not respond to pharmacological treatments with stimulants, and the factors that constitute a positive response are still unclear (Ogrim & Kropotov, 2019).

Typically, the pharmacological treatment of ADHD is long-term, and can last from several months to a number of years (Shah, Grover, & Avasthi, 2019). Children's adherence to medication over a long treatment period has been the subject of investigation in several studies. For example, Brinkman and his colleagues (Brinkman, Sucharew, Majcher, & Epstein, 2018) aimed to identify predictors of medication continuity in children. The researchers found that adherence to medication at the beginning of treatment (during the first 90 days) was related to parents' beliefs about the long-term course of ADHD and the ability to control ADHD with or without medication, as well as their perceived alliance with their child's doctor. In the long term, though, medication adherence was related to the child's own beliefs regarding how much control they had over their symptoms and the effectiveness of medical treatment (Brinkman et al., 2018).

Behavioral interventions for ADHD can be categorized into two themes: behavioral modification and skills training (Evans, Owens, & Bunford, 2014). Interventions of behavioral modification are based on the assumption that specific problematic behaviors associated with ADHD can be modified by controlling the surroundings that bring them about (Daley et al., 2014). In these interventions, parents learn to identify preconditions that are associated with problematic and disturbing behaviors in order to minimize them in the child's environment. Similarly, parents and teachers learn what antecedents lead to prosocial behaviors in the child in order to modify an environment to offer these conditions. In addition, parents learn to monitor the child's behaviors through praise, positive attention, and concrete rewards in the case of prosocial behaviors, and planned ignoring and time-outs in the case of disturbing behaviors (Knight, Rooney, & Chronis-Tuscano, 2008).

Systematic reviews of parent-based behavioral interventions showed that the effects of these methods on a child's prosocial behaviors are only moderate (Daley et al., 2014). Additionally, these effects could only be demonstrated for the youngest children (of preschool- and elementary-school ages) but not for adolescents (Knight et al., 2008). Furthermore, the effect of these interventions has been questioned, because when a child's behaviors were assessed by someone other than those who participated in the interventions, behavioral interventions showed no effect (Daley et al., 2014; Fabiano et al., 2009).

Skills-training interventions target the children themselves, and involve the training of cognitive skills. The focus of these interventions is to improve children's abilities by training various cognitive skills such as working memory, attention, executive functioning and organization skills, and impulse control. The methods of these interventions varied from computer-based sessions at the child's home to clinic- or school-based interventions in which the children learn techniques for organizing their school assignments. In the case of these interventions, the effect was also low (Evans et al., 2014).

Whereas both pharmacological treatments and behavioral interventions aim to eliminate the manifestation of the ADHD symptoms, educational interventions aim to adjust learning environments to the child's special needs in order to increase their participation and learning ability (Purdie et al., 2002). Educational interventions consist of academic management techniques whereby the physical classroom environment is arranged in a certain way or lectures are organized with consideration to the needs of the child (Purdie et al., 2002). Such techniques can entail working in small groups, providing frequent breaks between learning tasks, and giving instructions to the child individually (Harrison, Soares, Rudzinski, & Johnson, 2019).

As suggested by the above description, many types of interventions have been developed to help children with ADHD and their parents. The gold standard for evaluating the effect of an intervention is to use a Randomized Controlled Trial (RCT) research design (Wong et al., 2019). RCT is based on the assumption that individual differences, such as the individual's perceptions and beliefs, are randomly and normally distributed between the different intervention groups (Wadhwa & Cook, 2019). A consequence of this assumption is that individuals' subjective experiences are seldom treated as variables that play an important role in explaining the effect of an intervention (Koutsoklenis & Gaitanidis, 2017).

However, researchers have suggested that ADHD interventions should move away from this "one-size-fits-all" approach and toward more a personalized approach to interventions (Wong et al., 2019). Some researchers suggest that ADHD interventions should also acknowledge individual differences in terms of experiences, agency, and meaning-making, and consider such variations in the therapeutic process (Koutsoklenis & Gaitanidis, 2017).

## Concluding Summary

The main symptoms of ADHD are inattention, hyperactivity, and impulsivity (American Psychiatric Association, 2013). These symptoms are categorized as a developmental disorder when they are persistent, and are manifested in different settings in the child's life (American Psychiatric Association, 2013). The manifestation of ADHD is highly heterogeneous (Polanczyk & Rohde, 2007). Firstly, the diagnosis itself designates the severity of ADHD as "mild,"

"moderate," or "severe," while also dividing the symptoms into three types according to the dominant manifestation of either an "Impulsive/hyperactive," "Inattentive," or "Combined" type (American Psychiatric Association, 2013). Secondly, the symptoms themselves appear to manifest differently between boys and girls (Nussbaum, 2012; Gershon, 2002) and between different age groups (Lapalme et al., 2018; Willoughby, 2003). The risk of developing other mental health problems contributes to this heterogeneity (Biederman et al., 1991).

Studies on neurobiological aspects related to ADHD have identified dissimilarities in brain structures, brain functioning, and the functioning of neurotransmitters between children who clinically manifest the symptoms of ADHD and typically developed children (Biederman & Faraone, 2002). Furthermore, studies have shown that the heredity of ADHD is relatively high (Larsson et al., 2014). In addition, culture has shown to play an important role in the diagnosis, manifestation, and management of ADHD (Singh, 2002, 2008). The importance of socioeconomic factors has also been acknowledged for the understanding of the disorder (Russell et al., 2016).

The implication of ADHD on a child's everyday psychosocial functioning has been demonstrated in many studies (Kok et al., 2016; Arnold et al., 2020). However, the mechanisms behind the relationships between ADHD and daily functioning are still unknown (Gray et al., 2017). Several scholars suggest that this relationship might be moderated by an individual's appraisals of, and coping with, the symptoms (Emilsson et al., 2017; Wong et al., 2019; Wong et al., 2018). In addition, parents of children with ADHD have shown to be a vulnerable group in terms of well-being and parenting stress (Corcoran et al., 2017, Theule, et al., 2013). Some scholars suggest that parents' perceptions of their child's symptoms, as well as their coping with them, might moderate the relationship between having a child with ADHD and experiencing parenting stress (Harrison & Sofronoff, 2002).

Many types of ADHD interventions have been developed, and mainly include pharmacological, behavioral, and educational approaches (Purdie et al., 2002). However, the effects of existing interventions are inconsistent (Chan, Fogler, & Hammerness, 2016; Prasad et al., 2013), and the predictors of their effects are still unknown (Warikoo & Faraone, 2013). Recently, researchers suggested that ADHD interventions should move away from the one-size-fits-all approach toward a more personalized approach to interventions (Wong et al., 2019) and take considerations to individual differences in terms of experiences, agency, and meaning-making in the therapeutic process (Koutsoklenis & Gaitanidis, 2017).

## The Rationale of the Research Project

In this research project, I explored both children's and parents' perceptions of ADHD and their respective coping strategies. In order to highlight individual first-hand perspectives, the project is based on interviews with children diagnosed with ADHD and their parents. From a scientific perspective, this project is needed for three reasons:

1. To my knowledge, no qualitative studies have explored children's coping with their ADHD, and few have explored parents' coping with their child's ADHD. In addition, the patterns between these perceptions and acts of coping have not been explored.
2. Exploring patterns between perceptions and coping will contribute knowledge for use in research on the everyday functioning of children with ADHD and their parents.
3. With the aim of encouraging a more personalized approach to interventions, exploring children's and parents' perceptions and coping strategies will generate important knowledge to inform intervention research.

# Research Aims and Questions

The overall aim of this project has been to contribute to the theoretical understanding of how children with ADHD and their parents perceive and cope with the symptoms.

My research questions were:

1. How do children with ADHD perceive and cope with their symptoms?
2. What patterns can be identified between a child's perceptions of their ADHD symptoms and their coping with them?
3. How do parents perceive and cope with their child's ADHD-related behaviors?
4. What patterns can be identified between a parent's perceptions of their child's ADHD-related behaviors and their coping with them?

# Theoretical Frameworks

## Underlying Assumptions Regarding Science

In my work with the project, I have constantly struggled with a dilemma between two elements of knowledge. On the one hand, my aim with this research was to contribute knowledge about the reality, as I believe that children's and parents' perceptions of, and coping with, ADHD are *real* phenomena that exist independently from our observations and conceptualization of them. On the other hand, I have realized that the conceptualization of these real phenomena is affected by my assumptions, language, and previous experiences related to them. This led me to wonder: To what extent does the knowledge this project generates reflect the reality? Critical realism, which is the underlying ontological and epistemological approach in this project, provides an answer to this dilemma.

The philosophy of critical realism suggests that we need to distinguish between the reality as it is and our conceptualization of it (Bhaskar, 1998). According to this philosophy, structures, processes, and mechanisms that comprise reality exist independently from human consciousness of them. The problem, however, is that reality is covered by our socially determined assumptions about it (Danermark, Ekstrom & Karlsson, 2019).

While doing research, researchers have access to observable events in the world (i.e. empirical research data). Based on these observations, they can formulate assumptions about the real mechanisms that underlie the observed events (Danermark et al., 2019). These assumptions, however, can only be formulated as theories, which serve as the best possible conceptualizations for explaining relationships and patterns in the data (Danermark et al., 2019). Scientific knowledge is acquired by continually, consciously, and systematically assessing how close our knowledge about reality corresponds to reality as it is (Danermark et al., 2019).

The philosophy of critical realism assumes a similar ontology and epistemology for the natural and social sciences (Archer, 2000). Both the social reality and the natural reality are based on real mechanisms and structures. Both the natural scientist and the social scientist have access to these real mechanisms via their observations, and build conceptualizations of these structures based on their pre-assumptions. The difference between the social and the natural sciences, however, is that the objects of observation in the social sciences

are often other people. People, as opposed to natural objects, are active participants in searching for knowledge and building conceptualizations of the world (Archer, 1998). This means that structures and processes in the social world are more complex, uncontrolled, dynamic, and difficult to reveal (Danermark et al., 2019).

In addition, critical realism assumes that the reality, despite its complexity, can be stratified into different domains (Danermark, 2019). In order to deal with the complexity of the reality, researchers are to isolate and focus on one aspect of the studied phenomenon at a time, while keeping in mind the heterogeneity and complexity of the phenomenon (Danermark et al., 2019). This is also an underlying assumption in this project. As I mentioned earlier, I believe ADHD is a complex phenomenon that can be stratified into biological, psychological, social, and cultural domains. In this project, I have decided to focus on processes within the individual with regard to how ADHD is perceived and managed. The fact that this focus represents only a small part of a complex picture is something I always keep in mind.

Another critical realistic assumption I have made is that science should not merely be about observing and describing empirical events, but also conceptualizing reality and forming theories about the mechanisms that underlie these events. This assumption led to my ambition to not only describe the empirical data but also to conceptualize it and form a theoretical understanding of it.

To summarize my underlying assumptions regarding science, I assume, in accordance with critical realism, that the object of investigation for this research – individuals' perceptions of ADHD and their coping with it – reflect real phenomena that operate independently of our knowledge about them or the conditions that allow us to observe them. However, these phenomena are difficult to identify, as our observation of them is affected by our pre-assumptions about and understanding of them. Yet, I do believe that by applying methodological pluralism and reflecting rationally upon our observations and the conditions that may lead to such observations, as well as by being aware of our ontological assumptions, researchers are able to explore these processes and conceptualize them in a way that reflects the reality.

## Underlying Assumptions Regarding Human Actions and Social Structures

How a researcher approaches the social phenomenon they study is related to their underlying assumptions regarding the relationships between human actions and social structures. Conducting research on individuals in a social con-

text implies that I need to be explicit about my philosophical assumptions regarding human actions and the role of societal structures in formulating these actions.

Danermark and his colleagues (Danermark et al., 2019) distinguish between two types of paradigms within the social sciences: the fact paradigm and the action paradigm. The fact paradigm is based on the idea that social structures are relatively stable, independent from the individuals who live within them, and are the main explanation for an individual's actions. In other words, social structures, social positions, and functions best explain human actions.

The action paradigm, on the other hand, assumes that individuals are agents, acting based on the meaning they assign to their environment. The point of departure for this paradigm is that humans have both the ability and the drive to be active contributors, and intentionally influence their own functioning and life circumstances. Based on this assumption, in order to understand human actions we need to understand individual first-hand perspectives and the meaning individuals assign to their lived experiences (Danermark et al., 2019).

The conflict between these two paradigms has also been a dilemma I have struggled with in relation to this project. On the one hand, as proposed by the action paradigm, I assume that children and parents engage in making sense of their experiences, and that their actions are based on their beliefs, understandings, wishes, and needs. On the other hand, I acknowledge that both children and parents act in a social context, with its structures, norms, expectations, and positions, as proposed by the fact paradigm. Children, for example, are members of a family and pupils at a school, and some are even patients at a children's clinic. Parents also occupy social positions, such as being a father or mother, and are met with social expectations and structures related to these roles. These roles and positions constitute frames for children's and parents' beliefs and actions.

Also in relation to my assumptions regarding human actions, I found the philosophy of critical realism, particularly the concept of analytical dualism proposed by Archer (Archer, 2000), to be useful. Analytical dualism represents the idea that there is a dualism between social structures and individual agency. Social structures are the context in which individuals make sense of their world and take actions. At the same time, individuals' beliefs, intentions, needs, and wishes, as well as interactions between individuals, lead to the reproduction and transformation of the social structures (Danermark et al., 2019).

As social researchers, we should be aware of this link and acknowledge that there is a dualism – an interrelationship – between agency and society over time (Danermark et al., 2019). However, when conducting an analysis of social phenomena, it is possible to distinguish between the action paradigm and the fact paradigm *analytically* (Archer, 2000).

By applying analytical dualism to this project, I "picked up" children's and parents' beliefs and actions from the social context in which they are manifested, and focused on them. This means that my focus on individuals' perceptions and actions, without involving the social structures that interplay with them, was merely analytical. Philosophically, I do acknowledge the social structures that constitute the context in which these perceptions and actions take place; but analytically, I approach the studied phenomena from the perspective of the action paradigm.

## Theories of Coping as a Learning Process

As I mentioned earlier, in this project I approached coping as dynamic learning processes. In these processes, individuals learn about the medical condition they live with via experiences, appraisals, and acts. The theories of coping I have used helped me to explore and understand children's and parents' coping with ADHD as a dynamic learning process. I found two theories of coping useful: the Transactional Theory (Lazarus & Folkman, 1984), and the Common-Sense Model of Illness Representations (Leventhal, Meyer, & Nerenz, 1980). In this section, I will describe these theories and the ways they were useful in this project.

### Transactional Theory

The Transactional Theory is a cognitive-perceptual approach that connects between individuals' appraisals of their environment and their management of it (Lazarus & Folkman, 1984). The theory suggests that people constantly engage in interpreting events in their environment in order to evaluate the threat or potential harm they pose to their well-being (Lazarus & Folkman, 1984; Biggs, Brough & Drummond, 2017). Every time a transaction (an encounter) between an individual and the external environment occurs, two types of appraisals – primary and secondary – take place.

Primary appraisals are the interpretations the individual makes in order to evaluate the significance of an event for their well-being (i.e. Is it potentially harmful?). Primary appraisals are constituted by two types of appraisals. The first type are appraisals related to the nature and characteristics of the event, for example how familiar or ambiguous the event is to the individual (i.e. What is going on?). The second type are appraisals related to the individual's personal agenda, values, goals, beliefs, wishes, expectations, and personal needs (i.e. Is it in conflict with my beliefs and needs?) (Lazarus & Folkman, 1984; Biggs et al., 2017).

Based on the nature of the event and the individual's personal agenda, they evaluate it as insignificant, positive, or threatening. Interpreting the event as threatening will lead to emotional and bodily reactions in the form of negative

emotions such as stress, anxiety, frustration, or anger (Lazarus & Folkman, 1984; Biggs et al., 2017). In order to decrease these aversive reactions, the individual engages in secondary appraisals, which entail the interpretation of one's ability to deal with a threatening event. In other words, secondary appraisals are the evaluation of different possibilities for coping with the event (Lazarus & Folkman, 1984; Biggs et al., 2017).

The theory views coping as a dynamic process by which the individual changes their cognitive and behavioral efforts to manage environmental demands (Biggs, Brough, Drummond, 2017). Lazarus and Folkman (1984) suggest two types of coping strategies. The first, problem-focused, refers to strategies that aim to directly manage the threatening event. The second, emotion-focused, represents an individual's attempts to deal with the emotional adversity of the threat.

Boekaerts (1996) develops the model by adding four new components to the process of coping: coping repertoire, coping goals, coping intentions, and coping strategies. Coping repertoire is the collection of specific coping strategies that can potentially be used in order to manage an event perceived as harmful. The individual's coping repertoire widens with new experiences, and serves as a "bank" from which to choose coping strategies that are assessed to be useful in a specific event. Alongside the contextual characteristics of the event, individuals apply coping strategies based on their coping goals (the individual's general beliefs regarding how to restore well-being) and coping intentions (what the individual intends to achieve in the specific event). Coping, whichever strategy the person applies, leads to new interpretations of the event as well as an evaluation of the effectiveness of the chosen strategy. These new appraisals lead to new attempts to cope with the situation, or to a continuation of the current strategy (Boekaerts, 1996). In this sense, the Transactional Theory can be said to incorporate important aspects of learning driven by an individual's understanding of the environment and reacting to it.

## The Common-Sense Model of Illness Representations

The Common-Sense Model of Illness Representations is another cognitive-perceptual approach that addresses the relationship between illness cognitions and coping (Leventhal et al., 1980; Hagger & Orbell, 2003). According to this theory, people engage in perceptions of, and coping with, not only external events that have their source in environmental interactions but also events inside their body in the form of bodily sensations. The theory suggests that people form representations or mental models of their bodily sensations based on their experiences of the sensation and information from various social sources such as family, friends, educators, the medical care system, and the media (Leventhal et al., 1980). These representations are activated in specific events, and guide an individual's attempts to cope with their bodily sensations (Leventhal et al., 1980, Hagger & Orbell, 2003).

The Common-Sense Model suggests that, in the case of medical conditions, there are five dimensions of illness representation: (1) ***identity***, which includes beliefs about how the condition is identified, what experiences are expressions of the illness and what experiences are not, as well as how these experiences are labelled; (2) ***timeline***, which entails beliefs related to the duration of the illness, when it began and when it will end, as well as the stability or changeability of the symptoms; (3) ***consequences***, or beliefs people have about the impact the health condition has on their life and how they perceive the effects of the illness and/or treatment; (4) ***cause or underlying mechanism***, which is a system of beliefs related to the perceived reasons for the development of the illness and the mechanisms behind the manifestation of the symptoms; and (5) ***control***, which includes people's beliefs regarding how much they are able to manage or control the illness and its symptoms, as well as representations of how control should be achieved (Hagger & Orbell, 2003; Leventhal, Phillips, & Burns, 2016). According to the model, each illness condition has a characteristic set of components that constitute the illness representations with the unique features of a particular condition (Hagger & Orbell, 2003; Leventhal et al., 2016).

The Common-Sense Model also integrates aspects of learning driven by an individual's experiences (bodily sensations and social experiences), interpretations of these experiences, and reactions to them.

## The Use of Theories of Coping in the Project

Both the Transactional Theory and the Common-Sense Model enabled me to approach children's and parents' perceptions and coping as units within a dynamic learning process. In both theories, coping is conceptualized as the individual's reaction to their meaning-making of a life event. This event can be outside in the world or within the individual's body. Both theories also emphasize the individual's reconstructions of these meanings alongside the applied coping and new experiences. The theories of coping described above have been used differently in the different studies.

At the beginning of the project, my intentions were to collect and analyze the empirical data exploratively, without any particular theory in mind. However, during the research process it was difficult to achieve such a purely explorative approach. During the analysis of the interviews with children, I identified some patterns between the participants' ways of perceiving their symptoms and their attempts to cope with them. After the analysis, I recognized the usefulness of the Transactional Theory in making sense of these patterns. Similarly, the Transactional Theory helped me to theoretically understand the results I found after analyzing the interviews with parents; that is, when aiming to explore the parents' perceptions of, and acts of managing, their child's behaviors.

After conducting the first analysis of the interviews with the children, I wanted to further explore the children's perceptions of, and coping with, their ADHD. In order to look at the data in another way, this time I chose to use a theoretical perspective to guide my analysis. The theory I used to analyze the data was the Common-Sense Model. The reason for using the Common-Sense Model is that this model has been used extensively for understanding many different somatic conditions (Hagger & Orbell, 2003). In addition, several researchers have recently suggested that the model may be useful for understanding the relationships between an individual's perceptions and management of mental illness (Antoniades, Mazza, & Brijnath, 2017; Scerri, Saliba, Saliba, Scerri, & Camilleri, 2019), different types of disabilities (Mire, Brewton, Raff, McKee, & Tolar, 2018), and even ADHD (Wong et al., 2018).

Overall, the terms "understanding", "perceptions", "beliefs", "representations", "appraisals", and "interpretations" have been used interchangeably, and represent an individual's subjective cognitive processing. The terms "management" and "coping", which have also been used interchangeably, reflect actions (behavioral or cognitive) taken in order to approach an event that is perceived as harmful.

# Methodology

The research methods applied in this project are qualitative ones. The choice of qualitative methods was the result of my intention to explore individual first-hand perspectives as expressed by individuals who live with ADHD. Qualitative methods allowed me to conduct an open exploration of the complexity of both the children's and the parents' perceptions and coping with ADHD, and the ways in which perceptions and coping interplay with each other.

The overall aim of this project was to contribute to the theoretical understanding of how children with ADHD and their parents perceive and cope with the ADHD symptoms. Following this aim, I conducted four separate studies. In the first study (Study I), I aimed to explore what existing research tells us about how children perceive their life with ADHD. The method I applied in this study was a meta-synthesis analysis, which included a systematic search, and an integration of qualitative studies on what it is like to live with ADHD from the perspective of the children themselves. It is important to mention that in this study I did not specifically focus on the symptoms of the disorder, but rather tried to understand what it means for children with ADHD to live with the disorder in relation to the many different aspects related to it. Based on the results of Study I along with my interests as a clinician, I have sharpened my focus and aimed specifically to investigate children's and parents' perceptions of, and coping with, ADHD.

In the second study (Study II), I interviewed diagnosed children and analyzed the data in order to explore how children perceive and cope with their symptoms and whether there are patterns between their perceptions and coping strategies. In this study, I intended to approach the interviews as openly as possible and develop themes and categories exploratively based on the data.

After the second study, when I was very familiar with all the interview data and had identified some answers to my questions, I realized that there might be more to explore within the interviews. I wanted to identify further aspects related to children's perceptions of and coping with their ADHD. This realization led to the third study (Study III), in which the interviews with the children were analyzed using predefined theoretical themes based on the Common-Sense Model. The aim was to contribute to the exploration of children's perceptions and to illuminate new patterns between perceptions and coping strategies.

The fourth study (Study IV) aimed to explore the perceptions of parents and how they coped with their child's ADHD-related behaviors, in order to illuminate patterns between the parents' perceptions and coping strategies. This study was also based on semi-structured interviews, and my intentions were to approach the interviews exploratively and to develop a conceptualization based on the data itself. However, at this stage of the process, after having analyzed the interviews with the children, I had to acknowledge that the analysis of the parents' interviews was influenced in some ways by the Transactional Theory and the findings from Study II.

In the following section I will briefly describe the methodological procedures I have used, and the reasons I chose them. Table 1 summarizes the aims and methodological aspects of each study.

*Table 1. Summary of aims and methods in each study*

| | Aim | Methodological approach | Dataset |
|---|---|---|---|
| Study I | To explore what existing qualitative research tells us about how children perceive their life with ADHD | A meta-synthesis of qualitative studies | 16 peer-reviewed studies |
| Study II | To explore how children perceive and cope with their symptoms, and whether there are patterns between their perceptions and coping strategies | An explorative approach for analysis | Semi-structured interviews with 14 children |
| Study III | To contribute to the further exploration of children's perceptions and to illuminate new patterns between perceptions and coping strategies | Analysis of interviews based on predefined themes | Semi-structured interviews with 14 children |
| Study IV | To explore how parents perceive their child's ADHD and how they cope with their child's ADHD-related behaviors, as well as illuminating patterns between perceptions and coping | An explorative approach for analysis | Semi-structured interviews with 12 parents |

## A Meta-Synthesis of Qualitative Studies

The aim of the meta-synthesis was to systematically search for and review published qualitative studies on how children perceive their life with ADHD,

as well as to suggest a conceptual integration of the results of these qualitative studies. The reason I decided to conduct a meta-synthesis, rather than selectively reviewing studies that "fit" the project, is that I wanted to understand the whole picture, with all possible variations, of what previous studies report on children's own perceptions. This understanding was enabled by the systematic search and review of studies.

The methodological procedure I used for the meta-synthesis is the one suggested by Sandelowski and Barroso (2007). This procedure was used as it allows for an integration of studies' findings in a manner that is more than merely the sum of all the studies together. The aim of this integration was to make sense of what qualitative studies tell us about children's perceptions of their life with ADHD.

The method was applied in four stages. First, I had to determine the criteria for which studies were to be included in the synthesis. The inclusion criteria comprised peer-reviewed English studies, in which children were the only source of data and the methods for both collecting and analyzing the data were qualitative.

In the second stage, I systematically searched and retrieved qualitative research reports in electronic bibliographic databases. In the third stage, I read the identified studies by starting with their abstracts and moving on to the whole of the text in order to assess, in accordance with the inclusion criteria, whether they should be included in the synthesis. At the end of this stage, 16 studies were identified as suitable for inclusion in the meta-synthesis. In the fourth stage of the synthesis, I constructed a cross-study table with information from each of the studies regarding their different aspects. Using the cross-study table, I compared the studies and searched for patterns in order to identify themes and underlying conceptual relationships between them. The categorization was done based on the semantic relationships between the studies.

As the aim was to search for themes and patterns, I was interested in the contribution of the theme to the conceptual understanding of the phenomenon, rather than how prevalently the theme appeared within the results of the study. More detailed information on the procedures used can be found in the paper that corresponds to Study I.

## The Qualitative Interviews

The purpose of the interviews was to achieve rich descriptions of children's and parents' reflections on their behaviors and thoughts in the context of everyday life. The interview guide was treated as a flexible tool and was revised according to the content of the interview. This means that I have revised some questions based on the participant's responses. The methodological approach I used for data collection was the one suggested by Charmaz (2006). According to this approach, data collection and data analysis occurred simultaneously, in order to adjust and refine interview questions alongside the ongoing

development of conceptual understanding. After conducting the interviews, I transcribed them verbatim and exported their transcriptions to the software program NVivo (QSR International's NVivo 12, 2018). More detailed information on the interview guides can be found in the papers that correspond to Studies II and IV.

## Recruitment Procedures and the Participants

The children and parents who participated in the project (totaling 14 children and 12 parents) were recruited via psychologists working at schools in the city of Stockholm, Sweden. Eight of the children who took part in interviews had parents who were interviewed as well. Five parents were interviewed, but whose children were not interviewed, had children with ADHD.

Under the assumption that the children's and the parents' perceptions and coping might be related to clinical, cultural, educational, and socioeconomic characteristics, I attempted to maximize variation among the participants with regard to such characteristics. However, despite the variation among the participants in terms of child's and parent's sex, current age of the child, age at which the child received the diagnosis, treatment experiences, type of family, and type of school, I did not manage to reach variation in terms of the socioeconomic conditions of the parents. Both the parents who were interviewed and those whose children were interviewed were employed full-time and had an academic education. In addition, there was no variation between participants in terms of cultural background. Table 2 presents the characteristics of the sample of children, and Table 3 the characteristics of the sample of parents.

*Table 2. Characteristics of the sample of children*

| | |
|---|---|
| Child's sex: female/male | 6/8 |
| Age at time of interview | |
| Mean age ± SD (years) | 12.9±2.6 |
| Age range (years) | 8-17 |
| Years since receiving the diagnosis | |
| Mean age ± SD (years) | 3.2±2.5 |
| Parental arrangement | |
| Two-parent home | 11 |
| Joint physical custody | 3 |
| Siblings | |
| No siblings | 2 |
| Have siblings | 12 |
| Type of school | |
| Mainstream with no extra support | 8 |
| Mainstream with special support | 5 |
| Non-mainstream | 1 |
| Treatment experiences | |
| Medication | 10 |
| None | 4 |

*Table 3. Characteristics of the sample of parents*

| | |
|---|---|
| Parents' sex: female/male | 8/4 |
| Parent's-Child's sex | |
| Mother-Daughter | 3 |
| Father-Daughter | 1 |
| Mother-Son | 5 |
| Father-Son | 3 |
| Age of child at time of interview | |
| Mean age ± SD (years) | 10.75±3.11 |
| Age range (years) | 6-15 |
| Age of child upon receiving diagnosis | |
| Mean age ± SD (years) | 8.16±2.8 |
| Mode age (years) | 7 |
| Parental arrangement | |
| Two-parent home | 9 |
| Divorced | 3 |
| Siblings | |
| No siblings | 1 |
| Have siblings | 11 |
| Type of school | |
| Mainstream with no extra support | 10 |
| Mainstream with special support | 2 |
| Intervention experiences | |
| Medication | 4 |
| Parental educational course about ADHD | 11 |

## Explorative Analysis of Interviews

The aim of the explorative analysis of the interviews was to make clear any patterns within the empirical data, and to develop a theoretical understanding

based on the data itself. The method used for the analysis was the one suggested by Charmaz (2006). This method involves two stages of coding. In the first stage, the line-by-line initial coding, I coded every line in the interview based on the actions and meanings on which it rested. The analysis was based on the semantic content of what the participants said and did, and did not include interpretations of nonverbal elements that took place during the interviews such as pauses, laughter, or sighs.

In the second stage of the data analysis, the focused coding, I organized, categorized, and synthesized initial codes to propose an integrative theoretical conceptualization of the data. The categorization and synthetization of the data were based on the conceptual significance of the codes rather than their frequency. In addition, the analysis also involved the use of comparative methods in order to search for similarities and differences both within the same interview and across different interviews. This process led to a refinement of the theoretical understanding.

There are several reasons why I decided to use this approach. Firstly, the inductive characteristic of the approach met my intentions to conduct a study from the children's and parents' perspectives, without restricting my questions and analysis to predefined themes. The second reason is related to the particular emphasis the approach places on actions in the context of everyday life and beliefs related to these actions. In addition, this approach aims to search for processes and patterns in the empirical data rather than structures, which was useful with respect to the study aims.

## Analysis of Interviews Based on Predefined Themes

The aim of the analysis based on predefined themes was to further explore the children's perceptions of their ADHD as well as to search for further patterns between their perceptions and their coping with their symptoms.

The exploration of children's perceptions of ADHD was based on six predefined themes grounded in the Common-Sense Model. In the first theme, "Identity of ADHD", I categorized perceptions regarding what experiences are believed to be parts of ADHD. In the second, "Timeline of ADHD", I categorized beliefs related to the duration of ADHD, when it began, and when it will end. In the third, "Consequences of ADHD", I categorized perceptions of the impact of ADHD on their life. In the fourth, "Cause of ADHD", I categorized perceptions related to the perceived causes of ADHD. In the fifth, "Control of ADHD", I categorized statements regarding perceived control, as well as the need to achieve such control and how to do it. The sixth and last theme constitutes patterns between different types of perceptions and the ways the children coped with their symptoms, as the model suggests.

The method for analyzing the data was deductive qualitative content analysis, as suggested by Elo and Kyngäs (2008). This method was applied in three stages. In the first stage, I categorized meaning units that corresponded with

the predefined themes grounded in the Common-Sense Model. In the second, I analyzed meaning units within every theme in order to identify categories in the content of every theme. In the third, I analyzed and categorized into new themes the data that did not correspond with the Common-Sense Model dimensions.

The reason I chose this method is that it allows not only for an exploration of the interviews from already predefined themes, but also for the identification of themes in the data that are not captured by the theoretical model (Elo & Kyngäs, 2008). In this way, I could reflect on the contribution of the Common-Sense Model as a theoretical model for understanding ADHD, in relation to what dimensions it includes and what dimensions are missing from it.

## Procedures to Enhance Trustworthiness

The concept of trustworthiness within qualitative research is treated differently depending on the epistemological and ontological standpoint of the research (FitzPatrick, 2019). Taking a critical realist perspective, I refer to trustworthiness as the extent to which the inferences and conclusions I have made are based on the empirical data and reflect the reality (FitzPatrick, 2019). In order to enhance the trustworthiness of the studies' results, I applied a number of procedures.

Firstly, I acknowledge the fact that my positioning as a clinical psychologist at a child and adolescent psychiatric clinic may have had an impact on both the data collection and data analysis. This acknowledgment forced me to repeatedly reflect on the potential effects of my positioning on the research process. Systematic reflections and note-taking regarding the role the researcher's previous assumptions and understanding of the phenomenon play in the research process are suggested to enhance the trustworthiness of data collection and interpretation (Charmaz, 2006).

Secondly, I have repeatedly discussed my analysis with both experts on qualitative research methods, researchers within the subject area, and clinical psychologists working at child and adolescent psychiatric clinics. In this peer-review process, reviewers first received transcripts of one or two interviews, as well as my interpretations and categorizations of the interviews. At a later meeting with the reviewers, they gave their feedback on my interpretations and categorizations. Such a process is a suitable way of increasing the trustworthiness of the results (Charmaz, 2006).

The third procedure I have used in order to improve the trustworthiness of the results regarding children's perceptions of their ADHD was to use three different methodological tools to approach the phenomenon. These were the meta-synthesis of previous studies, the explorative analysis of interviews, and the analysis of the interviews based on predefined themes. Flick (2007) suggests that using different qualitative methods in order to understand similar

questions forces the researcher to look at the phenomenon from different angles, and as such contributes to the trustworthiness of the results.

Some researchers have also suggested that the use of computer-aided qualitative data analysis software (e.g. NVivo Pro) enables the researcher to conduct the analysis in a transparent way, and thus enhances the trustworthiness of the results (O'Kane, Smith, & Lerman, 2019). Therefore, the use of NVivo in analyzing the data may enhance the trustworthiness.

## Procedure to Enhance Research Ethics

Formally, Studies II, III, and IV were reviewed and approved by the Regional Ethics Committee in Stockholm (approval number 2016/683–31). As Study I was based on data from already conducted studies, no formal ethical approval was needed.

Besides the formal application, several further steps were taken to enhance research ethics. In order to ensure that confidentiality was maintained in relation to the parents and children during the recruitment procedure, the school psychologists who approached the parents and obtained permission to provide me with their contact details gave me no additional information about the child or the family.

Furthermore, when I contacted the parents by telephone, I informed them about the aim and method of the study, as well as the conditions of confidentiality and anonymity. After a parent agreed to be interviewed or to allow me to interview their child, I sent two letters to their home: one addressed to the child and one to the parent, including information about the project and the conditions for participation. By using these procedures, I hoped to guarantee that both the children and the parents would receive written information about the aim of the interview and the terms of participation. Prior to the interviews, I verbally repeated the aim of the interviews as well as the terms of participation. The parents and children then signed an informed consent form.

In addition, interviews with parents and children from the same families were conducted on separate occasions in order to enhance the child's and the parent's confidentiality.

Moreover, in order to guarantee that the participants' (especially the children's) choice to participate in the study was voluntary, no material compensation was offered for being interviewed.

In the *Discussion* chapter I further describe the ethical considerations I needed to address when conducting the studies.

# Results

This research aimed to contribute to the theoretical understanding of how children with ADHD and their parents perceive and cope with it, as well as to understand patterns between perceptions and acts of coping. Studies I, II, and III focused on the children's perceptions and coping, while Study IV focused on those of the parents. In the following section, I will summarize the main findings of each of the studies.

## Study I: A Meta-Synthesis of Qualitative Studies

The aim of this study was to explore what existing qualitative research tells us about how children perceive their life with ADHD. The study is based on a systematic search and integration of qualitative studies on what it is like to live with ADHD from the perspectives of the children themselves.

The integration of qualitative studies resulted in four themes: perceptions of ADHD as corporal and psychological sensations, perceptions of needs, perceptions of the close social environment, and perceptions of self.

### Perceptions of ADHD as Corporal and Psychological Sensations

Many of the qualitative studies reported that children perceive their ADHD symptoms as corporal and psychological sensations that they have difficulty controlling. The majority of the studies described that children perceive these sensations as experiences that have their origins within their body or in their biology. The integration of studies has also shown that children perceive these sensations as a source of difficulties and problems in their everyday life. Regarding this theme, there was relatively little variation between studies. Some examples from the integrated studies are:

> "I think ADHD is what controls me ... like a monster I think." (Gallichan, & Curle, 2008, p. 353)

> "Yes – I do believe I have ADHD, because I can tell that I am a slower learner and that's what I think that is. I have a hard time reading and stuff…" (Kendall, Hatton, Beckett & Leo, 2003, p. 120)

> "It's like a part of you, like it's hard…" (Kendall et al., 2003, p. 120)

## Perceptions Regarding the Needs They Have

The second identified theme involves the children's perceptions regarding their needs. The integration of studies revealed two, somewhat contradictory, categories of perceptions: "the need to adjust myself" and "the need to be accepted for who I am". The first category, "the need to adjust myself", expresses the children's desire to be able to adjust themselves in order to manage the challenges of everyday situations. Some examples of how the wish to adjust oneself can be achieved include being able to control one's behaviors, making an effort to listen carefully and to control frustrations by taking medication, trying very hard, or developing adaptation skills. An example of this first category of perceptions is quoted below:

> "I talked to my mum for like 3, 4 hours about like, what would happen, what I could make happen, what will happen, if it carried on […] reality hits you and it's like, right, ok I'm going to try and control myself now, I'm gonna try and do the best I can, not get in fights, not be disruptive." (Gallichan, & Curle, 2008, p. 354)

The second category reflects the children's perceptions of needing to be accepted for who they are without adjustments or efforts to control themselves. This is exemplified in the following quotation:

> "My Mum said, you don't have to tell everyone. But otherwise they just thought I was mad. And they looked at me weird, just like a normal weird kid. Well not weird, but strange. So I just told them, like, one by one and they just accepted me for what I was." (Grant, 2009, p. 50)

These contradicting themes of perceptions are particularly exemplified in perceptions related to medication. Whereas the results of some studies indicate perceptions of medication as a source of help, enabling behavioral control, and better adjustment to social demands, other results indicate the children's perceptions of medication as an unpleasant component in their life, serving as an obstacle to their being themselves.

## Perceptions Regarding the Close Social Environment

The third theme includes perceptions related to the children's closer social environment, such as their family, friends, and teachers. Once again, the results revealed that this theme also contained a somewhat contradictory variation of categories of perceptions among the studies. One category involved perceptions of others as a source of obstacles, that others' demands and expectations were perceived as the reasons for difficulties. In addition, others were perceived as the reason for stigmatization and social exclusion. Examples of such perceptions can be found in the following quotations:

> "I get so sick of the nagging – take your meds, do that, don't do that. It's their problem, and they should just leave me alone." (Krueger & Kendall, 2001, p. 66)

> "They don't want to go near me 'cos I'm hyper' [. . .] they don't realize … that I might have changed […] the first impression always sticks." (Gallichan & Curle, 2008, p. 351)

> "ADHD is when no-one believes you when you are saying the truth. Because everyone else is gonna be like against you for some reason." (Grant, 2009, p. 46)

> "I feel like I get, I don't know how to put it – like taken, picked out from like amongst the others. Say if you could like draw a coloured ring around everyone; they would draw a blue one around everyone else and they'd draw a red one around me.' (Grant, 2009, p. 45)

On the other hand, the other category consists of perceptions of others as a source of help and support – support that is necessary for everyday functioning. This perception is exemplified in the following quotation:

> "I feel supported by the teachers that understand I've got my condition...they like repeat things to me or if I kind of like miss it out, they come and stand by me or sit by me and tell me what to do." (Kendall, 2016, p. 30)

## Perceptions of Self

The fourth theme of perceptions is related to how children with ADHD perceive themselves. Two types of categories were identified here as well, indicating that there are variations in self-perceptions. The first category, "challenging self-identity", consists of negative views of oneself, and of one's hyper self as crazy, bad, and out of control. This category also includes descriptions of self in terms of ADHD symptoms and self-appraisals based on how others perceive them. Examples of perceptions in this category can be found in the following quote:

> "I've had pretty negative thoughts about myself and ADHD since I was little, especially when people are nagging me about things when I mess up. I try to do things right, but I can't. I think it's the way I'll always be." (Krueger & Kendall, 2001, p. 65)

On the other hand, the second category consists of normalizing perceptions of oneself. For example, as one of the participants in the study conducted by Kendall and her colleagues states, "I am just a regular person, like anybody else, it's just who I am" (Kendall et al., 2003, p. 123).

## Summary of the Results of Study I

The results of Study I are summarized in Table 4.

*Table 4. Themes and categories of children's perceptions of their life with ADHD*

| |
|---|
| **Perceptions of ADHD as Corporal and Psychological Sensations**<br>• ADHD means a lack of control<br>• ADHD means everyday difficulties<br>• ADHD is a part of the body |
| **Perceptions Regarding the Needs They Have**<br>• I need to be able to adjust myself<br>• I need to be accepted by others for who I am |
| **Perceptions Regarding the Close Social Environment**<br>• Others' demands and expectations are a problem<br>• Others stigmatize me<br>• Others make me feel I do not belong, I feel excluded/like an outsider<br>• Others are a source of support |
| **Perceptions of Self**<br>• Negative self-perception<br>• I am just like anybody else |

# Study II: An Explorative Analysis of Interviews with Children

The aim of this study was to explore how children perceive and cope with their symptoms, and to identify patterns between their perceptions and coping strategies. The study was based on an explorative analysis of interviews with 14 children diagnosed with ADHD. The analysis resulted in seven themes describing how the children perceive and cope with their ADHD symptoms, the role emotions play in the process of coping, and patterns between perceptions and coping strategies.

## My ADHD Experiences

The first theme describes the children's perceptions of their ADHD symptoms, or what experiences they perceived as being due to their ADHD. Four

categories of perceptions constitute this theme. The first category indicates that children perceive their ADHD as bodily, emotional, and cognitive sensations. Perceived cognitive sensations included difficulty paying attention when someone was talking to them, daydreaming, or having a great deal of thoughts in their head. Bodily sensations the children perceived as being part of their ADHD included being tired or not having energy, as well as being very energetic and restless. Feelings of boredom and having difficulty motivating themselves were also perceived as expressions of ADHD. Strong emotions and rapid changes from one type of emotion to another were also experiences they perceived as being part of their ADHD.

The second category consists of perceptions of the ADHD as unpleasant and irritating, while the third category indicates that these experiences are overwhelming and difficult to control. The following quotes exemplify these perceived experiences of ADHD:

> "I get really, really thrilled about everything. A little, little thing, I get thrilled and think it's super exciting…It feels like I have too many thoughts then, and it feels like I'm going to explode. And it's not all that nice to feel like I'm going to explode." (Amanda, 17 years old)

> "Sometimes when I'm sitting in a lesson, suddenly, I can, I can just, sit still and be quiet. And it feels like I'm still conscious but can just be totally gone. I don't even think about anything when it's happening. I don't think. I just zone out." (Julia, 12 years)

> "If I'm angry I can be happy in the blink of an eye…if it's like this, if I get angry or sad because I've stubbed my toe, I start laughing because I get sad. So it can change very quickly." (William, 12 years)

However, the fourth category consists of the perceptions expressed by two of the participants, whereby the symptoms of ADHD were sometimes perceived as empowering. The following is an example of such a perception:

> "It's my inner ADHD that helps me, that makes me think that I really want to win and get a trophy. Which helps me to be good at getting a trophy." (Carl, 12 years)

## The Causes of ADHD

In this theme, variation was found among the participants regarding their ways of understanding the causes of their symptoms. Three perceived categories of causes were identified: "Because there is something wrong with me", "Because there is something wrong with my environment", and "Because it is a part of my personality".

The first category, "Because there is something wrong with me", includes perceptions of ADHD as a result of a stable deficit, or a flaw in their body.

Some believed they had been born with a defect, while others believed they had gotten it later in life. Some perceived their "deficit" as a constant untreatable flaw, while others believed it could be cured with time. The following quotations exemplify this category:

> "I think I was born with it. But that they didn't notice it when I was a baby, they noticed it after a while, a few years…kind of like if you can't sit still, if you move all the time." (Frank, 8 years)

> "Illness, that's something that's hereditary, that you can give, that's contagious. It runs in the family. Like if the mother has it the child will get it…I have an aunt who seems to have it. She seems to be crazy about cats." (Ellen, 10 years)

The second category, "Because there is something wrong with my environment", includes perceptions of ADHD as a result of contextual conditions in their environment, including characteristics of the physical environment, practical circumstances, and the social milieu. This category of perceptions can be found in the following quotations:

> "I've noticed it…when I got my own room at Dad's place, and now that I have my computer at Mom's we don't argue like ever." (Adam, 13 years)

> "It was also that a lot of Science lessons were early in the morning, and I think that had a really big effect. I had a really hard time focusing then, and it made me do a lot worse in all the subjects." (Karoline, 16 years)

> "My best friend, she's a lot like me in many ways, so when we're with each other it's almost like we hype each other up so that we get to a whole new level of I don't even know what." (Amanda, 17 years)

The third category, "Because it is a part of my personality", comprises the perception that the cause of the ADHD is the child's personality, nature, or character. Here, the symptoms were perceived as manifestations of who they are. Being hyperactive, not focusing, and being emotionally explosive were perceived just like any other personality trait, albeit less appreciated. These perceptions are described by Felicia:

> "Sometimes I think like how my life would be different from how I live today if I hadn't had ADHD. Not really that I wake up one morning and see that it's gone, but if it hadn't existed in the first place. Would there be any difference? …Would I have had the same friends? How would I be perceived? What would my personality have been like? How much of the person I am today would I have been then? I mean, there isn't a clear boundary between who I am and what ADHD is." (Felicia, 16 years)

The expression of the three categories of perceived causes varied both between and within participants. Whereas some children consistently expressed one of the three types of explanations, other children perceived the cause of

their ADHD differently in different situations. Some expressed ideas and beliefs concerning the causes of their symptoms that were in some way incoherent with each other. For example, in some situations the same individual perceived their ADHD as a result of unreasonable demands from the environment, and in other situations as a result of a stable deficit such as a medical condition within themselves. However, many of the participants expressed a more consistent way of perceiving the causes of their ADHD.

## The Implications of ADHD

This theme consists of perceptions regarding the kind, and the degree, of the implications of the ADHD symptoms on the child's life. Variation was found between the participants in terms of the potential implications of their ADHD. Whereas some perceived specific and minor implications of their symptoms, others perceived the implications as excessive and significant. While all the children perceived the implications as negative, some perceived them as positive in certain situations. Areas in which the ADHD symptoms had implications included school performance, social activities, and when pursuing hobbies. This variation can be found in the following quotations from the interviews with Karolin and Arthur.

> "Everything took more time for me and I was always lagging behind, no matter if it was in Dance or if it was Math or whatever. And I wasn't really on the same page as everybody else. The whole time." (Karolin, 16 years)

> "It's nothing dangerous, but it can affect life with disturbances now and then. It's no big deal. In school, I notice things like that…but otherwise it's pretty uneventful. Concentration problems can be irritating in school, but otherwise it works pretty well." (Arthur, 14 years)

Incoherence in perceptions was also manifested in the way some of the participants perceived the potential threat of their ADHD symptoms, with some perceiving them as posing an insignificant threat in certain situations but as having major consequences for their well-being in others. However, many of the participants expressed a more consistent way of perceiving the implications of their ADHD, referring to it more often and more coherently during the interview.

## Coping with ADHD

In this theme, three types of categories of reactions were identified regarding the participants' attempts to cope with their symptoms. The first category, "following the ADHD", is characterized by the participants accepting their ADHD-related sensations and going along with them. Such reactions include

being active when one's bodily sensations indicate a need to be active, following one's daydreaming, putting off homework when one is not motivated to do it, or letting oneself be overwhelmed by emotions. Arthur and William describe using this coping strategy:

> "Sometimes it's pretty hard to sit still and just talk in principle and not do anything…and that's why I have to get the salt, go get a glass of water, or have a drink and then go and get more." (Arthur, 14 years)

> "Sometimes I talk with my friends next to me or go around to these people. If we're in the middle of some work, maybe I'll go to the toilet, or run up and down the stairs to work off all the energy." (William, 12 years)

The second category of coping with ADHD involves controlling oneself, and is characterized by the participants' attempts to take control over their symptoms. Such attempts included trying hard to control one's bodily sensations through relaxation, attempts to control behaviors by putting one's hands in one's pockets, and attempts to control one's thoughts by forcing oneself to think alternative thoughts. This category is illuminated by the following quotations:

> "I do like that, try to be calm. I do like this: 'Remember that you're not allowed to fight, not allowed to fight, not allowed to fight, not allowed to fight', like nine times and then you can just walk away." (Frank, 8 years)

> "It feels like I need, yeah in school I have to not only listen to the teacher and what they say, and take notes and ask questions. I also have to work at staying present in it." (Julia, 12 years)

> "I imagine that I have ants in my pants and that I need to kill them." (Johan, 13 years)

The third category of coping is characterized by the participants' attempts to change the environment in order to prevent or minimize their ADHD. Such acts include changing the physical environment by going to another room in order to be able to focus on tasks, writing on a computer, or changing one's social environment by choosing calmer friends or studying with peers who are able to motivate them. Changes to the environment were made either by taking the responsibility for doing this themselves, or by asking permission from or for the help of others, such as parents or teachers. Such a coping strategy is illuminated by Adam's description:

> "It's usually really loud at the dinner table at Dad's place. There are seven of us sitting at the same table, so I think it's better to sit by myself and watch some movie on YouTube while I eat." (Adam, 13 years)

Changes to the environment also include formulating tasks differently in order to make them more manageable, as well as avoiding a particular milieu in which the symptoms were frequently manifested. Such avoidance of a specific social milieu is described by 16-year-old Kitty:

> "I've been at Physical Education and we had like football or something…and this, that I'm supposed to run and chase that ball and get the ball in the goal was tough…it like ended up that when I knew what kind of PE lesson it would be, I would purposely 'forget' my PE clothes." (Kitty, 16 years)

Several participants showed clear tendencies to react according to a particular type of coping strategy, whereas others used all the strategies in various ways.

## Emotions Following Coping with ADHD

This theme consists of the repertoire of emotions accompanying reactions to ADHD symptoms. In this theme, a category of identified negative emotions involved feelings of shame, guilt, and anger. In addition, a category of positive emotions following coping with ADHD was identified, entailing feelings of pride, relief, and satisfaction.

Feelings of shame, reported by many of the participants, were related to situations in which peers commented negatively on the participants' management of their ADHD, or in situations in which the participants' management led to criticism from teachers. This is expressed in the following quotation:

> "I feel childish saying 'No, I have to avoid this because it's not fun,' and it feels childish and embarrassing to say." (Karolin, 16 years)

Feelings of guilt were expressed in relation to situations in which the reaction to the symptoms led to inconveniencing or harming someone else, such as damaging another's property or hurting someone emotionally or physically. Feelings of guilt are expressed by Ellen:

> "It often happens at the dinner table that my older sister hates things that I don't like. Then I have to hold on to it; otherwise, I get this kind of guilt because she gets really sad." (Ellen, 10 years)

Feelings of anger were related to situations in which the management of the symptoms was connected to failing at an important task. Anger was especially expressed when the management of the symptoms was perceived as unfair or as a disadvantage in comparison to peers, as Julia describes in her interview:

"J: Yes, then I think 'how did this happen?' I thought 'I was trying to focus. Now I was actually trying to focus and I had no thoughts in my head but still it happened.' So then I'm usually just like 'Ah, thanks a lot, ADHD.'
N: 'Thanks a lot, ADHD' – what does that mean?
J: I mean sarcastically. If you say 'Thanks a lot' to someone, it's obviously not the case; I'm saying thanks in that way." (Julia, 12 years)

However, positive emotions were also expressed in relation to coping with the symptoms. Pride was expressed when the management of the symptoms had positive social implications, for example when controlling one's impulses was appreciated by others. Physical satisfaction and relief were related to the coping strategy of following the symptoms, such as when being physically active. The quote below illustrates this satisfaction:

"…on the breaks I usually run a lot. I think it's nice. My feet get such a feeling, kind of, so I really want to run. That it's so fun to run". (William, 12 years)

## Coping with Negative Emotions

Participants had various strategies for coping with negative emotions following their coping with their symptoms. These categories of strategies were both cognitive and behavioral, each attempting to manage a different negative emotion.

The "Blaming ADHD" coping strategy involves the individual placing the blame for their disturbing behaviors on a separate entity called ADHD. For some of the participants, blaming ADHD was an effective way to reduce perceived self-responsibility and thus also reduce feelings of guilt. This is illuminated by the following quotation:

"Once I hit the table so hard .. A lot of people get scared when I hit the table ... then I think 'Stupid ADHD, why did you do that?' I blame it." (William, 12 years old)

The second strategy for coping with negative emotions involved informing others about the diagnosis. In situations in which others had criticized the participants for their actions, some of them informed the others about the formal ADHD diagnosis. Informing others about the diagnosis was an attempt to manage shame, as described by Karolin:

"I'm pretty loud and can sometimes scream (laugh) and then my friends usually say 'Karolin, what are you doing? Shhh' ... I say 'Sorry. Yes. I know I have ADHD, I should try to be better.' It feels great to have something concrete to say afterward: 'Oh I have ADHD.' To really be able to pinpoint it." (Karolin, 16 years old)

## Patterns between Perceptions and Coping

This theme includes identified patterns between the ways children perceive their symptoms and the ways they attempt to cope with them. One such category of patterns is related to the children's perceptions of the reasons for their ADHD. Children who perceived the causes of their ADHD to be a deficit within themselves tended to cope with these sensations by self-controlling. On the other hand, coping behaviors that relied on attempts to change the environment were related to perceptions of the ADHD as the result of factors within the environment. The children who perceived ADHD as part of their personality were also the ones who accepted the symptoms without attempting to prevent them. The following quotation exemplifies this pattern:

> "... sometimes in the classroom, after two hours of lessons, when I sit down I have ants in the chair ... and then I can tell my teacher that I can't do any more and I can go out to the corridor and take an iPad and work with something there, and when I feel like 'Now I can probably work' I can go into the classroom and continue". (Adam, 13 years)

The second category of patterns is related to the children's perceptions regarding the implications of the symptoms. Those who perceived their ADHD as a threat were also the ones who engaged in self-control and attempts to regulate their behaviors. On the other hand, perceiving the symptoms as less significant for their well-being was a characteristic among the participants who accepted the symptoms and reacted according to them. The role of the implications of ADHD in how the individual coped with it is illustrated in the interview with Carl:

> "N: How does it work to do homework with a friend?
> C: It's much better because you don't want to embarrass yourself because then the friend gets angry at you.
> N: Is it bad to be embarrassed?
> K: Yes. You don't want to scream at your friend when you get angry when you do homework with your friend, like I can do when I do homework with Mom and Dad.
> N: You don't want to scream at a friend. What will happen if you do that?
> C: Not good. He would stop being a friend of mine. It's not that I want to scream at Mom or Dad either, but sometimes I get angry". (Carl, 12 years)

## Summary of the Results of Study II

Table 5 summarizes the themes found in the analysis. Each theme is exemplified by the categories comprised within it.

*Table 5. Themes and categories of children's perceptions of, and coping with, their ADHD symptoms*

| |
|---|
| **My ADHD Experiences**<br>• Unpleasant sensations in the body that are difficult to control<br>• Empowering in some situations |
| **The Causes of ADHD**<br>• Because there is something wrong with me<br>• Because there is something wrong with my environment<br>• Because it is a part of my personality |
| **The Implications of ADHD**<br>• Perceived implications for friendships, school, and hobbies |
| **Coping with ADHD**<br>• Following the symptoms<br>• Controlling myself<br>• Making changes to the environment |
| **Emotions Following Coping with ADHD**<br>• Shame, guilt, anger, bitterness, pride, relief, and satisfaction |
| **Coping with Negative Emotions**<br>• Blaming ADHD<br>• Informing others about the diagnosis |
| **Patterns between Perceptions and Coping**<br>• The cause of ADHD is a deficit within oneself – Self-control<br>• The cause of ADHD is my environment – Making changes to the environment<br>• ADHD is a result of my personality – Following the symptoms<br>• ADHD has few minor implications on life – Following the symptoms<br>• ADHD has many negative implications on life – Self-control |

# Study III: Analysis of Interviews with Children Based on Predefined Themes Grounded in the Common-Sense Model

The aim of this study was to further explore children's perceptions of their ADHD symptoms and to illuminate patterns between their perceptions and coping strategies. In this study, I analyzed the interviews with the children based on the predefined themes grounded in the Common-Sense Model: (1) Identity of ADHD, (2) Consequences of ADHD, (3) Cause of ADHD, (4) Timeline of ADHD, (5) Control of ADHD, and (6) Patterns between perceptions and coping. Data that did not fit into these six themes were further analyzed and categorized into a seventh theme, titled Uniqueness of ADHD.

As the first three themes (Identity, Consequences, Cause) have already been described in the results of Study II (under the themes titled My ADHD Experiences, The Causes of ADHD, and The Implications of ADHD), here I will describe the four additional themes that Study III added to the overall results: Timeline, Control, , Uniqueness, and Patterns between perceptions and coping.

## Timeline of ADHD

This theme includes the children's perceptions regarding the duration of their ADHD. In this theme, two categories of perceptions were identified. The first category captures perceptions of how long the symptoms will last in the short term or the specific moment. The second captures perceptions of how long ADHD will last in the long term, in relation to one's entire life.

In both categories, the children were heterogeneous in their beliefs. While some of them perceived ADHD as a lifelong condition, others believed they had developed it later in life and that it would disappear with age. Some believed the symptoms were temporary, something they experienced only sometimes, while others perceived ADHD as a condition they constantly had. These different beliefs are illuminated by the following quotations:

> "This is something I was born with and will have for the rest of my life." (Julia, 12 years)

> "I got it when I was five or something, that's when you get ADHD." (Leo, 8 years)

> "It disappears when you're 14 or something." (Frank, 8 years)

## Control over ADHD

The theme of control comprises perceptions related to controlling the symptoms. This theme contains two categories.

The first category includes perceptions related to the desire to achieve control over the symptoms, and reflects both expressions of not wanting to control one's ADHD on the one hand and expressions of striving after achieving control on the other.

The second category regarding control consists of perceptions of different measures one needs to take in order to control their symptoms. Here there was variation among the children with regard to their beliefs about how to achieve control. Some believed they could achieve control over their ADHD by trying hard, while others believed motivation and trying hard did not help. The quotations below illuminate these perceptions:

> "…if I really, really have to sit still, I think it'll work." (Adam, 13 years)

> "Even though I really try hard, it ends up like that." (Julia, 12 years)

Other measures to achieve control involved getting help from others such as friends, parents, and teachers, taking medicine, or making changes to their environment:

> "I need someone to pull me down to the ground and just say 'take it easy'." (Amanda, 17 years)

> "There's another room I usually go to when it's time for the Math lesson. And I can sit there and I can take it easy." (Ellen, 10 years)

> "I take medicine to be calmer; without this medicine I get irritated." (Carl, 12 years)

## Uniqueness of ADHD

This theme captures perceptions concerning the presentation of the ADHD symptoms in other individuals and the ways in which the symptoms are unique to them. Two categories of perceptions were also identified here.

In the first category, ADHD is perceived as a spectrum in which the symptoms are represented to different degrees within different individuals. Here, the children perceived the difference between individuals with ADHD and individuals without ADHD as a quantitative one, and that ADHD is an experience shared by all humans; individuals with a diagnosis of ADHD, however, experience them more intensively or more often than others. Examples of such beliefs can be found in the following quotation:

> "The other pupils in my class only have to study the day before an exam, so the material will sink in, but I have to study for a week." (Carl, 12 years)

In the second category ADHD is perceived as a dichotomy, a unique experience that characterizes only individuals with ADHD. Here the difference between individuals with ADHD and others is perceived as qualitative, as expressed by Johan and Karolin:

> "To me ADHD means to be special ... I do different things in a different way from the others." (Johan, 13 years)

> "These things are things that only I have difficulty with, or only people with ADHD have difficulty with." (Karolin, 16)

## Patterns between Perceptions and Coping

In this study, an additional pattern (besides those from Study II) between perceptions of, and coping with, ADHD was identified between perceptions regarding the uniqueness of the symptoms and the participants' attempts to control themselves. Perceptions of ADHD as an experience located along a spectrum (i.e., that all individuals have these experiences to some degree) were related to attempts at self-control, while perceptions of the experience of ADHD as a separate and unique category, on the other hand, were related to managing the symptoms by making adjustments to the environment by avoiding problematic situations or following the symptoms.

## Summary of the Results of Study III

Table 6, below, summarizes the themes found in the analysis, each one exemplified by the categories that comprise it.

*Table 6. Themes and categories of the children' perceptions of their ADHD symptoms based on Common-Sense Model dimensions*

| |
|---|
| **Timeline of ADHD**<br>• In the short term: Chronic (all the time)/Temporary (for the moment)<br>• In the long term: Lifelong/Limited to a specific period of life |
| **Control over ADHD**<br>• No desire to control<br>• Perceived control by applying different measures |
| **Uniqueness of ADHD**<br>• ADHD as a spectrum – Quantitative difference from others<br>• ADHD as a dichotomy – Qualitative difference from others |
| **Patterns between Perceptions and Coping**<br>• Perceiving ADHD as a spectrum – Controlling oneself<br>• Perceiving ADHD as a dichotomy – Making changes to the environment |

# Study IV: An Explorative Analysis of the Interviews with Parents

The aim of this study was to explore parents' perceptions of, and coping with, their child's ADHD-related behaviors, as well as to illuminate patterns between their perceptions and coping. The analysis led to the development of the following six themes: (1) perceptions of ADHD as a source of difficulties; (2) perceptions of ADHD as a result of a biological deficit that leads to an inability within the child; (3) coping directly with the child's ADHD behaviors,;(4) coping with negative emotions toward the child; (5) coping with other's complaints;(5) negotiating ADHD within everyday demands, personal values, needs, and wishes; and (6)patterns between perceptions and coping strategies.

## Perceiving ADHD as a Source of Difficulties

All parents perceived their child's ADHD-related behaviors as a source of difficulties, obstacles, or disturbing elements. Three categories of perceived difficulties were identified. The first captures difficulties involved with managing everyday routines and family procedures that the parents believed were necessary in order to have a functioning family life. Such difficulties included getting the child ready for school, having family dinners, and performing the child's hygiene. These perceived difficulties were often accompanied by feelings of being overwhelmed and confused, and were associated with a lack of control. This category of perceptions is illuminated in the following:

> "It's like sitting with a rubber ball. He stumbles around all the time. First, he never comes when he's called. Almost never. ...and when he does come he starts picking up things that aren't on the table. … I think in normal cases you would explode with anger: 'Sit down and eat!'" (Mother of Albin, 12 years)

The second category consists of perceptions regarding the child's behaviors as a source of difficulties when other people complain about the behaviors. This could involve a teacher complaining about the child's disturbing behaviors in the classroom, or complaints from the parents of other children with whom the child came into conflict with, being perceived as problems. Perceiving difficulties as the result of complaints and demands of others was often related to shame, as expressed by one of the interviewed mothers:

> "…then it also came up that many had complained about him in class and felt he'd disturbed other students, and that some parents had expressed views about us as parents, that we hadn't raised him right…That makes me so sad." (Mother of August, 8 years)

The third category of perceived difficulties due to their child's ADHD-related behaviors concerned the implementation of personal values. Parents had clear expectations for how they would like things to be in their family, what kind of parents they would like to be, what values they had, and what they considered important. Such values included the ideas that one should have positive emotions toward one's child; that parents should guarantee their child's safety, happiness, and satisfaction; and the idea that siblings should be nice and generous to each other. When they were not able to implement such personal values, parents experienced sorrow and guilt. The following quotation is an example of such perceptions:

> "With Alice, you often feel like 'God, she doesn't listen, she has no respect, she gives no respect,' you know." (Mother of Alice, 6 years)

## Perceiving ADHD as a Result of a Biological Dysfunction

This theme represents parents' perceptions of their child's behaviors as a result of a biological dysfunction. Here the child's ability is perceived as qualitatively poorer than that of other children, and this lack of ability is believed to lead to the child's disturbing behaviors. Consequently, the child's behaviors are not related to a lack of motivation within the child or the child's personal agenda. In addition, the theme includes perceptions of the child's needs as qualitatively different than those of other children.

For parents, receiving the diagnostic label was a clear threshold to perceiving their child's behaviors in terms of biological inability. The following quotation illuminates this theme of perceptions:

> "I don't want to say it's wrong, but with Emma it's that something doesn't work for her, or her brain works in a different way ... eventually I understood that the brain of a child can work in a way that's different from the average, and that could explain some of these behaviors." (Mother of Emma, 16 years)

## Coping Directly with the Child's ADHD Behaviors

This theme represents parents' attempts to directly manage their child's ADHD-related behaviors by adjusting their own behaviors and actively searching for knowledge of methods to do this. Two categories of adjusted behaviors were identified: adjusting proactive behaviors toward their child, and adjusting reactive behaviors toward their child. The third category consists of parents' attempts to actively search for, and acquire, knowledge.

The first category reflects the parents' attempts to adjust their proactive behaviors toward their child in order to compensate for the child's perceived inability. Such proactive behaviors, which were often a consequence of conscious decision-making, involved planning and preparing everyday activities, presenting new activities to the child in advance, adjusting their ways of speaking to the child and the content of what they said, and using assistive pedagogical tools. The parents' use of this strategy is exemplified by the following quotations:

> "I think more about how I present things, due to the diagnosis. That I don't do it this way anymore; that instead of saying 'Can you go upstairs and get this
> and this and this?' I have to say 'Can you go upstairs?' Then
> when he's upstairs I can say 'I need three things: this, this and this.
> Did you hear me? Do you remember what I said? Do you remember how many things?'" (Father of Oliver, 10 years)

> "Now I know that it's about the brain and that it's about deficits in concentration and impulsivity. And I know he's immature compared to others. Then you have to make a clearer plan for him." (Mother of Sebastian, 12 years)

The second category of strategy used by the parents was to adjust their reactive behaviors toward their child when the child's behavior needed to be corrected. Reactive behaviors included explaining instructions to the child in a pedagogical manner about what they should do instead, or even making a conscious decision to ignore the problematic behavior in order not to offend or agitate the child. Here as well, the adjustment of reactive behaviors was related to the perception of the child's behaviors as the result of a biological dysfunction. This category of coping strategy is illustrated by these quotations:

> "He can say 'I hate you, I'm tired of you, what an ugly shirt you have on.' It's absolutely not acceptable. Then he has to say three nice things to his brother ... then hug him, help him up, look him in the eye: 'Are you okay'? Give him a hug, and then it's done. But I need to help him to think more about the consequences." (Mother of August, 8 years)

> "ADHD makes it difficult for him to concentrate, difficult for him to listen; he's in his own world sometimes. And then you have to wake him up, look at him, take care of him." (Father of Sebastian, 12 years)

The third type of behavioral strategy aimed at managing the child's ADHD involved acquiring knowledge and becoming an expert. Many parents described an ongoing process of actively searching for knowledge they could use when they needed to manage their child's ADHD-related behaviors. The knowledge they referred to was mainly theoretical and specifically related to ADHD in children, and came in the form of self-help books and formal courses. Alma's mother describes this category of coping:

> "I've gone to all the courses. I've gone through the entire ADHD center program for parents. I've attended the lecture on neuropsychiatric medication and stuff… I talked to lots of other parents about this when I attended those courses." (Mother of Alma, 16 years)

## Coping with Negative Emotions toward the Child

This theme, reflecting parents' attempts to cope with negative emotions toward their child, consists of three categories of coping. In the first category, negative emotions toward the child were replaced with empathy. By perceiving their child's behavioral problems as a result of a biological disability, they could replace their feelings of anger and irritation with feelings of empathy and compassion.

The second category reflects coping with negative emotions by distinguishing between the "diagnosis" and the child. By having a diagnostic label, a distinction emerged between the child and the label, making the label a legitimate scapegoat at which they could direct their negative emotions.

The third category reflects parents' coping through a process that can be called "acquiring pedagogic distance". When they focused on the pedagogical components of problematic situations, the problem took on a theoretical dimension and the emotional component of the parents' reactions decreased. This category of coping is exemplified by one of the mothers who participated in the study:

> "I would've had a very hard time seeing and accepting and relating to these behaviors if there hadn't been a name for it and a description of what it was and a theory of what it was in the brain that made it this way." (Mother of Lilly, 14 years)

With regard to all coping categories, being able to regulate negative feelings toward one's child was expressed by parents as a relief and as potentially empowering.

## Coping with Others' Complaints

This theme reflects parents' attempts to cope with others' criticism of or complaints about their child's behaviors, as well as the negative emotions related to this criticism, such as embarrassment or shame, by informing others about the formal diagnosis.

Parents believed that, by informing other adults about their child's diagnosis, they were positioning themselves as parents with different parental prerequisites to which different standards should be applied when they were evaluated. By communicating that "under the circumstances" they were "doing a pretty good job", they could transform their feelings of shame into feelings of pride and self-worth. However, parents did not always choose to inform people about their child's diagnosis, even when they were met with blame and disapproval; they did so only when they trusted the other adult and believed their reaction would be one of understanding and empathy. Oliver's father describes this category of coping:

> "It felt a lot easier to explain to people how he is and how to relate to it. And coming away from the feeling that people are looking at your child and thinking he's undisciplined – 'Why haven't his parents managed to rein him in?'" (Father of Oliver, 10 years)

## Negotiating between ADHD and Personal Values and Wishes

This theme reflects the parents' coping with their difficulty implementing personal values and needs by "negotiating", or by engaging with what one parent termed an "inner dialogue", in order to reach a compromise or an integration

of ADHD with these values and wishes. Parents attempted to reach a compromise by negotiating between being the parent of a child with ADHD and their wish to be a "regular" parent with a "regular" relationship with their child. This theme is comprised of three categories of negotiation strategies.

The first category reflects the compromise being managed by not thinking too much, being less conscious of their own and their child's behaviors, and being spontaneous and less pedagogical. An example of this category can be found in the following quotation:

> "Right now we're playing a strategic game, a kind of card game, that we both think is really fun and are completely absorbed in. And then in these situations I'm just out to beat him at the game and, like, I don't think for a second about how I'm behaving so he won't get angry. I'm hoping he loses because I want to win." (Father of Oliver, 10 years)

The second category entails limiting the usefulness and validity of the diagnosis to only problematic situations. In situations when the children did not behave in a deviant way, or in a way that the parents perceived as problematic, the parents did not think about or reflect upon the child's diagnosis. In these situations, they regarded their children as quite ordinary, making them a typical parent of a typical child. With the help of this strategy, parents limited the ADHD to only certain aspects of life, which made all the other parts manageable. August's mother describes using this strategy:

> "Then, when he's sitting and building Legos, I also know he's so talented. His skills emerge. Then I'm very proud and happy about him. It's like he's himself when he's at one with himself. At one with himself. Then, it's not so much the diagnosis. It's August without a diagnosis. Or without the difficulties that play out." (Mother of August, 8 years)

The third category of negotiation aims to find a compromise between ADHD, everyday needs, and one's own values. This compromise was made by consciously reflecting on and questioning the meaning of these needs and values. Here, Leo's mother talks about how she does this:

> "We don't argue about small things that are actually unimportant ... for example, here during the day he wanted to wear two different boots. A winter boot and a rubber boot. 'Yes, you can.' I feel like it's not important. I thought 'Yes, he has something on his feet anyway. It's fine.' And I thought like this: It's a little charming to be a little Pippi Longstocking too ... The important thing is that he doesn't go barefoot and get cold." (Mother of Leo, 8 years)

## Patterns between Perceptions and Coping

This theme comprises patterns between the ways in which parents perceived their child's ADHD-related behaviors and their attempts to cope with these behaviors.

Compared to the variation found among the children, little variation was found among the parents with regard to their different perceptions of their child's symptoms. All the parents believed that their child's behaviors were disturbing and challenging, and that they had their cause in a biological dysfunction within the child. This relative homogeneity within the parental group made it difficult to explore patterns between different types of perceptions and applied coping strategies.

However, the analysis did indicate apparent patterns between the parents' perceptions of the biological causes of their child's behaviors – that is, perceiving their child's ability as qualitatively poorer than that of other children – and the ways the parents managed these behaviors and the negative emotions that accompanied them.

One such pattern appears between the parents perceiving their child's behavior as a result of a biological dysfunction or inability, and the parents' adjustment of their behaviors toward their child in order to either compensate for this inability or prevent its manifestation. For example, perceiving that their child has difficulty remembering what they should do led parents to adjust their demands, or how they formulated their demands. Similarly, perceiving their child's behaviors as a result of a biologically based difficulty to control their impulses led to a self-adjustment to how the parents reacted to their child's behaviors. Additionally, perceiving the reasons for their child's disturbing behaviors as medical was also related to how the parents coped with negative emotions. For example, they would replace feelings of anger and irritation with feelings of empathy and compassion, or distinguish the "child" from the "symptoms".

## Summary of the Results from Study IV

The results are summarized in Table 7 below.

*Table 7. Themes and categories of parents' perceptions of, and coping with, their child's ADHD-related behaviors*

| |
|---|
| **Perceiving ADHD as a Source of Difficulties**<br>• Difficulty managing everyday routines<br>• Difficulty managing complaints from others<br>• Difficulty implementing personal values |
| **Perceiving ADHD as a Result of a Biological Dysfunction**<br>• The child's ability is qualitatively poorer than that of other children<br>• Disturbing behavior is not related to a lack of motivation in the child<br>• The child has needs different from those of other children |
| **Coping Directly with the Child's ADHD Behaviors**<br>• Adjusting proactive behaviors toward their child<br>• Adjusting reactive behaviors toward their child<br>• Actively searching for, and acquiring, knowledge |
| **Coping with Negative Emotions toward the Child**<br>• Replacing negative emotions with empathy and compassion<br>• Distinguishing between the "diagnosis" and the "child"<br>• Acquiring "pedagogic distance" |
| **Coping with Others' Complaints**<br>• Informing others about the formal diagnosis |
| **Negotiating between ADHD and Personal Values and Wishes**<br>• Not thinking too much and being spontaneous<br>• Limiting the validity of the diagnosis<br>• Questioning the meaning of one's values |
| **Patterns between Perceptions and Coping**<br>• Perceptions of biological causes of their child's behaviors -– Adjusting reactive behaviors toward their child<br>• Perceiving the child's ability as qualitatively poorer than that of other children -– Adjusting proactive behaviors<br>• Perceptions of biological causes of their child's behaviors -– Regulating negative emotions toward their child |

# Discussion

The overall aim of this project has been to contribute to the theoretical understanding of how children perceive and cope with their ADHD symptoms as well as how parents perceive and cope with their child's ADHD symptoms.

The specific research questions I aimed to answer were:

1. How do children with ADHD perceive and cope with their symptoms?
2. What patterns can be identified between the children's perceptions of their symptoms and their coping with them?
3. How do parents perceive and cope with their child's ADHD-related behaviors?
4. What patterns can be identified between the parents' perceptions of, and their coping with, their child's ADHD-related behaviors?

At the beginning of this chapter, I will integrate the results of the different studies and discuss how they relate to each other and to previous studies. Later in the chapter, I will elaborate on the contributions of the results in terms of theory, science, and clinical work. At the end of the chapter, I will discuss the methodological limitations and ethical issues related to the project.

## Discussion on Main Findings

### Children's Perceptions of, and Coping with, ADHD

In the first stage of this project, I conducted an overview and an integration of the findings from previous qualitative studies on how children with ADHD perceive their life with the disorder. Based on the findings reported by these previous studies, the overview identified four themes of children's perceptions, concerning: (1) their experiences of their ADHD symptoms; (2) their needs; (3) the role of other individuals around them, such as family, peers, and teachers; and (4) the self.

The integration of previous studies indicates that there is relatively little variation in how children perceive their experiences of their ADHD symptoms. A main finding was that children perceive their symptoms as bodily,

cognitive, and emotional sensations. They perceive these sensations as difficult to control, and as a source of difficulties in life. The integration of studies further indicates that there is variation in how children perceive their social environment. Two types of perceptions were identified: (1) others are a source of support, and (2) the demands of others are a source of problems. In addition, findings of previous studies suggest that there is variation in how children perceive their needs. Some findings indicate that children perceive that they need to be able to control or adjust themselves to the demands of others, while other findings indicate that children perceive a need to be accepted for who they are, without changing or regulating themselves. The overview also revealed that perceptions of self are a main theme in the life of children with ADHD. Many of the studies reported children's perceptions regarding the self, with a focus on the question of "who I am in relation to my symptoms". In the case of perceptions of the self, there was also variation in the findings. Some studies indicate that children with ADHD a have a negative self-image, while others report normative self-perceptions whereby the children consider themselves to be like "any other kind of child".

The results of Studies II and III, which are based on interviews with children, showed that the children's perceptions of their symptoms could be categorized into six themes. Figure 1 illustrates these themes.

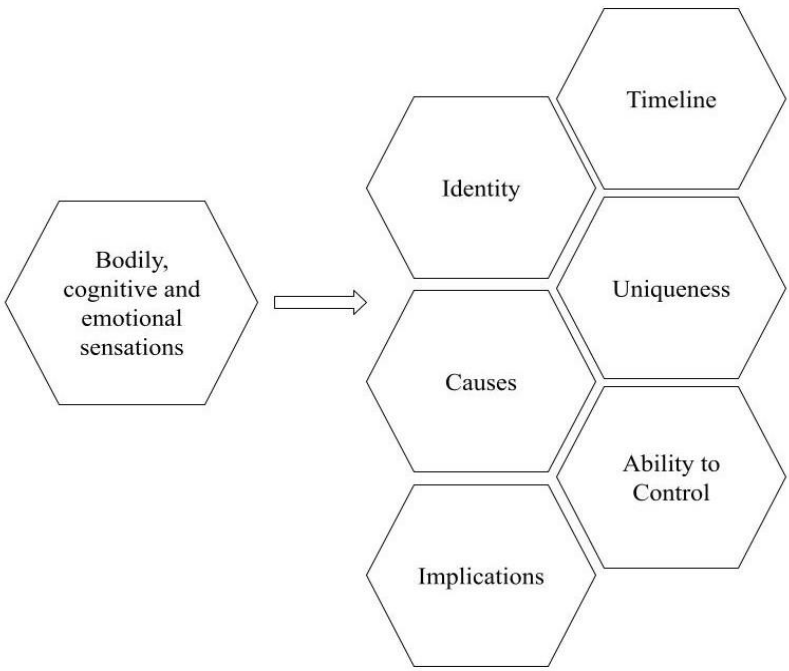


*Figure 1. Six themes of how children perceive their ADHD*

The first theme entails perceptions related to how the symptoms of ADHD are experienced. Similar to the results of the overview, there was little variation in how the children perceived their experiences of the symptoms. The dominant perspective from both the overview and my own interviews was that the ADHD symptoms involved disturbing, unpleasant, and overwhelming corporal, emotional, and cognitive sensations. However, in my own interview studies I was able to identify that the symptoms could also be perceived as positive and empowering by some individuals in some situations. Similar results were reported in another qualitative study recently conducted in Sweden, which found that children reported appreciative perceptions of their ADHD in certain contexts (Andersson Frondelius, Ranjbar, Danielsson, 2019).

The second theme of the children's perceptions is related to the symptoms' causes. Children perceive the causes of their symptoms in several different ways: as a result of a biological deficit within themselves, as a result of environmental-social factors, or as a result of their personality. Variations in the children's perceptions of their symptoms' causes can be a possible explanation for the variation that was found in the overview of studies regarding children's perceptions of the social environment. It might be suggested that children who perceive that the cause of their symptoms is a deficit within themselves also believe that they need help from others to compensate for this deficit. On the other hand, children who perceive that their ADHD is a result of overly high demands and expectations of others perceive these others as obstacles as well.

Likewise, variations in the children's perceptions of the causes of ADHD may also explain the variations identified in the meta-synthesis regarding the children's perceptions of their personal needs. Perceiving the causes of ADHD in terms of "a deficit within oneself" may be related to a perceived need to improve oneself and strive to achieve self-control. Perceiving the causes of ADHD as "a part of my personality", on the other hand, may be related to a need to be "accepted for who I am". Interestingly, in the quantitative study conducted by Wong and her colleagues (Wong et al., 2019), no significant variation was found among the participants with regard to the perceived causes of ADHD. In their study, a great majority of the participants perceived the causes of ADHD to be biological, while only a few perceived psychological or environmental aspects to be causes. However, the lack of variation in their results might be explained by the fact that all their participants were recruited in connection with visiting their healthcare provider at a psychiatric clinic.

The third theme of the children's perceptions identified from the interview studies concerns the potential implications of the symptoms of ADHD, or the impact of these symptoms, on their well-being. This theme includes a spectrum of beliefs along which ADHD is perceived as a great threat in many areas of life at one end of the spectrum, through the belief that it has only a few threatening implications, to, at the other end, the belief that is has a limited

impact on only one domain in life. This variation has also been observed in the study conducted by Wong and her colleagues (Wong et al., 2019).

The fourth theme includes the children's perceptions of their ability to control their symptoms by applying different measures. Some of these measures include trying very hard, making changes to their environment, asking for help, or taking medication. The children's perceived ability, or rather their perceived inability, to manage their ADHD symptoms is a theme that corresponds a great deal with the findings in the meta-synthesis study with respect to the perceptions of the symptoms as being difficult to control. In my interview studies, however, I identified that when the children referred to using different techniques in order to achieve control they varied in how they perceived their ability.

The fifth theme includes the children's perceptions of the time frame of their symptoms. The results showed that children vary in their perceptions regarding the time frame of the symptoms: some perceive them as something they will always have, while others believe the symptoms will go away with age. Variations in the children's perceptions of the timeline of ADHD may be related to variations in the perceived causes of their symptoms. It might be assumed that perceiving the symptoms as temporary may be related to the perception that ADHD has environmental causes, whereas perceiving the symptoms as chronic from birth may be related to perceiving them as part of "who one is" or as the result of a biological deficit.

The sixth theme of perceptions comprises perceptions regarding the uniqueness of the symptoms for individuals with ADHD, and whether or not other individuals experience them. In this theme, there is a variation in beliefs. Some children believe that the symptoms are unique to individuals with ADHD, and that there is a qualitative difference between having ADHD and not having ADHD. Others perceive experiencing the symptoms as a spectrum, whereby all people experience them to a certain degree but that having a diagnosis means that a person has the symptoms to a greater extent or more often. Here, the children may perceive themselves along a spectrum in relation to others. This variation in how children perceive the uniqueness of the symptoms may explain the variation in the theme "perceptions of self" that was identified via the meta-synthesis of the qualitative studies. It may be assumed that when perceiving ADHD as a spectrum, the children positioned themselves in a "worse" position in comparison to others. This might lead to the development of negative self-perceptions. On the other hand, when positioning oneself in a unique category where one stands alone, comparison with others is avoidable and might lead to the perception of self as being like "any other kind of child".

The results of Studies II and III indicate that children differ in how stable their perceptions of their symptoms are. Whereas some have different ways of perceiving the symptoms based on different situations, which can result in having contradictory beliefs, others are more stable in their beliefs and have a

clearer tendency to perceive the symptoms in a particular way. There may be two explanations for this variation. One might be that the stability of the meanings children give to their symptoms is a question of their psychological maturation, which means that the more mature children are the more coherent their meaning-making is. Another possible explanation might be that stable meaning-making is related to more stable environmental contexts in the child's life. Children who have a more stable and coherent environment, in which their parents, siblings, teachers, and peers construct similar environments, might perceive their symptoms similarly in different situations.

Study II also showed that children apply various coping strategies to manage their symptoms. In the first strategy, controlling the symptoms, the child engages in efforts to control the symptoms by, for example, controlling thoughts or trying hard to stay in place. The second strategy consists of attempts to eliminate symptoms by making changes to the environment, negotiating social demands, or asking for help. In the third strategy, children accept the symptoms and follow them as they would any other need in their body. Examples of this third type of coping include running around when perceiving a need to be active, acting emotionally, or talking excessively. These identified coping strategies correspond well with the coping strategies Hampel and her colleagues examined in boys with ADHD (Hampel et, al., 2008). Similar to their results, the results of Study II also show that children with ADHD apply self-control, distraction, self-encouragement, avoidance, and asking for social support as strategies for managing their ADHD. The novel contribution of this project is its illumination of the children's first-hand perspectives regarding how some children with ADHD put these strategies to use.

Searching for patterns between the ways the children perceive their ADHD and the ways they attempt to cope with the symptoms enabled me to understand the possible perceptions underlying the use of a specific coping strategy. The results have shown, for example, that the children who perceived the causes of ADHD as social/environmental were the ones who engaged in making changes to their environment and negotiating demands. On the other hand, children who perceived the symptoms as the result of a biological deficit within themselves engaged in attempts to control themselves and achieve mastery over the symptoms. Children who believed that the ADHD symptoms were part of their personality, however, did not engage in preventing their symptoms and instead "followed"' them.

Another interesting pattern that was manifested in the interviews was between the perceptions regarding the uniqueness of the symptoms and the participants' attempts to control themselves. Perceptions of ADHD as an experience located along a spectrum – that is, regarding the difference between themselves and others as merely quantitative – were expressed by the participants who also expressed a use of self-control as a strategy for coping with their symptoms. On the other hand, the participants who perceived ADHD as a unique and separate category were also those who expressed that coping

with their symptoms included making changes to their environment. An explanation for this interesting pattern might be that perceiving oneself in an inferior position along a spectrum may increase one's desire to reach a better position on this perceived spectrum. On the other hand, positioning oneself in a singular category, together with other individuals with ADHD, might lead to a stronger belief in one's right to negotiate the adjustment of demands from others. Less surprising patterns were manifested in the interviews between the perceived ability to control the symptoms and the expression of using self-control strategies. Figure 2 summarizes the patterns found between different types of perceptions and different types of coping.

| **Perceptions of ADHD** | **Coping with ADHD** |
|---|---|
| The cause of ADHD is a deficit within oneself | Strategies for controlling oneself |
| The cause of ADHD is my environment | Making changes to the environment |
| The cause of ADHD is my personality/who I am | Following the ADHD |
| Perceiving ADHD as a spectrum | Strategies for controlling oneself |
| Perceiving ADHD as a dichotomy | Making changes to the environment |
| Perceiving ability to control | Strategies for controlling oneself |

*Figure 2. Patterns between the children's perceptions of ADHD and their coping strategies*

## Parents' Perceptions of, and Coping with, ADHD

The results of Study IV showed that parents perceive their child's ADHD-related behaviors as a source of difficulties. These difficulties can be divided into three domains: (1) difficulty managing everyday routines, (2) struggles with managing demands or criticism from others outside the family, and (3) difficulty implementing personal values, wishes, and needs. These perceived difficulties are coupled with negative emotions of frustration, anger, sadness, sorrow, and shame.

Previous studies have shown that parents of children with ADHD perceive their parenting demands as significantly higher than those of parents of typically developed children (Theule et al., 2013). In addition, studies reported that being the parent of a child with ADHD is associated with an emotional

burden (Corcoran et al., 2017). The three domains of perceived difficulties identified in Study IV might explain the parents' stress and emotional burden reported in previous studies.

A formal ADHD diagnosis served as a threshold for parents to perceive their child's behaviors as the result of an inability within the child caused by a biological deficit. Perceiving the child's ADHD-related behaviors as manifestations of a medical condition leads to various coping strategies in order to manage perceived difficulties. Three groups of coping strategies were found. The first group consists of behavioral procedures that the parents apply in order to compensate for the child's perceived biological deficit, and in this way prevent the child's disruptive behaviors. These procedures include adjusting one's proactive and reactive behaviors toward the child, as well as acquiring knowledge about ADHD. Another strategy involves attempts by parents to manage negative emotions, in relation both to their child (i.e. frustration and anger) and to others (i.e. shame). By interpreting their child's behaviors as an inability, they can replace feelings of frustration and anger with empathy and compassion. This replacement also occurs when parents employ coping strategies such as "acquiring pedagogic distance" or "blaming the diagnosis". In their coping with negative emotions in relation to others, parents inform these others about the formal diagnosis.

Finally, the third strategy consists of using cognitive techniques to find a "balance" or a "compromise" between the everyday needs and demands of the family, including the parents' own wishes and values, and the perceived needs of the child. These cognitive strategies include evaluating the different needs against each other, arranging them according to importance, and prioritizing the demand or need that is assessed as the most important.

Unlike the children, the parents did not vary in their perceptions of the ADHD-related behaviors. This lack of variation led to the identification of patterns between the parents' perceptions and their coping strategies only with respect to the perceptions of ADHD as a medical condition. Figure 3 illustrates patterns between the parents' perception of the ADHD behaviors as the result of a medical condition and how they attempt to cope with these behaviors.

| Perceptions of the child's ADHD-related behaviors | Coping with the child's ADHD-related behaviors |
|---|---|
| The cause of the child's behaviors is biological | Adjusting reactive behaviors toward the child |
| The child's ability is poorer than that of other children | Adjusting proactive behaviors toward the child |
| The child has needs that are different from those of other children | Regulating negative emotions toward the child |
| The child's behaviours are not caused by a lack of motivation in the child | Acquiring knowledge about ADHD |
| | Informing others about the formal diagnosis |
| | Negotiating with ADHD |

*Figure 3. Pattern between the parents' perceptions of, and coping with, their child's ADHD-related behaviors*

These results correspond well to those of previous studies. In their study, Harrison and Sofronoff (2002) found that parents who perceived their child's behaviors in terms of "wanting to get attention", "the child's nature", "to get a reaction", and "laziness" experienced higher levels of parenting stress than those who perceived their child's behaviors as the result of biological factors. These differences can be understood in light of the findings from Study IV. This study found that when parents perceive the child's behaviors as a consequence of a biological deficit, this leads to a chain of behavioral, emotional, and cognitive coping strategies that all aim to decrease perceived difficulties.

In their qualitative study based on interviews with parents, Williams and colleagues (Williams et al., 2014) identified two types of coping pathways: cognitive and emotional. Whereas the cognitive pathway is a conscious one, involving rational problem-solving whereby the parent perceives control over the situation, the emotional pathway is driven by negative emotions whereby the parents react irrationally. The identification of these two pathways is also manifested in the results of the current study, as many of the identified coping strategies are based on rational and planned problem-solving. However, in Study IV, the results showed that the parents strived to integrate the spontaneous and emotional pathway with the rational one, with the rationale that both of them together constitute normal parenthood.

An interesting finding to reflect upon relates to the study by Podolski and Nigg (2001), which investigated the effect of different coping strategies on perceived stress. In their study, the researchers identified that cognitive reframing and spiritual support were two strategies that were significantly related to lower perceived stress in parents. Whereas many of the parents I in-

terviewed described cognitively reframing the meanings of their child's behaviors in order to make them more manageable, none of them mentioned seeking spiritual support.

# Contributions of the Results

## Theoretical Contributions

During the project, I approached coping as a learning process in which children and parents learn about the child's ADHD. By taking a first-hand perspective and grounding the results in the children's and the parents' own words, I was able to explore the dynamic process of building personal meanings of ADHD. The results of the project illuminate that children and parents learn about ADHD in their everyday life via their experiences of the symptoms, as well as their perceptions of and reactions to these experiences.

Regarding the children, we can imagine their learning process as having four stages. In the first stage, children experience their ADHD symptoms via bodily sensations. These sensations can include intensive emotions, restlessness and unease in the body, and disturbing thoughts.

In the second stage, the child makes sense of these sensations by perceiving them via six themes: Identity (by categorizing them and labeling them as ADHD), Cause (by perceiving the causes of the sensations), Implications (by assessing their possible outcomes), Control (by assessing their own ability to control the sensations), Timeline (by perceiving how long the sensations last), and Uniqueness (by perceiving whether the sensations are manifested by others or are unique to themselves).

In the third stage, these perceptions lead the child to apply a certain coping strategy. The fourth stage, the outcome of this coping strategy, constitutes feedback concerning the validity of the perceptions the child holds. When the consequences of the applied coping strategy are in line with the child's existing beliefs about ADHD, the belief is strengthened. On the other hand, when the consequences of a particular coping strategy contradict the child's existing beliefs, these beliefs are challenged and reformed.

Throughout this process, children build personal meanings of their ADHD. Figure 4 suggests a theoretical understanding of the children's processes of learning about their ADHD via their coping strategies:

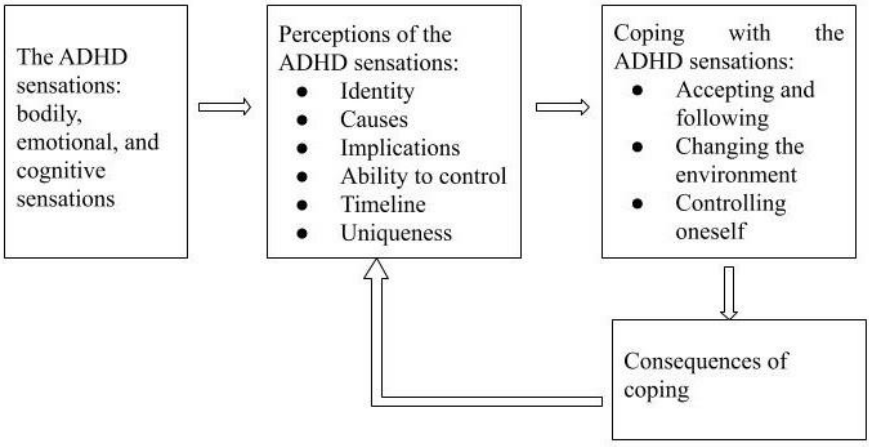


*Figure 4. Children's learning process regarding their ADHD via coping*

Also for parents, the meaning-making regarding ADHD through coping can be seen as constituted by four stages. In the first stage, parents experience their child's ADHD symptoms through the behaviors related to them, by observing the behaviors themselves or by receiving information about them from others. In the second stage, parents make sense of these behaviors by perceiving them via two themes: (1) perceiving the child's behaviors as a source of difficulties, such as difficulty managing everyday life routines, managing complaints from others, and being able to fulfill their needs and values; and (2) perceiving the child's behaviors as the result of a biological dysfunction within the child, and regarding the child's abilities and needs as qualitatively different than those of other children.

In the third stage, perceptions of their child's behaviors as a source of problems and as a biological impairment lead to a chain of coping strategies. These strategies include behavioral, cognitive, and emotional attempts that parents apply in order to manage their perceived problems.

In the fourth stage, based on the outcomes of the applied coping strategies, the parents evaluate their perceptions, reform their existing beliefs, and form new meanings. Figure 5 illustrates the learning process among parents:

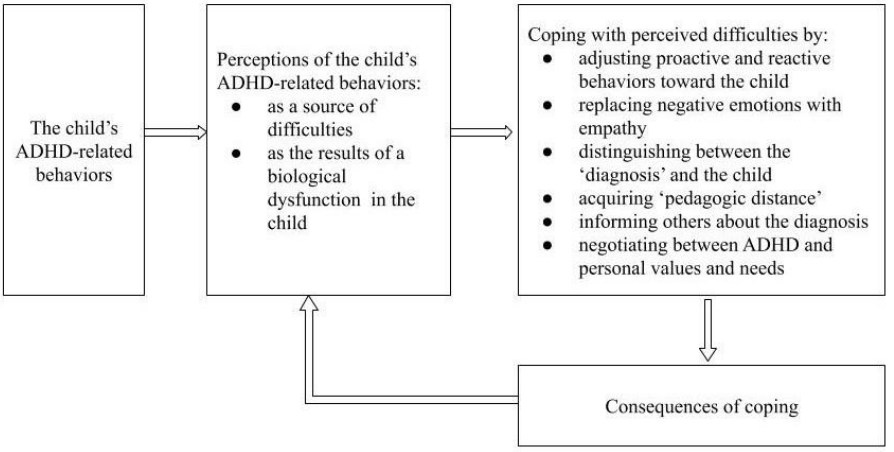


*Figure 5. Parents' learning process regarding their child's ADHD via coping*

It is important to point out that children and parents also learn about ADHD in other, more formal, ways. Parents learn about their child's ADHD already during the diagnostic process, for example when filling out different questionnaires about their child's behaviors or through diagnostic interviews. In addition, parents and children form meanings about ADHD by receiving the diagnostic label, participating in courses organized by the healthcare system, and reading information about ADHD in books, in social media, and online. The theoretical contribution of this project, however, is that it illuminates the learning-through-coping processes in which children and parents learn about ADHD by coping with its symptoms.

An additional theoretical contribution of this project is that it suggests an explanation for a phenomenon researchers refer to as the "positive illusory bias of children with ADHD" (Owens, Evangelista, Goldfine, Hoza, & Kaiser, 2007). The positive illusory bias refers to the tendency of children with ADHD to underestimate the severity of their symptoms while overestimating their competence and performance in comparison to their parents' estimations (Owens at el., 2007).

This difference between children's and parents' estimations can be understood by the differences in their learning-through-coping processes. While the point of departure in the children's learning-through-coping process is their sensations within their body, the parents' learning-through-coping is based on their observations of their child's behaviors or others' complaints related to them. What parents experience as ADHD-related behaviors are actually a manifestation of a single specific type of coping that the child applies in order to manage the symptoms. That is, when the child applies the coping strategy "following my symptoms", this is when the parents experience their child's

ADHD. On the other hand, the child's behaviors related to the coping strategies of "controlling oneself" or "making adjustments to the environment" are not experienced by the parents and they therefore do not perceive them as ADHD.

While children learn about their ADHD by applying various coping strategies in order to manage their symptoms, parents learn about their child's condition only when the child uses the strategy "following my symptoms". When children learn about their ADHD by also applying the coping strategies of "controlling the sensations" and "making adjustments to the environment", this may lead them to estimate their competence to be higher and the severity of their symptoms lower compared to their parents' estimates.

The project makes a further contribution with respect to the theoretical understanding of how children and parents perceive and cope with ADHD, by illuminating the possible patterns between perceptions and coping strategies. Both the Transactional Theory (Lazarus & Folkman, 1984) and the Common-Sense Model (Leventhal et al., 1980) suggest that an individual's reactions to a medical condition are grounded in how they perceive the condition. As the Transactional Theory suggests, the results of the project showed that the children and parents perceive the symptoms of ADHD with respect to the threatening implications they have for their well-being, as well as to their available resources for managing these symptoms.

According to the theory, this evaluation occurs in every new encounter with the symptoms, specifically in relation to the contextual features of the encounter. Contrary to this, however, the analysis of the empirical data has shown that both the children and parents maintain perceptions or representations of the ADHD symptoms that are more stable and general beyond a specific event. These general themes of perceptions are consistent with the Common-Sense Model (Leventhal et al., 1980). Interestingly, even though the Common-Sense Model was originally developed in order to understand individuals' ways of coping with somatic illnesses, the analysis of the interviews with the children suggests that it also does a good job of capturing an individual's perceptions of ADHD. However, with regard to ADHD, children with the disorder also have perceptions regarding the uniqueness of their symptoms and how the symptoms are experienced by others. The results thus contribute to theory development specific to the case of perceptions of, and coping with, ADHD.

## Scientific Contributions

Children with ADHD comprise a heterogeneous group. The results of this project indicate that children vary in their ways of perceiving their ADHD, and this variation in perceptions is also related to variations in how children cope with their symptoms. An important implication of these results is the need to consider these variations in our understanding of individual differences in the everyday functioning, well-being, and stress of children with ADHD.

In addition, variations in perceptions and coping strategies need to be included in our understanding of individual differences in the effectiveness of various interventions. The results of this project suggest that there are patterns between the beliefs children and parents have about ADHD, and the strategies they use in order to manage it. Including individual beliefs and coping in understanding the usefulness of an intervention will help us move away from the one-size-fits-all approach to interventions toward a more personalized approach.

This research project has generated several suggestions for future research. One is to quantitatively investigate whether children have any tendencies to perceive their symptoms in a more coherent way, or if they have different perceptions of their symptoms in different situations, depending on temporary factors. Another suggestion for future research is to quantitatively investigate relationships between children's perceptions, coping strategies, and psychosocial outcomes, such as their perceived stress, well-being, and everyday functioning. Lastly, this project conducted separate analyses for children and parents. An integration of parents' and children's perceptions, however, is an important aspect to explore. What happens when a child and a parent do not perceive ADHD in the same way? What are the implications of this? What could be the consequences of such differences or similarities? These are just some of the additional questions that should be targeted in future studies.

## Contributions for Clinical Work

An important application of this study within the clinical setting is the potential to develop an instrument with the aim of uncovering knowledge regarding a child's own perspectives on their ADHD. The qualitative analysis of the interviews with the children in this study, and the identification of themes related to perceptions, can serve as a good basis for developing such an instrument.

Developing a questionnaire that allows children to indicate their own beliefs, understandings, and thoughts regarding their symptoms will make it easier for clinicians working with these children to include the children's perspectives in a systematic way within the healthcare process.

The systematic inclusion of children's perceptions within their own healthcare would not only be in line with the Convention on the Rights of the Child (The United Nations, 1989) but might also contribute to an improvement of personalized treatment methods and, consequently, to their effectiveness (Ben-Arieh, 2005; Wong et al., 2019).

# Methodological Limitations

The aim of this project was to contribute to the theoretical understanding of the perceptions of ADHD held by children and parents, and how each group copes with either their own or their child's ADHD. In order to achieve the aim of the project, I used three qualitative methods: a meta-synthesis of previous qualitative studies, an explorative analysis of interviews with children and parents, and an analysis of the children's interviews based on predefined themes. In the following section, I will discuss the limitations of the methods I applied with regard to data collection and data analysis.

## Data Collection

Three sets of data were used, each generated in a different way. In Study I, the data was generated through a systematic search for previous qualitative studies. In Studies II and III the data was collected through interviews with children, and Study IV was based on data collected through interviews with parents. In the following section I will illuminate aspects related to the validity and transferability of the results, which in qualitative research refers to the ability to transfer the research findings to groups other than the specific group that participated in the research (Cho & Trent, 2014), in relation to what data was collected and how this was done.

### Collecting Data via a Systematic Search for Studies

A synthesis of already published qualitative studies regarding a specific phenomenon enables one to make sense of what research has already discovered about the subject (Saini & Shlonsky, 2012). In addition, the integration of studies allows us to explore the subject based on data from a large number of individuals, and may lead to a greater richness of data in terms of the manifestation of the phenomenon (Saini & Shlonsky, 2012). For example, the 16 studies included in the meta-analysis in Study I were based on interviews with 205 participants, both boys and girls, from seven countries.

However, integrating the results of previous studies can also carry a risk of losing the children's first-hand perspectives, which is what I was interested in looking at in the study. By collecting data based on already interpreted interviews, with the aim of understanding the children's own understanding of living with ADHD, I moved one step away from the children's own words and unintentionally included within my analysis the voice of those researchers' interpretations of the children's words, which may have implications on the validity of the results.

Another methodological limitation of the meta-synthesis is that the search for studies was not limited to a particular time period, despite the fact that the diagnostic criteria for ADHD are different in the various editions of the Diag-

nostic and Statistical Manual of Mental Disorders and the International Classification of Diseases. Including studies from different periods of time may carry the risk of integrating studies that do not investigate the same phenomenon. Yet, I assume that the differences between the various versions of the diagnostic manuals have not necessarily resulted in substantial differences in the experiences of children diagnosed according to the different versions. This procedure may also have had a negative effect on the validity.

Finally, economic considerations dictated exclusion criteria that disregarded studies published in languages other than English. This may be the reason for the dominance of selected studies conducted in North America and Europe. As cultural aspects may play a role in an individual's experiences and understanding of their ADHD, the relative homogeneity of the studies in terms of national context may constitute a limitation of the transferability of the results.

### Collecting Data via Interviews

Collecting data via interviews was a method I chose in order to be able to explore the children's and parents' beliefs and thoughts.

However, using interviews as a tool for generating data has its implications. Some researchers have discussed children's ability to contribute knowledge regarding their life via interviews (Vogl, 2015). By studying more than 100 semi-structured interviews with children, Vogl (2015) has shown that children under the age of seven demonstrated such a lack in both verbal and conversational skills (such as an idiosyncratic and undifferentiating use of words, and unsolicited explanations of answers to questions) that it directly affected the utility of the interview as a method of data collection. However, the verbal and interactive skills of children older than seven years of age are at such a level that they did not constitute an obstacle to the applicability of interviews (Vogl, 2015).

Collecting data via interviews should also be considered in relation to the possible effect of the ADHD symptoms on the interviews' content. In order to limit the possible effect of the children's hyperactivity, impulsivity, and attention deficit on the data collection, the children themselves were allowed choose whether and how they want to keep themselves occupied during the interview (e.g., walking around in the room or jumping on a trampoline). In addition, I tried to be concrete and consistent in my interviewing, basing my questions on the child's specific everyday events.

### Characteristics of the Participants

The recruitment procedures and the participants' characteristics might have had an effect on the transferability of the results.

In the *Background* chapter, where I described this research project, I presented a range of variation in characteristics among the children with ADHD and their parents. Some of these variations include clinical characteristics such

as receiving the formal diagnosis, and sociodemographic variations such as cultural and school characteristics. However, while variation was found among the children and the parents in terms of sex, age, and diagnosis characteristics, I could not reach variation among them in terms of socioeconomic background. All parents, both those I interviewed and those whose children I interviewed, had a university education and stable employment conditions. Such characteristics of the sample may have had implications for the transferability of the results.

One inclusion criterion, for both the children and the parents, was that the child had a formal ADHD diagnosis. The reason for such a criterion was to guarantee, to a certain degree, that all the children and parents would have experiences regarding the phenomenon of ADHD. However, the criterion of a formal diagnosis might mean that the perceptions and coping described by the group of participants are different from those among children who have ADHD but lack a formal diagnosis, as well as those of their parents. Here also, this methodological aspect might have limited the transferability of the results. Another implication of deciding to interview parents who had chosen to conduct a neuropsychiatric evaluation of their child may be the relatively little variation among the parents in terms of their perceptions of their child's behaviors as a biological dysfunction. It may be the case that recruiting parents with children who have ADHD from the general population (and then assessing the current state of the child's symptoms during recruitment) would result in a broader variation between the parents' perceptions of and coping with their child's behaviors.

## Data Analysis

In all four of the studies in this project, the focus of the analytical process was to explore, categorize, and search for perceptions of ADHD and coping with ADHD, as well as the patterns between the two. An implication of such a focus is that other aspects and patterns in the material were overlooked.

In the meta-synthesis, for example, no attention was given to the possible differences in the results between studies conducted at different periods of time or in different countries, or that applied different qualitative methods. Similarly, in the analysis of the interviews, no attention was given to the possible patterns between participant characteristics such as the child's age (both currently and when the diagnosis was received), sex, time since receiving the diagnosis, subtype of ADHD, or school and treatment experiences and the ways the participants perceive and cope with their symptoms. This limitation of the analysis may have had negative implications for the validity of the results.

A final methodological point to address here is that the data analysis did not consider the frequency of certain experiences, perceptions, or strategies

reported in the interviews; instead, the focus was on the additional contribution of the certain experience/perception/strategy for coping in order to provide a conceptual understanding of these processes. A limitation of this approach is that common aspects that appeared in several interviews were interpreted as having the same level of importance as aspects that appeared in only a few interviews, which may be a problem in terms of the validity of the results.

## Ethical Considerations

When conducting research involving highly sensitive matters in the lives of individuals, there are many ethical aspects to consider. In this part, I will reflect upon the ethical problems I experienced and my attempts to solve them.

### Interviewing Children and Parents about a Highly Personal Matter

Ethical considerations related to conducting qualitative interviews with children in research are discussed extensively in the literature (Alderson & Morrow, 2011). In the course of working with this research project, I have encountered several ethical problems related to interviewing children and parents for research purposes. In the following section, I will base my reflections on three ethical principles a researcher is obligated to guarantee to participants: autonomy, confidentiality, and privacy (Greig, Taylor & MacKay, 2007). I will discuss how these three demands sometimes came into conflict with the need for empirical data.

Regarding the ethical obligation to guarantee the children autonomy in their decision to participate in the research, I continually reflected upon the question of the extent to which the children I interviewed could make an independent decision to participate in the study: Are they actually free from any control or manipulation by gatekeepers such as parents or school psychologists? Can I guarantee that they understand that they can refuse to participate, and that they have the freedom to make their own decisions?

In order to increase the children's autonomy, I informed them very specifically and repeatedly, both verbally at the beginning of every interview and in a written letter sent to them in advance of the study, about their right to decline participation without fearing repercussions or consequences. I also informed them about their right to decide what they did and did not want to share during the interviews.

However, as other researchers have indicated (Christensen & Prout, 2002), children do not always openly say that they do not want to be interviewed. In one of the interviews, for example, the child systematically talked about other

subjects (such as computer games and the Second World War) that I interpreted as having no relevance to the research subject. Here, I faced the ethical dilemma of whether I should keep asking the child questions with the hope of getting some useful data, even though it appeared that they were not interested in my agenda, or should I end the interview and allow them to talk with me about what was interesting to them? This dilemma was even more prominent considering the attention deficit characteristics ADHD implies. In this case, I decided to value the child's right to autonomy over their participation (although they did not express an unwillingness to participate), even at the expense of only collecting a limited amount of data from the interview.

My ambition to guarantee the children's autonomy with respect to their decision to participate, as well as their autonomy to decide what they wanted to tell me during the interviews, led to my decision not to offer concrete compensation for participation in the study. This decision might be the reason for the limited variation in the socioeconomic characteristics of the participants, and for the fact that I could recruit only children and parents with a relatively high socioeconomic background. After all, research has shown that individuals from lower socioeconomic backgrounds are more willing to participate in research when offered fair compensation (Webb, Khubchandani, Striley, & Cottler, 2019).

The ethical aspect of confidentiality refers to the researcher's responsibility to conceal information (name and personal details) that can lead to the identification of a participant (Alderson & Morrow, 2011). As I interviewed the children individually, after the interviews were over the parents of the children who were interviewed frequently asked about their child's answers out of a concern for the child's well-being. Several parents explained that they would like to know what their child had said out of curiosity, especially as their child did not often share their thoughts and experiences with them. As the parents were the gatekeepers to the children's participation, it often felt difficult to maintain the principle of confidentiality in light of the parents' urging. I felt I had to give a neutral and uninformative response to the parent, so I thanked them for their trust and said I had very much enjoyed interviewing their child. In several cases, I noticed the parent was disappointed in me for not disclosing more information.

The aspect of privacy was the principle I ethically struggled with the most. The demand for privacy in research refers to the researcher's responsibility to avoid undue intrusion into an individual's personal affairs (Alderson & Morrow, 2011). This research project is about a highly personal matter, and in order to answer my research questions I needed to have access to the personal experiences, thoughts, emotions, and wishes of the individual participants. How could I judge when personal knowledge about a participant is *undue or unjustified* considering the research questions? In the case of the children's interviews I did not need to choose between the value of collecting personal data and the risk of being intrusive, as all of the interviews stayed within the

boundaries of my interview guide. However, this was not the case for the interviews with the parents. On several occasions during some of the interviews with the parents, I had this dilemma on my mind. In one of the interviews, for example, the interview's content was on a personal level, and this information was not necessary to achieve the aims of the project. In the case of this interview, I decided to stop recording and continue talking with the parent, but no longer in the capacity of their being a research participant.

## Conducting Research as a Practitioner

Working as a clinical practitioner during the first years of conducting the project sometimes involved a conflict between two ethical considerations: on the one hand, the responsibility to acquire scientific knowledge as a researcher; and on the other, the obligation I have as a practitioner to satisfy an individual's need for care.

The competing commitments related to simultaneously carrying out the role of a researcher and that of a clinician have been discussed by other researchers (Lidz et al., 2009; Lawrence, Albert, Lidz, & Appelbaum, 2012). These researchers, for example, have indicated that there is a risk that the researcher's obligation to approach the studied phenomenon critically and to contribute scientific knowledge may come into conflict with the clinician's need to be able to adjust themselves to the clinical procedures and healthcare methods that are available at the clinic (Lidz et al., 2009; Lawrence et al., 2012). Although other scholars suggest that having these two roles may contribute to the methodological quality of the study being conducted (FitzPatrick, 2019), based on my experience I argue that having those two roles at the same time is problematic from an ethical point of view. Very often during the interviews, parents raised a good deal of questions that I used to answer as a clinical psychologist Questions such as "What methods are effective?" or "What are the effects of medicines?" presented a dilemma: should I share my professional knowledge with the parents as a clinician when my reason for meeting with them was to listen to their own experiences, or should I pretend that I do not have the answers? What is more ethically justified –– satisfying an individual's need for care or acquiring scientific knowledge?

# Summary in Swedish/ Sammanfattning på svenska

## Bakgrund

Attention Deficit Hyperactivity Disorder (adhd) är en funktionsnedsättning som innebär att individen har påtagliga svårigheter att behålla fokus, att reglera aktivitetsnivån i kroppen, samt att kontrollera sina impulser (American Psychiatric Association, 2013). Dessa svårigheter kan komma till utryck på olika sätt. Till exempel, svårigheterna att behålla fokus kan visa sig via irritation eller ilska hos ett barn när barnet blir avbrutet mitt i en uppgift. Uppmärksamhetssvårigheter kan även visa sig som svårigheter att följa instruktioner eller att komma ihåg vardagliga händelser (American Psychiatric Association, 2013). Svårigheterna att reglera aktivitetsnivån i kroppen kan manifesteras genom beteenden såsom att ofta lämna sin plats, klättra på möbler eller springa runt, även i situationer där det är förväntat av barnet att sitta på sin plats (American Psychiatric Association, 2013). Impulsiviteten kan framträda genom farligt agerande, eller att ta saker som inte tillhör en utan tillåtelse, intensivt pratande, och svårigheter att vänta på sin tur (American Psychiatric Association, 2013).

Med utgångspunkten att dessa beteenden förekommer i viss utsträckning hos de flesta barn, kräver diagnostiseringen att dessa beteenden pågår under längre tid, och att de visar sig i skilda kontexter, som till exempel såväl hemma i relationer med både föräldrar och syskon, som i skolan under lektion och rast i relation till både lärare och klasskamrater (American Psychiatric Association, 2013).

Att vara ett barn med adhd innebär en hel del vardagliga psykosociala utmaningar. I skolan presterar barn med adhd sämre akademiskt och har oftare disciplinära problem (Arnold et al., 2020). Vidare har barn med adhd högre risk att hamna i lång skolfrånvaro, både i jämförelse med barn utan någon diagnos och i jämförelse med barn med andra neuropsykiatriska diagnoser (Black & Zablotsky, 2018).

I relationer med jämnåriga hamnar de oftare i konflikter, känner sig utanför och har svårt att utveckla kamratskap (Kok, Groen, Fuermaier, & Tucha, 2016). Barn med adhd upplever sig oftare utanför gruppen och att de blir avvisade eller stigmatiserade av andra (Hoza, 2007). Dessutom uppfattar klasskamraterna barn med adhd som irriterande, störande, och oförutsägbara

(McQuade & Hoza, 2008). När det gäller relationer inom familjen, upplever barnen ofta konflikter och negativa känslor i relation till såväl föräldrar (Chang & Gau, 2017; Edwards, Barkley, Laneri, Fletcher, & Metevia, 2001) som syskon (Chang & Gau, 2017; Mikami & Pfiffner, 2008).

Även att vara en förälder till ett barn med adhd kan innebära psykosociala utmaningar. Forskning har visat att föräldrar till barn med adhd upplever betydligt mer stress (Theule, Wiener, Tannock & Jenkins, 2013), samt känner sig maktlösa och upplever frustration i relation till vardagliga rutiner och krav (Corcoran, Schildt, Hochbrueckner, & Abell, 2017)

Nyligen har flera forskare uppmärksammat behovet av att belysa barnens och föräldrars förstahands- uppfattningar och hanteringsstrategier av adhd (Emilsson et al., 2017; Wong et al., 2019; Wong et al., 2018; Harrison & Sofronoff, 2002). Detta behov grundar sig i tre argument:

(1) För att kunna förstå orsakerna till de psykosociala konsekvenserna som att leva med adhd innebär, behöver vi förstå hur barnen och deras föräldrar uppfattar och hanterar symptomen i vardagliga situationer (Wong et al., 2018; Harrison & Sofronoff, 2002).

(2) Kunskap om hur barn och föräldrar uppfattar och hanterar symptomen kan användas för att individualisera behandlingsinsatser för adhd och avbryta den ’samma skostorlek passar alla’-attityd som ibland förekommer inom vården (Wong et al., 2019).

(3) Enligt FNs barnkonvention (The United Nations, 1989), som nyligen blev svensk lag (SFS 2018:1197), ska barn ha rätt att uttrycka sina uppfattningar och få dessa beaktade i frågor som rör dem. I och med att forskning är en viktig social arena har barn även en viktig roll i att få sina perspektiv beaktade i forskning (Ben-Arieh, 2005).

## Syften och metoder

Syften med avhandlingen har varit att bidra till kunskapen om hur barn med adhd och deras föräldrar uppfattar och hanterar symptomen i vardagen, samt att utforska om det finns mönster mellan typer av uppfattningar och typer av hanteringsstrategier.

Avhandlingen utgörs av fyra studier, som alla är baserade på kvalitativa metoder. De tillämpade kvalitativa metoderna gav möjlighet till en öppen och nyanserad utforskning av komplexiteten i individernas egna tankar, beteenden och känslor relaterade till att leva med adhd. I den första studien genomfördes en systematisk sökning och en syntes av publicerade kvalitativa studier om barns egna uppfattningar om att leva med adhd. Den andra och tredje studien grundar sig på analyser av intervjuer med 14 diagnostiserade barn, i åldrarna 8-17 år. Den fjärde studien är baserad på en analys av intervjuer med 12 föräldrar till barn med diagnosen. Både barn och föräldrar rekryterades av skolpsykologer i skolor i Stockholm. En variation bland deltagarna fanns i

termer av barnets ålder, kön, tid sedan diagnostiseringen, och typ av behandling. Variation avseende deltagarnas socioekonomiska status var dock begränsad i och med att alla intervjuade föräldrar samt föräldrar till de intervjuade barnen har universitetsutbildning och arbete.

## Resultat

En integrering av resultatet av delstudierna har visat att barn med adhd har varierande uppfattningar om sina symptom. Sex teman av uppfattningar av symptomen har identifierats. Det första temat, ’identifiering av symptomen’, innehåller uppfattningar relaterade till kroppsliga upplevelser som barnen kopplar till sin diagnos. Uppfattningarna hos barnen var genomgående att adhd innebär irriterande och störande kroppsliga, tankemässiga och känslomässiga upplevelser. Hos några av de intervjuade fanns dock även uppfattningen att symptomen var som en slags kreativ superkraft.

Det andra temat, ’orsaker till symptomen’, beskriver uppfattningar om bakomliggande förklaringar till symptomen. Här fanns en variation mellan barnen och tre typer av uppfattade orsaker identifierades: (1) symptomen orsakas av brister i min hjärna, en oförmåga inom mig; (2) symptomen orsakas av sociala eller fysiska faktorer i min omgivning; och (3) symptomen är ett utryck för min personlighet, för vem jag är.

Det tredje temat, ’konsekvenserna av adhd’ avser barnens uppfattningar om de eventuella effekterna som symptomen kan ha för deras liv. Inom detta tema ryms uppfattningar om effekten adhd har på möjligheten till att få vänner, utföra skolarbetet eller att sysselsätta sig själv med ett fritidsintresse. Även i den kategorin har det visat sig att barnen varierade i sina uppfattningar. Medan en del uppfattade att adhd har stora konsekvenser för flera områden i livet, uppfattade andra att symptomen har begränsade konsekvenser för endast ett fåtal livsområden.

Det fjärde temat, ’kontroll’, innehåller uppfattningar gällande barnens förmåga att uppnå kontroll över symptomen genom att tillämpa olika strategier. Tre huvudsakliga strategier är att anstränga sig hårt, att göra ändringar i sin omgivning, och medicinering. Även i denna kategori fanns variation bland barnen. Medan en del upplevde avsaknad av möjlighet att kontrollera sina symptom, uppfattade andra att en sådan kontroll kan uppnås, bara de får tillämpa rätt strategi. Några barn uppfattade att kontroll över symptomen inte var nödvändig.

I det femte temat, ’tidsramen’, inkluderas barnens uppfattningar av hur länge symptomen kommer att pågå, både när det gäller på kort sikt och på lång sikt. Även här fanns det en variation bland barnens uppfattningar. En del uppfattade att symptomen är kroniska och upplevs hela tiden medan andra upp-

fattade att symptomen är tillfälliga- kommer och går. En del trodde att de kommer att ha symptomen under hela livet andra trodde att adhd är begränsad endast till en viss livstid.

Det sjätte temat, 'symptomens unikhet', behandlar uppfattningar om huruvida symptomen upplevs som unika endast för individer med adhd eller som något mer eller mindre alla individer upplever. Inom detta tema noterades också variation. Å ena sidan uppfattades adhd av en del barn som ett spektrum, där symtomen representeras hos alla individer i varierande grad. Här uppfattades skillnaden mellan individer med diagnosen och individer utan diagnosen som kvantitativ. Alla upplever symptomen i en viss grad. Individer med diagnosen upplever enbart symptomen mer intensivt eller oftare. Å andra sidan uppfattades adhd av vissa som en dikotomi, en unik upplevelse som kännetecknar endast individer med adhd. Här uppfattades skillnader mellan individer med adhd och andra som kvalitativa.

I avhandlingen framkom visare att en variation finns i hur barn hanterar sina symptom. Tre huvudsakliga hanteringsstrategier identifierades: (1) kontrollera sig själv, i vilken barnen riktar in sig mot att reglera sina beteenden, känslor, tankar och sin uppmärksamhet; (2) göra förändringar i miljön, som exempelvis att välja att byta till ett annat rum, förhandla krav som ställs av andra eller välja att vara med vissa personer i stället för andra; och (3) följa symptomen och tillfredsställa omedelbara behov.

Flera barn visade en tendens att uppfatta och hantera adhd konsekvent trots varierande situationer. Däremot var andra barn inkonsekventa i sina uppfattningar och hanteringsstrategier och ändrade dessa från en situation till en annan.

Avhandlingen fann tre möjliga mönster mellan uppfattningar gällande orsaken till symptomen och de tillämpade hanteringsstrategierna: (1) barn som uppfattade sina symtom som en följd av en inre brist hade en tendens att hantera symptomen via självkontroll, (2) de barn som uppfattade sina symtom som ett resultat av problematiska miljöfaktorer hanterade symptomen via att göra förändringar i sin miljö; och (3) barn som uppfattade symptomen som en del av sin personlighet följde sina symptom i stunden.

Dessutom observerades två möjliga mönster mellan den uppfattade unikheten av adhd och hanteringsstrategierna: (1) uppfattningar av symptomen som ett spektrum, en gemensam upplevelse för alla människor i en viss grad, var förknippade med hantering av symptomen via självkontroll; och (2) uppfattningar av symptomen som en unik upplevelse endast för vissa individer, var förknippade med hantering av symptomen via förändringar i sin miljö.

När det gäller föräldrarnas uppfattningar, har avhandlingen påvisat en övergripande uppfattning av symptomen som en källa till svårigheter. Tre typer av svårigheter som föräldrarna såg hade sin orsak i symptomen identifierades. Den första var att hantera vardagliga rutiner som föräldrarna tror är viktiga för familjens fungerande som till exempel att kunna ha lugna middagssituationerna eller hygienrutiner för barnet. Dessa svårigheter var ofta förknippade med

brist på kontroll, förvirring och överväldigande. Den andra typen av svårigheter som föräldrarna uppfattade orsakas av barnets symptom var att hantera andras klagomål, som exempelvis när pedagoger i skolan ringer hem för att berätta om konflikter barnet har hamnat i eller när föräldrar till andra barn utrycker kritik mot barnets uppförande. Dessa svårigheter var ofta relaterade till skam hos föräldrarna. Den tredje typen av svårigheter var att kunna implementera personliga värderingar och livsregler. Dessa regler och värderingar var till exempel att komma i tid, att barnet ska uppföra sig artigt, att föräldrar bör garantera barns säkerhet, eller att syskon ska vara trevliga och generösa mot varandra. Uppfattningen av symptomen som en källa till dessa svårigheter förknippades med känslor av sorg och skuld.

Forskningen har även visat att föräldrarna uppfattade att barnets adhd-relaterade beteenden är ett resultat av en biologisk brist i hjärnan. Beteenden sågs inte som ett resultat av brist på motivation eller barnets egen agenda utan ett resultat av en oförmåga hos barnet. Föräldrarna uppfattade även barnets behov som annorlunda än andra barns.

Föräldrarnas uppfattningar av barnets symptom som en källa till svårigheter och som ett resultat av en biologisk brist hos barnet var förknippade med strategierna föräldrarna tillämpade för att hantera sina svårigheter.

För att direkt hantera barnets adhd-relaterade beteenden anpassade föräldrar sina egna båda proaktiva och reaktiva beteenden gentemot barnet. Anpassning av proaktiva beteenden syftade till att förhindra eller förebygga symptomen genom till exempel att vara extra tydlig och upprepa instruktioner, förbereda barnet inför nya aktiviteter, och undvika att ställa krav. Föräldrarnas reaktiva beteenden vid adhd-relaterade beteenden syftade till att stödja barnet att rätta till sitt beteende. För att kunna hantera sådana beteenden sökte föräldrar aktivt kunskap om metoder i böcker, på Internet och tog kurser inom vården.

Även föräldrarnas hantering av negativa känslor mot sitt barn präglades av uppfattningen att symptomen var ett resultat av en biologisk brist och oförmåga hos barnet. Tre sätt att hantera sina negativa känslor mot barnet kunde identifieras. För det första, genom att uppfatta sitt barns beteendeproblem som ett resultat av ett biologiskt funktionshinder ersattes känslor av ilska och irritation med empati och medlidande. För det andra, genom att ha en diagnostisk etikett uppstod en skillnad mellan barnet och etiketten, vilket gjorde den till en legitim syndabock att rikta in sina negativa känslor på. Det tredje sättet föräldrarna hanterade negativa känslor på var en process som kan betecknas som ’förvärvande av ett pedagogiskt avstånd’. Genom att fokusera på de pedagogiska komponenterna i problematiska situationer får problemet en teoretisk dimension och den känslomässiga komponenten i föräldrarnas reaktion minskar.

Föräldrarnas hantering av andras kritik över barnets beteenden, liksom den relaterade skam de kände i samband med kritiken, var genom att informera andra om den formella diagnosen. Detta gjordes som en upplysning om att de

har andra förutsättningar som föräldrar. Genom att berätta om diagnosen förmedlar de att 'givet omständigheterna gör jag ett rätt bra jobb' vilket leder till att kritik ändras till stöd och skammen till känslor av stolthet och egenvärde. Det var emellertid inte alltid som föräldrar valde att informera andra om sitt barns diagnos, även när de möttes med kritik. Att informera andra om diagnosen gjordes endast när föräldrarna upplevde förtroende gentemot andra vuxna och förväntade sig en förstående och empatisk reaktion.

En sista strategi som föräldrarna tillämpar är att ifrågasätta och omförhandla sina familjeregler och värderingar. Till exempel, flera föräldrar berättade att värderingar som de tidigare hade, som att familjen ska äta middagar tillsammans, att barn ska ta ansvaret för städningen av sitt rum eller att man ska äta med bestick blev ifrågasatta och omdefinierade. Under den processen ställer föräldrarna sig frågan 'hur viktig är regeln eller värderingen för mig i relation till mitt barns behov och förutsättningar?' för att kunna prioritera och utvärdera reglerna de kan tänka sig att kompromissa om.

## Diskussion

Avhandlingen har både teoretiska och kliniska implikationer. Teoretiskt bidrar den till vår förståelse av samspelet mellan individers uppfattning av sin adhd och deras hantering av symptomen. Avhandlingen belyser också att hanteringen av adhd kan ses som en lärandeprocess, i vilken barn och föräldrar lär sig om adhd och skapar en personlig mening av vad adhd innebär för dem. När barn och föräldrar uppfattar symptomen på ett visst sätt hanterar de dessa utifrån dessa uppfattningar. Konsekvenserna av deras hantering utgör en återkoppling för giltigheten av dessa uppfattningar. Via hanteringsprocessen utvärderas befintliga föreställningar om adhd och nya uppfattningar skapas. Det är dock viktigt att poängtera att barn och föräldrar även lär sig om adhd på andra sätt, via till exempel information från bekanta, från vården, böcker eller Internet. Resultatet illustrerar emellertid det informella lärandet som sker via hanteringsprocessen. På den kliniska arenan är resultatet viktigt eftersom det belyser variationen mellan barn i hur de uppfattar olika aspekter relaterade till sina symptom och tillämpade hanteringsstrategier. Dessa variationer bör beaktas i samband med utvecklingen av interventioner som syftar till att hjälpa barnen. Avhandlingens identifiering av barns olika symptomuppfattningar kan utgöra en grund för utvecklingen av instrument som kan användas i det kliniska arbetet för att få kunskap om barnens egna perspektiv på ett systematiskt sätt.

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