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Young people's perceptions of and coping with their ADHD symptoms: A qualitative study

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Abstract:

Purpose: This study aimed to explore how young people with ADHD perceive and cope with their ADHD symptoms in the context of their everyday life. The research also explores relationships between types of perceptions and types of coping.

Method: A qualitative, inductive approach using individual semi-structured interviews to elicit and analyse young people's perceptions of and coping with their ADHD symptoms.

Results: Analysis of interviews with 14 young people has shown a variety of perceptions regarding the mechanism behind the ADHD symptoms. Three types of perceived reasons for the ADHD symptoms were found: because there is something wrong with me, because there is a mismatch between me and the environment, because this is my personality. Variation was also found regarding the perceived threat of the symptoms. The results identified three ways of coping with symptoms: following the symptoms, changing the environment, controlling oneself. A possible relationship between type of perception and type of coping was identified.

ABOUT THE AUTHOR

Noam Ringer In my research I am interested in processes of self-management and coping among children with ADHD and their parents. More specifically, how do children with ADHD and parents to those children experience, perceive and cope with the child's ADHD-symptoms in daily life. The research reported in this paper is used for the development of an intervention program aiming to increase self-management skills in young people with ADHD. In addition to my work as a researcher, I work as a clinical psychologist, specialized in children and adolescents with neurodevelopmental disabilities.

PUBLIC INTEREST STATEMENT

Attention Deficit Hyperactivity Disorder (ADHD) is a diagnosis characterized by severe difficulties maintaining attention, coupled with impulsivity and hyperactivity. The negative implications of ADHD on children's everyday functioning have been demonstrated by numerous studies. This study aims to explore how young people with ADHD perceive and cope with their ADHD in the context of everyday life. An analysis of interviews with fourteen children with ADHD has showed a variations of perceptions regarding the mechanism behind the ADHD-symptoms. Three types of perceived reasons for the ADHD-symptoms were found: "because there is something wrong with me", "because there is a mismatch between me and the environment", and "because this is my personality". The analysis indicates three ways to cope with symptoms: accepting the symptoms, changing the environment, and controlling oneself. A possible relationship between type of perception and type of coping was identified. This study highlights the importance of identifying children's perceptions of their ADHD in order to understand their attempts to cope with it.

Conclusion: Young people with ADHD perceive and cope with their symptoms in various ways. Perceptions of and coping with ADHD may relate to each other. This study highlights the importance of identifying young people's perceptions of their ADHD in order to understand their attempts to cope with it.

Subjects: ADHD & ODD in Children & Adolescents; Stress in Children & Adolescents; Disability

Keywords: ADHD in children; coping; perceptions; lived experiences; qualitative method

1. Introduction

Being a child living with Attention Deficit Hyperactivity Disorder (ADHD) means living an everyday life full of challenges. ADHD is a diagnosis characterized by severe difficulties maintaining attention, coupled with impulsivity and hyperactivity (American Psychiatric Association, 2013). The inattention component can be manifested in making careless mistakes, not seeming to listen when directly spoken to, daydreaming, distractibility, and difficulty focusing on a single task (American Psychiatric Association, 2013). Symptoms of hyperactivity can be expressed as fidgeting, talking excessively, and restlessness (American Psychiatric Association, 2013). Though these behaviours are also observed in typically developed children, they are categorized as a disorder when they persist over time, interfere with the child's functioning, and are manifested in a range of environments (American Psychiatric Association, 2013).

The implications of ADHD on children's everyday functioning has been demonstrated in several studies. In the academic context, for example, children with ADHD have difficulties remembering and applying knowledge, as well as organizing, completing, and returning assignments (Dupaul, Morgan, Farkas, Hillemeier, & Maczuga, 2016; DuPaul, Morgan, Farkas, Hillemeier, & Maczuga, 2018; Efron et al., 2014; Kent et al., 2011, Loe & Feldman, 2007). In addition, children with ADHD have difficulties adjusting their behaviours to what is appropriate in the classroom, and often have disciplinary problems (Conners, Sitarenios, Parker, & Epstein, 1998,Reid, Trout, & Schartz, 2005). In the context of peer relationships, children with ADHD experience more conflicts with peers, feel that they are rejected more often than others, and develop fewer dyadic friendships (Aduen et al., 2018; Heiman, 2005; Hoza, 2007). Within a family context, ADHD is associated with an increased likelihood of parent-child arguments, anger, and negative communication (Chang & Gau, 2017; Edwards, Barkley, Laneri, Fletcher, & Metevia, 2001), as well as impaired relationships with siblings (Mikami & Pfiffner, 2008). Furthermore, research has shown a strong association between ADHD and symptoms of anxiety, depression, and self-rated lower well-being (Biederman, Newcorn, & Sprich, 1991; Pliszka, 2003; Schatz & Rostain, 2006).

Considering the negative consequences of ADHD on children's well-being, together with its relatively high worldwide prevalence rate of approximately 5% (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007,Willcutt, 2012), there is a great need to understand the nature of the relationship between the symptoms of ADHD and its psychosocial implications.

According to Lazarus and Folkman's transactional stress-coping theory, an important aspect to consider in order to fully understand the psychosocial impact of a health-related condition is the individual's appraisals related to the condition they live with (Lazarus & Folkman, 1984). This perceptual-cognitive approach suggests that as individuals confront particular stimuli (e.g. bodily sensation, stimuli within the environment) they form beliefs or appraisals of the stimuli; appraisals that in turn guide the formation and selection of coping strategies. The model distinguishes between two kinds of appraisals: primary and secondary. In the process of primary appraisals, the individual assesses the personal meaning of the event: what does the event mean for my well-being? This process can lead to one of three possible reactions based on the individual's interpretation of the event: the evaluation that the event has positive meaning (e.g. the event is

a challenge that means personal growth), which will lead to positive emotions; the evaluation that the event is neutral, which will not have any emotional effect on the individual; and the evaluation that the event has a negative or threatening meaning for the individual, which will result in feelings of irritation, frustration, anxiety, anger, or grief. Secondary appraisals include the individual's assessment of possible strategies for coping with the event. According to the model, there are two major functions for coping. The first means to deal with the problematic event itself, and involves attempts to alter the stressor, while the second targets the elimination of the negative emotional reaction related to the event (Lazarus, 1993; Lazarus & Folkman, 1984).

Based on this perspective, it can be assumed that it is not the magnitude of the ADHD symptoms itself, but rather the individual's appraisals related to these symptoms and his or her attempts to cope with them, that will determine the psychosocial implications of ADHD.

Several studies have tried to gain an understanding of how young people with ADHD perceive their ADHD symptoms. Wiener and colleagues (Wiener et al., 2012) compared children with ADHD and typically developed children with regard to their perceptions of their self-reported most problematic behaviours. They found that, whereas children with ADHD perceived their behaviours as less controllable, there was no difference between the groups with regard to attributing these behaviours to internal causes. In addition, their results showed that children with ADHD perceive their behaviours as more harmful, stigmatizing, and embarrassing.

In a qualitative study based on interviews with young people with ADHD, it was found that ADHD-related behaviours were perceived as uncontrollable compulsive biological traits, triggered or prevented by various situational factors (Honkasilta, Vehmas, & Vehkakoski, 2016). Another qualitative study found that young children with ADHD perceive their behaviours as a mismatch between themselves and conventional society, a process the researchers described as "unconventional 'square pegs' attempting to fit into the 'round holes' of conventional society". Attempts to fit in included actions such as getting support, adjusting their environment, and attempting to make sense of their condition (Gallichan & Curle, 2008).

In a meta-synthesis of 16 qualitative studies on young people's perceptions of their ADHD it was found that children and adolescents perceive their behaviours, emotions, and cognitions as being uncontrollable and biologically governed, as well as being the reasons for making life difficult (Ringer, 2019). It was also found that young people have ambivalent appraisals regarding their social environment—at the same time that others are perceived as a source of demands, they are also perceived as a source of support. In addition, the meta-synthesis identified ambivalent appraisals related to one's own psychological needs—at the same time that young people with ADHD perceive a need to change themselves and adjust to conventional demands, they also perceive a need to be accepted as they are.

In another systematic review of studies concerning young people's perceptions of their ADHD, the authors searched for predefined dimensions of perceptions, in accordance with the common-sense model of illness representations (Wong, Hawes, Clarke, Kohn, & Dar-Nimrod, 2018). These predefined dimensions of perceptions were: (1) perceptions of how the ADHD symptoms are defined and labelled; (2) perceptions concerning the cause of the ADHD; (3) perceptions of the duration of ADHD; (4) perceptions of the consequences of ADHD on everyday functioning; (5) perceptions regarding control over the symptoms; and (6) the perception of having a comprehensive understanding of the disorder. The review identified variation in the ways children and adolescents perceive their ADHD, a variation in perspectives that has been manifested in all dimensions.

The aim of the following study was to add to the knowledge of how children and adolescents with ADHD perceive and cope with their ADHD symptoms. More specifically, the study aimed to explore: (1) how young people with ADHD perceive their ADHD symptoms, (2) how young people

with ADHD attempt to cope with these symptoms, and (3) relationships between the ways young people with ADHD perceive their ADHD symptoms and their strategies for coping with these symptoms.

To capture the complexity of children's perceptions of and attempts to cope with ADHD-related symptoms in the context of everyday life, this study applied qualitative research methods, which allow for an open-ended and contextual exploration of phenomena (Saini & Shlonsky, 2012). In addition, this study is based on the assumption that research in which children are the source of information about their life has high methodological validity since it provides first-hand contextual information (Ben-Arieh, 2005; Ben-Arieh, Casas, & Frønes et al., 2014). Such knowledge is valuable from a clinical perspective, and is essential for helping children with ADHD.

2. Method

2.1. Study design

This is a qualitative study, based on semi-structured individual interviews. The methodological approach suggested by Charmaz (Charmaz, 2006) was used as a guide for participants' recruitment, the interview process, and data analysis. This approach suggests an inductive perspective for data analysis, whereby data collection and data analysis are carried out simultaneously in an iterative process, and literature review is done after the data analysis has been completed (Charmaz, 2006). The aim was to make patterns visible and understandable, and to propose a substantive model of young people's perceptions of and coping with their ADHD symptoms. This approach is especially suitable for this study as it emphasizes actions in the context of everyday life and beliefs related to these actions, as well as enables an analysis of processes rather than structures.

2.2. Ethical approval

The study was reviewed and approved by the Regional Ethics Committee in Stockholm; approval number 2016/683–31.

2.3. Recruitment procedure and study participants

Inclusion criteria for the study were young people aged seven to 19 years, who had been clinically diagnosed with ADHD. The reason for this age span is that this is the period in life in which children and adolescents in Sweden typically go to school. To maximize variation in the data, an effort was made to enrol both girls and boys, as well as to include variation in terms of the child's age at the time of the interview and at the time of receiving the diagnosis, any additional neurodevelopmental diagnosis, treatment experiences, form of school, and type of family.

Participants were recruited via school psychologists working in public schools in the city of Stockholm, who informed children with an ADHD diagnosis and their parents about the study and asked if they would consent to being contacted by the author. Parents of potential participants were contacted by telephone and informed about the study's aim and method, as well the conditions of confidentiality and anonymity. An informed consent form was signed by both the participants and their parents prior to the interview. Participants were not offered compensation for their participation.

The study group of 14 participants consisted of six girls and eight boys, aged 8–17. Table 1 describes further characteristics of the children who chose to participate.

2.4. Data collection

The purpose of the data collection was to achieve rich descriptions of young people's reflections on themselves and their behaviours, thoughts, beliefs, and emotions in the context of everyday life. The interview guide (see Table 2) was treated as a flexible tool, and was revised according to the content of the interview.

Table 1. Demographic and clinical characteristics of the study participants

Pseudonym	Age	Age when diagnosed	Type of school	Treatment experiences	Parental arrangement	Number of siblings
Felicia	16	15	Mainstream, no specific extra support	Medication	Divorced	0
Kitty	16	14	Non-mainstream	Medication	Nuclear family	1
Carl	12	6	Mainstream, no specific extra support	Medication	Nuclear family	2
Karolin	16	10	Mainstream, no specific extra support	Medication	Nuclear family	1
Arthur	14	10	Mainstream, no specific extra support	None	Nuclear family	1
Julia	12	5	Mainstream with one-to-one classroom support	Medication	Nuclear family	0
Leo	8	7	Mainstream with one-to-one classroom support	None	Nuclear family	1
Johan	13	9	Mainstream with one-to-one classroom support	Medication	Nuclear family	2
Ellen	12	10	Mainstream with classroom one-to-one support	Medication	Divorced	1
Adam	12	10	Mainstream, no specific extra support	Medication	Divorced	1
William	12	9	Mainstream, no specific extra support	Medication	Nuclear family	1
Amanda	17	14	Mainstream, no specific extra support	None	Nuclear family	2
Christopher	13	13	Mainstream, no specific extra support	None	Nuclear family	2
Frank	8	7	Mainstream with one-to-one classroom support	Medication	Nuclear family	2

Table 2. Sample of initial interview questions
Initial open-ended questions
1. What does it mean for you to have ADHD?
2. How do you know you have ADHD?
3. Have you told anyone about the diagnosis? In what way? What was the context? What were your thoughts about telling about the diagnosis? What did you say? What reactions have you received? How did you react?
4. Can you tell me about a regular day in your life?
Intermediate questions
1. Tell me about (specific everyday activities that the child implies are challenging, such as having dinner together/preparing for school/taking care of your child/helping your child with homework). What do you do? What do you think about? How do you feel? What do you think about your behaviour? Why do you think it is a challenging situation?
2. Do you think having ADHD plays a role in this situation? In what way? Do you think about ADHD when acting that way?
3. Tell me about a specific situation you think works well for you. What does it look like? What do you do? How do you think and feel? Do you think ADHD plays a role here? Why do you think this situation works well?
Concluding questions
1. Do you think it is different for you than for other children?
2. Is there anything you would like to say to other children with ADHD? Do you have some suggestions for them?
3. Is there something else you think I should know in order to understand the way you think about ADHD and what you do so that your life will be as good as you want it will be?

Data collection started in November 2017, and ended in September 2018 when saturation had been reached in terms of the emergence of categories and concepts, after interviews with 14 children and adolescents. Interviews were conducted in places that were convenient to the participants: at their home, at their school, in public libraries, or at the author's office at the university. All interviews were conducted by the author and lasted 20–80 minutes. The interviews were audio-recorded and transcribed verbatim by the author.

2.5. Data analysis

The purpose of the data analysis process was to inductively develop abstract analytic codes and categories from the data, and to suggest a theoretical model describing young people's appraisals related to their ADHD experiences and acts of coping related to these experiences. Coping was considered to be the individual's efforts, such as thoughts or acts, to deal with situations he or she perceives as challenging, regardless of whether these efforts are successful or not. Since the interest of the study was to explore processes of self-management, acts related to medication were not included in the analysis since the assumption was that children are dependent on a parent for taking medication.

The data analysis involved two stages of coding. In the first stage, the line-by-line initial coding, data were broken up into their component parts and properties, and defined by the actions and meanings on which they rested. The initial coding also involved comparative methods in order to search for similarities and differences both within the same interview and in different interviews, a process that led to a refinement of the codes. In the second stage, the focused coding, the most significant and frequent initial codes were selected, organized and synthesized to propose an integrative theoretical conceptualization of the data. Alongside the coding processes, extended notes were written regarding personal reflections and explorations of ideas generated during the coding. These notes were used to direct further data collection and in the construction of a theoretical conceptualization.

In order to increase the validity of the data analysis, internal peer reviews were applied during the interpretation and categorization of data. Peer review was done in the form of four seminars,

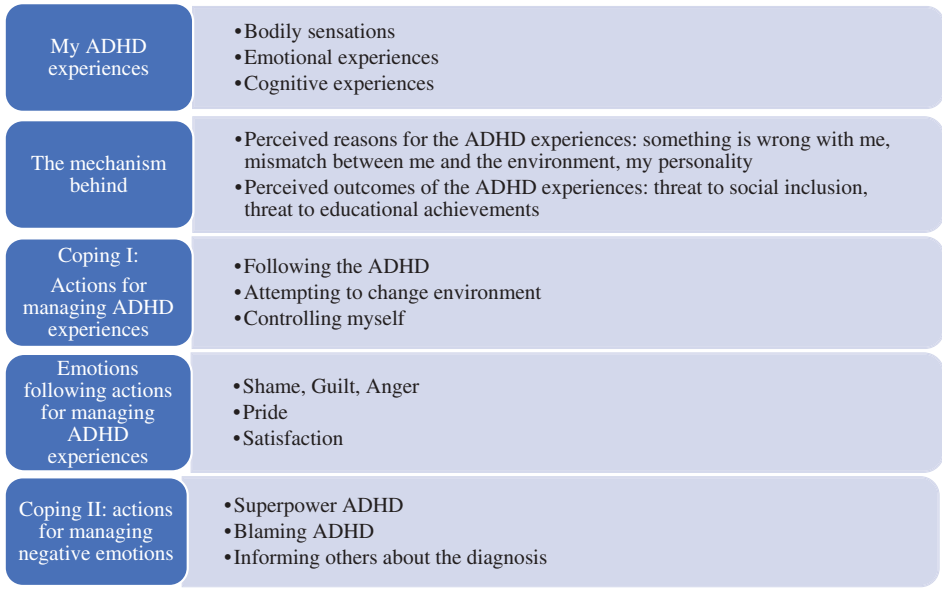

Figure 1. Themes and sub-themes describing perceptions of and coping with ADHD symptoms.

at which reviewers had in advance received a transcript of an interview, as well as the author's interpretations and categorization of this interview. During the seminars, the reviewers gave feedback on the author's interpretations and categorization. The reviewers were both researchers with extensive experience in the field of qualitative research methods, as well as clinical psychologists working at child and adolescent psychiatric clinics.

3. Results

The analysis of the empirical data resulted in a model, consisting of five main themes describing how young people experience, perceive, and cope with their ADHD symptoms. The model also includes the young people's emotions related to these experiences and their reactions to these emotions.

Figure 1 illustrates themes and subthemes describing perceptions of and coping with ADHD-symptoms.

3.1. Theme 1: My inner ADHD-related experiences

The first theme describes experiences the participants perceived as being the symptoms of ADHD. These experiences entailed inner experiences of bodily, emotional, and cognitive sensations, which were described by all participants as irritating or unpleasant. The results show few differences between the participants in terms of the experiences they attributed to their ADHD symptoms. All participants described corporal experiences such as having a strong need to be active, having unpleasant sensations in their body while sitting still which disappear when they are active again. Cognitive experiences that all participants mentioned when describing their ADHD included difficulty paying attention when someone is talking to them, daydreaming, and losing focus. Many of the participants described experiences of being overwhelmed by having a great deal of thoughts in their head. Several participants described experiences of being tired, not having energy, feeling bored, and having difficulty motivating themselves to get started on school assignments.

The following is how two participants described their ADHD experiences:

> 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. (Elsa)

> 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)

In addition, all participants described their ADHD experience by being overwhelmed by strong emotions that they have difficulty regulating or controlling, shifting rapidly from one emotion to another, and being easily irritated. One participant reveals her emotional experience related to her ADHD:

> 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. (Ellen)

3.2. Theme 2: Perceptions of the mechanism behind ADHD experiences

This theme reflects participants' perceptions of the mechanism behind their ADHD experiences, and consists of their ideas and thoughts related to the reasons they have these experiences and the implications of them on their life.

3.2.1. Subtheme 1: Perceptions related to reasons for my ADHD experiences

Variation was found between participants regarding their ways of understanding the reasons for their ADHD experiences. Three models of explanations were identified.

3.2.2. Model of explanation 1: Because there is something wrong with me

According to this model, the participants perceived the source of their ADHD experiences as a stable deficit in their body: having a stable flow within themselves, an inner mechanism that was responsible for the problem. 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 flow, while others believed it could be cured with time. This model of explanation is related to perceptions of being a qualitatively different other: others who do not have ADHD do not have these ADHD experiences, and individuals with ADHD are unique in this way. This model of explanation is clearly expressed by two of the participants:

> 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. (Carl)

> 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)

3.2.3. Model of explanation 2: Because there is a mismatch between me and the environment

Participants with this model of explanation perceived their ADHD experiences as contextual, a result of a vulnerability within themselves which expresses itself in a specific context. This explanatory model emphasizes the context in which the ADHD experiences take place. These contextual conditions included aspects such as characteristics of the physical environment, practical circumstances, and the social milieu. Examples of this model can be found in the following descriptions:

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

> 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. (Karolin)

> 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. (Kitty)

3.2.4. Model of explanation 3: It is a part of my personality

In this model of explanation the participants, three of the older girls, perceived their ADHD experiences as a characteristic in their personality. Being hyperactive, having difficulty paying attention, and being emotionally explosive were perceived like any other personality trait, albeit less appreciated. This model of explanation is expressed very clearly in the following descriptions:

> 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)

> I think ADHD is my personality. Without it, I'd be a whole other person. (Elsa)

The use of these three explanatory models varied both between and within participants. Whereas some consistently used one of the three explanations, others used the three interchangeably.

3.2.5. Subtheme 2: Perceptions related to the outcomes of the ADHD experiences

This subtheme captures perceptions related to the possible outcomes or implications of the ADHD experiences, specifically implying the potential threats it may present in different areas of everyday life. The most distinct areas of life in which the experiences were perceived to possibly have an impact were those of educational achievements and social inclusion. However, variation was found between the participants in terms of the harm that can potential be caused by the impact of the ADHD experiences. Whereas some perceived specific and minor implications of their ADHD experiences for their educational performance, others perceived the implications of these experiences as excessive and significant. These different perceptions are articulated well in the following examples:

> Everything took more time for me and I was always lagging behind, no matter if it was in dance or if it was maths or whatever. And I wasn't really on the same page as everybody else. The whole time. That I didn't really get what was going on, that I had problems when others didn't have any problems. And then, I didn't like myself. (Felicia)

> 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)

Also in the area of social participation, especially with regard to developing friendships, variation was found between the ways participants perceived the potential threat the ADHD experiences might have. While some perceived the experiences as a hindrance to building peer relationships, others perceived them as insignificant in this regard.

Perceptions regarding the implications the ADHD experiences may have for pursuing their interests also varied between participants. At the same time that two of the participants perceived their ADHD experiences as a threat to dancing ballet and riding a motorcycle, activities these participants enjoyed doing in their free time, two of the boys who play football and hockey perceived their ADHD experiences as contributing to their performance.

All participants perceived the implications of the ADHD experiences as insignificant when it came to having a satisfying relationship with their parents. They expressed similar perceptions, involving

the notion that their parents would feel love and devotion towards them regardless of whether they had the ADHD experiences or not.

3.3. Theme 3: Coping with the ADHD experiences

This theme reflects participants' actions in order to manage their ADHD experiences. Three types of reactions were identified, all used by all participants. Which type of coping was applied changed from one situation to another, and seems to be dependent on the characteristics of the situation and the type of the ADHD experience to be managed. However, several participants showed clear tendencies to more often react according to a particular type of coping.

3.3.1. Following the ADHD experiences

This type of reaction is characterized by the participants accepting their ADHD experiences and going along with them. Such actions included activating oneself if having the bodily sensation of needing to be active, following one's daydreaming, putting off homework when not motivated to do it, or letting oneself be overwhelmed by emotions. Examples of such coping can be found in the following:

> 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, or drink and go get more. (Arthur)

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

3.3.2. Controlling myself

This group of acts is characterized by participants' attempts to take control over their ADHD experiences. These acts of self-regulation included, for instance, attempts to control their bodily sensations through relaxation, attempts to control behaviours by putting their hands in their pockets, and attempts to control their thoughts by forcing themselves to think alternative thoughts:

> 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. (Frans)

> 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. That I don't think about anything else, that I don't look at my phone or start defacing something. (Felicia)

3.3.3. Changing the environment

These types of actions are characterized by participants' attempts to change the environment in order to prevent or minimize the ADHD experiences. Such acts included changing the physical environment by, for example, going to another room in order to better be able to focus on tasks or writing on a computer, as well as changing one's social environment by choosing calmer friends or studying with peers who have the ability to motivate you. In the following, one of the participants describes his coping with an overwhelming environment:

> 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)

Changes to the environment also include formulating tasks differently in order to make them more manageable. For example, one of the participants talked about his struggles to motivate himself to do homework. In order to manage his difficulties he divides the task into smaller parts, which he completes one after the other. A more extreme type of changing the

environment entailed avoiding a particular milieu in which the ADHD experiences were frequent. One of the participants reveals:

> 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)

Changes to the environment were made either by taking the responsibility for doing it themselves or by asking for permission or help from others, such parents or teachers. In their attempts to change the environment, many of the participants informed people about their formal diagnosis.

3.4. Theme 4: emotions following coping with the ADHD experiences

The repertoire of emotions accompanying the reactions to the ADHD experiences varied both between and within participants from one situation to another. Identified emotions were feelings of shame, guilt, anger and bitterness, as well as feelings of pride, which some of the participants reported in certain situations. In addition, some of the participants described feelings of satisfaction on some occasions. Feelings of shame, reported by many of the participants, were related to situations in which peers commented negatively on the participants' ADHD-related behaviours, or in situations in which the participants' behaviours led to criticism from teachers. Notably, no participants expressed having feelings of shame in the context of the family. In the following, one of the participants tells about such situations:

> It didn't go well then…my teacher would ask me 'are you really listening?' Or sometimes, so I would learn my lesson, she'd say 'okay, Felicia, now show us the routines' and I didn't know what I was supposed to do. It wasn't fun, I thought it was embarrassing. (Felicia)

Feelings of guilt were expressed in relation to situations in which the ADHD experiences led to inconveniencing or harming someone else, such as damaging another's property or hurting someone emotionally or physically. Feelings of anger were related to situations in which the ADHD experiences were connected to failing in an important task or were perceived as showing weakness. Feelings of anger were also connected to the perception of unfairness at having difficulties one's peers do not need to struggle with.

Feelings of pride were related to situations in which the ADHD experiences were managed in a way that led to others' approval or praise, or when the participants themselves perceived their coping in a positive way in relation to themselves or others. Feelings of satisfaction were related to situations in which bodily sensations of a need to be active were satisfied, as described in the following by one of the young boys:

> In school I usually get hyped up like this. At the breaks I usually run a lot. I think it's nice. I like to run, it feels nice then. (William)

3.5. Theme 5: Coping with negative emotional reactions

This theme captures participants' acts aimed at managing negative emotions related to their reactions to their ADHD experiences. These acts include both thoughts and ideas with regard to their ADHD experiences and behaviours, each act attempting to manage a different negative emotion.

3.5.1. Superpower ADHD

This type of coping seems to target feelings of anger and bitterness, as they were often expressed in relation to these feelings. This subtheme includes statements in which participants, in particular

challenging situations, perceived parts of their ADHD as being super abilities. Such statements included comparing themselves with famous successful figures (e.g. Albert Einstein or a famous Swedish singer) or describing themselves as having special powers.

3.5.2. Blaming ADHD

This subtheme consists of statements in which participants place the blame for disturbing ADHD-related behaviours on a separate entity called ADHD. All participants talked about the experience of blaming ADHD, albeit with different approaches to using the strategy. Whereas for some of the participants blaming ADHD was an effective way to reduce perceived self-responsibility and thus also reduce feelings of guilt, others were strongly critical of not taking responsibility for their own behaviour. Notably, this issue of blaming ADHD versus taking responsibility seems to be a concern among young people with ADHD, as it was a repeated theme, initiated by the participants themselves, in all interviews.

3.5.3. Informing others about the diagnosis

In situations in which the participants were criticized by others for their acts, some of them informed those around them about the ADHD diagnosis. Informing others about the diagnosis may be perceived as a way to prevent social criticism and shame.

3.6. Analysis of relationships between perceptions and acts of coping

As mentioned, perceptions related to the ADHD experiences changed not only between but also within participants. Some participants expressed ideas and beliefs concerning their ADHD experiences that were in some way incoherent with each other, perceiving in some situations these experiences to be the result of unreasonable demands from the environment and in other situations to be the result of a stable deficit, a medical condition within themselves. Incoherence in perceptions was also manifested in the way some of the participants perceived the potential threat of their ADHD experiences, from perceiving these experiences as posing an insignificant threat in some situations to having major consequences for their well-being in others. However, many of the participants expressed a more dominant way of perceiving the mechanism behind their ADHD experiences, referring to it more often and more coherently during the interview.

There was variation both between and within participants with regard to type of coping as well. While some participants interchangeably used all types of acts to manage their ADHD experiences, others were more consistent in having a typical way of reacting to these experiences.

An analysis of possible relationships between the ways the participants perceived their ADHD experiences and the ways they coped with them suggests that those who perceived the reason for their ADHD experiences to be a deficit within themselves, as well as those who perceived them as a threat, tended to cope with these experiences by self-controlling. An example of this relationship is illustrated in the following:

> When I'm tired and hungry and thirsty, then I have like no reactions in my brain, and then I sort of don't think about what I'm doing. And then I'll bang on the table…I've even written on a Post-it note 'don't play if you're hungry or tired or thirsty' because then maybe your reaction will be slower. I've written that on a Post-it note. So I'll remember it. (William)

On the other hand, coping behaviours that relied on attempts to change the environment were related to perceptions of the ADHD experiences as the result of a mismatch between one's own abilities or needs and the characteristics of the environment. This relationship is illustrated in the following:

> …sometimes in the classroom, after a two-hour lesson, when I'm sitting down I kind of get ants in my pants so I go around and talk with a lot of people, but I've gotten a little stress ball I can

> sit and mess around with and I can tell Charlotte, my teacher, that I can't take it anymore and then I can go out in the hallway and take a tablet and work on something there, and when I feel like 'now I can probably work', then I can go in the classroom and continue. (Adam)

In addition, relationships were also observed between perceptions regarding the implications of the symptoms and coping with the symptoms. While perceptions of the symptoms as threatening were related to attempts to control the symptoms, perceiving the symptoms as insignificant to one's well-being were related to reacting according to the symptoms themselves.

4. Discussion

This study is based on young people's own descriptions of their experiences, perceptions, and acts in the context of their everyday life. In-depth interviews with 14 informants were analysed inductively, in order to search for themes and patterns. The aims were to explore how they perceive and cope with their ADHD symptoms, as well as to explore relationships between types of perceptions and types of acts of coping.

The data analysis showed that there is variation between participants with regard to the mechanism they perceive to be behind their symptoms of ADHD, the reasons for and the implications of the symptoms, as well as the coping behaviours they applied in order to deal with these symptoms.

Similar to results from previous studies (Gallichan & Curle, 2008; Honkasilta et al., 2016; Wiener et al., 2012), three types of perceptions regarding the reasons for the ADHD symptoms were identified: the perception of the symptoms as a result of a deficit within oneself, the perception that the symptoms are a result of a mismatch between who one is and one's environment, and the perception that the ADHD symptoms are personality traits.

The data analysis identified three types of acts of coping with the ADHD symptoms: acts aiming to control oneself, acts aiming to make changes to the environment, and acts which follow the ADHD symptoms. Acts of coping were accompanied by emotional reactions. Such emotions included both negative emotions of shame, guilt and anger, as well as positive emotions of satisfaction and pride. Acts of coping with negative emotions were also identified.

However, variation has been manifested not only between but also within participants. While some participants were consistent, using only one explanatory model, many of them used different models over the course of the interview. In addition, several informants expressed contradictory perceptions regarding the threatening implications of the symptoms throughout the interview, perceiving the ADHD symptoms as dangerous to their well-being in one situation and as insignificant to their well-being in another.

This inconsistency in perceptions can be explained in several ways. One explanation may be related to the characteristics of the disorder, as its symptoms may be manifested differently in different contexts (Li & Lansford, 2018; Miguelez-Fernandez et al., 2018; Walerius, Reyes, Rosen, & Factor, 2018). According to this explanation, young people change their perceptions of their ADHD from one context to another since they experience their symptoms differently in different contexts. A second explanation for this inconsistency may be related to the fact that ADHD is a diagnosis constructed by diverse manifestations of symptoms. According to this explanation, different perceptions may be related to different symptoms. A third explanation could be that the changeability in perceptions reflects an ambivalence or confusion in the young people's understanding of the condition. This last explanation has been suggested in other studies (Ringer, 2019), and is reasonable considering the fact that such inconsistency was not manifested by all participants; this may imply that some young people, but not others, experience an ambivalence in their perceptions of the mechanism behind their ADHD symptoms. Further research is needed in order

to further explore the characteristics of this group of young people who inconsistently apply different explanatory models regarding their ADHD symptoms.

According to Lazarus and Folkman's transactional theory of psychological stress and coping (Lazarus & Folkman, 1984), two types of perceptions of ADHD symptoms are related to coping with these symptoms. The first type comprises those related to the threatening implications of the symptoms. While experiencing the symptoms of ADHD in a certain context, the young person evaluates the consequences of these symptoms for their well-being. These perceptions determine the potential threat of the symptoms, and correspond with the primary appraisals in the model. The second type of perceptions are those related to the reasons for the symptoms. Having in mind a model of explanation for the symptoms leads to a repertoire of strategies for coping with them. These perceptions correspond with the secondary appraisals in the model.

As suggested by Transactional Theory, coping with the symptoms of ADHD corresponded with the individuals' appraisals of these symptoms. Participants who have perceived the symptoms as threatening have also expressed attempts to control these symptoms, whereas perceiving the symptoms as insignificant to their well-being was related to accepting and following the symptoms. Appraisals of the reasons for the ADHD symptoms were also related to types of coping: perceiving the symptoms as the result of a disease, a deficit within oneself, was related to self-control; perceiving the symptoms as the result of a mismatch between oneself and one's environment was related to attempts to modify the environment; and perceptions of the symptoms as personality traits were related to accepting and following the symptoms. However, further research is needed in order to establish the suggested relationships between certain types of appraisals and certain types of coping. In addition, further research is needed in order to explore the relationship between certain types of appraisals, certain types of coping, and psychosocial well-being among young people with ADHD.

Even if the main focus of this study was coping with the symptoms of ADHD, the analysis of the interviews has also revealed coping, which is related to the emotions that accompany the initial coping with the symptoms. These emotions were part of a feedback, sometimes as a result of self-evaluation and sometimes as a result of feedback from others. Negative emotions, in their turn, needed to be managed through different coping strategies. According to Transactional Theory, coping is a dynamic process which involves a constant changing of cognitive and behavioural efforts to manage the problem (Lazarus, 1993). The identified themes can be understood as parts of a dynamic process of coping, in which appraisals, behaviours, and emotional reactions, together with social input, interact with each other.

There are some methodological limitations to consider when interpreting the results of this study. All informants who agreed to participate in the study were from a specific sociodemographic segment, having parents with a university education and relatively high economic status. In addition, this was a clinic-referred sample, which means that only young people with a formal ADHD diagnosis participated in the study. Experiences of young people with the symptoms of ADHD without a formal diagnosis were not captured in this study. In order to fully explore the broad repertoire of perceptions of and coping with symptoms of ADHD, there is a need to also investigate these processes in a community-based sample with representation from various socioeconomic groups.

4.1. Implications for rehabilitation

- ADHD among children and adolescents has significant implications for their everyday functioning and well-being.
- Knowledge about how young people with ADHD perceive and cope with their ADHD symptoms is important for optimal rehabilitation.

- It is important to consider the relationships between young people's beliefs regarding their health condition and their attempts to cope with it, in order to help them to make sense of their experiences.
- This study highlights the voices of children and adolescents concerning their own health condition.

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