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To cite this article: Noam Ringer, Jenny Wilder, Max Scheja & Anders Gustavsson (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](https://doi.org/10.1080/1034912X.2019.1596228)

To link to this article: <https://doi.org/10.1080/1034912X.2019.1596228>



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Published online: 01 Apr 2019.



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## Managing children with challenging behaviours. Parents' meaning-making processes in relation to their children's ADHD diagnosis

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### ABSTRACT

This study investigates parents' lived experiences of having a child diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). The aim was to explore parents' meaning-making processes in relation to their children's ADHD with a focus on understanding the impact that receiving a diagnosis had on the parents' perceptions of, and ways of managing, their children's challenging behaviours. Drawing on data collected through semi-structured interviews with 12 parents, we carried out a content analysis of the parents' accounts, producing a range of categories describing different aspects of the parents' meaning-making processes in relation to their child receiving an ADHD diagnosis. Five conceptual categories were identified, describing components of a process of adaptation through which the parents – using the diagnosis as a tool – were able to transform feelings of distress over their difficulties in managing their child's challenging behaviours into feelings of being able to cope with these challenges of integrating the ADHD diagnosis into everyday family life. This research suggests that understanding the long-term processes involved in parents' meaning-making of an ADHD diagnosis is important and can open up a pathway to developing initiatives to support parents in dealing with their child's challenging behaviours in everyday life.

### KEYWORDS

Adaptation; ADHD; children; coping; diagnosis; meaning-making; parenting-stress; qualitative research; self-management

## Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a complex disorder that affects people's everyday lives. The behaviour of children with ADHD is often perceived by parents as challenging to manage, and research has shown that parents of children with ADHD experience more stress than do those of children without disabilities. Learning about the diagnosis when their child is still young may alter parents' perceptions of the child's behaviour and may give them new perspectives on their child and their own parenting. This study explores parents' meaning-making processes in relation to their child receiving an ADHD diagnosis.

ADHD is a neurodevelopmental disorder characterised by hyperactivity, impulsivity, and difficulty maintaining attention, which persist over time, are manifested in a range of social environments, and interfere with the child's functioning and development

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(American Psychiatric Association [APA], 2013). Manifestations of the inattention component of ADHD can include daydreaming, distractibility, and difficulty focusing on a single task, whereas the hyperactivity component can be expressed as fidgeting, excessive talking, and restlessness (Biederman, 2005). The prevalence of ADHD is estimated at 5–7% worldwide, which makes it one of the most common psychiatric disorders in children and adolescents (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007; Willcutt, 2012). The disorder's secondary consequences, such as social, emotional and learning impairments (Wehmeyer, Schacht & Barkley, 2010), together with its relatively high comorbidity with psychiatric disorders such as disruptive behavioural disorders, depression and anxiety disorders (Pliszka, 2003), lead to its profound effect on the lives of the children and their families.

Although the aetiology of ADHD is still unclear (Thapar & Cooper, 2016), twin studies reported a strong genetic effect in the manifestation of the disorder (Biederman, 2005; Rydell, Taylor, & Larsson, 2017). In addition, recent twin studies have also shown that ADHD is better viewed as an extreme of a continuous, rather than as one category, as it is defined in clinical use (Larsson, Anckarsater, Råstam, Chang, & Lichtenstein, 2012). The manifestation and prevalence of ADHD are also associated with various noninherited factors such as pre- and perinatal factors, environmental toxins, dietary factors, and psychosocial adversity (Thapar, Cooper, Eyre, & Langley, 2013). These factors have been conceptualised as nonspecific triggers of an underlying predisposition to ADHD (Biederman, 2005).

Treatments for ADHD include interventions directed at the child such as pharmacological treatments (Reichow, Volkmar, & Bloch, 2013) and cognitive behavioural therapy (Cortese et al., 2015; Daley et al., 2014), interventions directed at parents such as parental education and training (Zwi et al., 2011), and interventions directed at teachers (for example see Veenman, Luman, Hoeksma, Pieterse, & Oosterlaan, 2016).

Substantial research has focused on parents of children with ADHD, particularly with regard to the experience of parenting stress (Theule, Wiener, Tannock & Jenkins, 2011; Li, Jiang, Du, & Coghill, 2016; Pimentel, Vieira-Santos, Santos, & Vale, 2011). Parenting stress is a distinctive type of psychological stress which arises when parents' perception of parenting demands is much higher than their perceived resources for dealing with these demands (Deater-Deckard, 1998). Parenting stress is 'role specific' and a distinct reaction to the specific demands associated with parenthood (Deater-Deckard, 1998).

In a meta-analysis of 44 quantitative studies, conducted by Theule, Wiener, Tannock and Jenkins (2012), it was found that parents of children with ADHD experienced significantly more parenting stress than parents of children without ADHD. The analysis also found that the type and severity of child's symptoms, as assessed by the parents, may be part of the explanation for parents' elevated levels of stress. For example, even if a child's symptoms of inattention had a significant effect on the parents' stress, the greatest contribution to parental stress was the child's symptoms of hyperactivity and impulsivity. Parents of children with ADHD together with conduct problems, such as oppositionality and externalising behavioural problems, have experienced significantly more stress than have parents of children with ADHD who did not have conduct problems. Differences in parental stress between Mothers and Fathers were also investigated. The analysis showed that Mothers and Fathers experienced the same level of the kind of stress that concerns factors within the parent, such as perceived ability, but that Mothers experienced more stress than Fathers

regarding stress related to the parents' perception of the child's characteristics. The authors conclude that considering the well-established fact that parents of children with ADHD experience more parental stress than do those of children with typical development, 'further research on parenting stress and ADHD should focus on the mechanisms of this relationship' (ibid p. 12), as well as parental and contextual factors related to the phenomenon.

Several studies have focused specifically on the relationship between externalising child behaviour and parenting stress. Some scholars have suggested that parental stress should be seen as a cause rather than a consequence of behaviour problems among children with ADHD, raising the assumption that high parental stress may lead to negative parenting practices, which in turn may lead to challenging behaviours in children (Haack, Villodas, McBurnett, Hinshaw, & Piffner, 2016); However, other researchers emphasise the substantial impact of children's behavioural problems on parenting stress, suggesting that the children's problems affect the parenting stress more than vice versa (Mackler et al., 2015). The current study fits within this last approach.

Based on a literature review on the subject, Morgan, Robinson, and Aldridge (2002) suggested that two mechanisms contribute to stress in parents of children with externalising behaviours: (a) parental perceptions of the availability of their resources for dealing with the child's behaviour and (b) parents' perception of their child's behaviours such as selective attention to negative aspects, making negative attributions about these behaviours, and having a lower threshold for tolerating behavioural problems.

In a study of different contextual factors' predictability of parenting stress (Theule, Wiener, Rogers, & Marton, 2011), it has been shown that marital status was a significant predictor, with single parents of children with ADHD experiencing significantly higher levels of distress in comparison to partnered parents. On the other hand, child gender, parent age, and parent education were not correlated with such distress.

Parents' lived experience of having a child with ADHD has also been of interest in considerable qualitative research. Corcoran, Schildt, Hochbrueckner, and Abell (2017) have analysed the results of 73 qualitative studies on the subject and found that parents of children with ADHD experience emotional burden in the form of feelings of exhaustion, isolation, anxiety, irritation, desperation, frustration, anger, powerlessness and helplessness. In addition, the analysis also showed that parents struggled to identify reasons for their children's misbehaviour, to be able to manage it, to make sense of the ADHD label, and to come to terms with the diagnosis. This last process was 'made more difficult by the fact that there are no definitive biological tests but only behaviours to define ADHD, and that many different presentations in children fall within the category of what is referred to as ADHD.' (ibid. p. 344). These results suggest that stress experienced by parents of children with ADHD might also be related to the understanding and meaning-making of the label of the diagnosis.

Therefore, the objective of the following study was to explore parents' meaning-making processes in relation to their children's ADHD. More specifically, we aimed to understand the impact of children's ADHD diagnosis on their parents' perceptions of their children's challenging behaviours, as well as parents' perceptions of their own ability to manage these behaviours in the context of everyday life.

In order to achieve the aims of the study, we used inductive qualitative methods. Inductive qualitative research allows for an open-ended exploration of the complexity of meaning-making processes and enables the revelation of contextual aspects related to

these processes (Saini & Shlonsky, 2012). Understanding the mechanism of parenting stress experienced by parents of children with ADHD is important not only because it has consequences for parents' life quality, but also because of its crucial implications for parents' management of their child's chronic condition (Ryan & Sawin, 2009).

## Method

### *Study Design*

This is a qualitative study, employing semi-structured individual interviews. The methodological approach suggested by Charmaz (2006) was used as a guide for the recruitment, interview process, and analysis of data. This approach suggests an inductive perspective for data analysis, whereby data collection and data analysis are carried out simultaneously in an iterative process (Charmaz, 2006). The aim is to make patterns visible and understandable, and to propose a substantive theory on the meaning-making of ADHD diagnosis among parents whose child has received this diagnosis. This approach is especially suitable for this study as it emphasises actions in the context of everyday life and beliefs related to these actions. This approach is also appropriate as it enables an analysis of actions and processes rather than structures, and the intention here was to explore processes of change with regard to receiving the diagnosis.

### *Ethical Approval*

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

### *Recruitment Procedure and Study Participants*

An iterative theoretical sampling was applied, a process of simultaneously collecting, coding, and analysing data to guide the adjustment of interview question development and subsequent participant recruitment. Inclusion criteria were parents of children aged three to 19 years who had been clinically diagnosed with ADHD. To maximise variation in the data, an effort was made to enrol both Mothers and Fathers, and parents of both male and female children with ADHD, as well as to include variation in terms of the child's age at the time of the interview and at the time they received the diagnosis, any additional neurodevelopmental diagnosis, treatment experiences, and the type of family.

Participants were recruited via school psychologists working in public schools in the city of Stockholm, who informed parents about the study and asked if they consented to be contacted by the first author. Two of the participants were recruited via other participants. Potential participants were contacted by telephone and were informed about the aim and method of the study, as well the conditions of confidentiality and anonymity. An informed consent form was signed by participants prior to the interview. Participants were not offered compensation for their participation.

The study group of 12 participants consisted of four Fathers (three with sons, one with a daughter) and eight Mothers (four with sons and four with daughters). All parents were employed full-time and had an academic education. None of them were members

in an association related to the diagnosis. All children whose parents were interviewed attended mainstream schools and had no additional psychiatric disorders. All parents had only one child diagnosed with ADHD. [Table 1](#) describes further characteristics of the parents and their children.

### Data Collection

The purpose of the data collection was to achieve rich descriptions of parents' reflections on themselves, their behaviours, thoughts, beliefs, and emotions in the context of everyday family life in relation to their child's ADHD diagnosis. The interview guide was treated as a flexible tool, and was revised according to the content of the interview and based on the need to check and refine the conceptual categories (see [Table 2](#)).

The data collection started in November 2016 and finished in August 2017, after interviews with 12 parents, when saturation had been reached in terms of the

**Table 1.** Description Of Sample In Terms Of Characteristics of Family and Child's Diagnosis and Therapy.

	Age of child at time of interview	Age of child when received diagnosis	Other diagnoses besides ADHD	Treatment experiences	Parents' marital status
Arthur's Mother	13 years	9 years	No	Parental educational course	Married
Arthur's Father	13 years	9 years	No	Parental educational course	Married
Karolin's Mother	15 years	10 years	Asperger syndrome	Parental educational course and medication	Married
Philippa's Mother	15 years	15 years	No	Parental educational course and medication	Married
Jacob's Father	10 years	8 years	No	Parental educational course and medication	Married
August's Mother	8 years	7 years	No	Parental educational course	Married
Oliver's Mother	10 years	7 years	No	Parental educational course	Married
Oliver's Father	10 years	7 years	No	Parental educational course	Married
Liam's Mother	11 years	10 years	No	Parental educational course and medication	Divorced – the child lives with her every second week
Alice's Mother	6 years	6 years	No	Parental educational course	Divorced – the child lives with her every second week
Alice's Father	6 years	6 years	No	Parental educational course	Divorced – the child lives with him every second week
Julia's Mother	12 years	4 years	Dyslexia	Parental educational course	Married

**Table 2.** Sample Of Initial Interview Questions.

Initial Open-ended Questions
<ol style="list-style-type: none"> <li>1. Can you tell me about how you came to decide to conduct a neuropsychiatric assessment on your child? What happened that led to this?</li> <li>2. Can you tell me about your reactions when your child had received the diagnosis. What was it like? What did you think and feel?</li> <li>3. Have you told anyone about the diagnosis? In what way? What was the context? What were your thoughts about telling people about the diagnosis? What did you say? What reactions did you receive? How did you react?</li> <li>4. What has happened since your child received the diagnosis?</li> <li>5. Tell me about a regular day in your family life.</li> </ol>
Intermediate Questions
<ol style="list-style-type: none"> <li>1. Tell me about (specific everyday activities that the parents imply 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 are your thoughts about? How do you feel? What do you think about your behaviour?</li> <li>2. Do you think the ADHD diagnosis plays a role in this situation? In what way?</li> <li>3. Tell me about such a situation before your child received the diagnosis. What did you do then? Do you remember what your thoughts were then? How did it feel then?</li> <li>4. Tell me about a specific situation that you think works well between you and your child. What does it look like? What do you do? What do you think about and how do you feel? Do you think the ADHD diagnosis plays a role here?</li> <li>5. Is there a difference between how you do things during the (specific discussed situation) today with the diagnosis and before the diagnosis?</li> </ol>
Concluding Questions
<ol style="list-style-type: none"> <li>1. Do you think your child's ADHD diagnosis has changed your way of thinking about being a parent?</li> <li>2. Does your child's ADHD diagnosis has an effect on the way you perceive yourself? In what way?</li> <li>3. If, instead of the diagnosis, you had received information about your child in terms of specific difficulties such as 'your child has difficulty remembering/planning/taking initiative', do you think it would have been different or the same? In what way?</li> <li>4. Is there something else you think I should know in order to understand how the diagnosis plays a role in your everyday life?</li> </ol>

emergence of categories and concepts. Interviews were conducted in places that were convenient to the participants, at their homes or workplaces, as well as the first author's office at the university. All interviews were conducted by the first author and lasted 40–80 minutes. The interviews were audio-recorded and transcribed verbatim by the first author.

### **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 to explain processes related to parents' perceptions of self in relation to their child's diagnosis. 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 was done with the help of questions regarding the participants' actions and the meaning of these actions. These questions included: 'What process is at issue here?', 'How does this process develop?', 'How does the participant think and feel while involved in the process?' (Charmaz, 2006, p. 127). 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 of the

data analysis, the focused coding, the most significant and frequent initial codes were sifted, organised and synthesised to propose an integrative theoretical conceptualisation 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 conceptualisation.

### ***Researchers' Positioning and Reflexivity***

Our personal positioning in the course of carrying out this research was subject to reflection during the whole research process. This study forms part of the doctoral dissertation of the first author, who also works as a clinical psychologist at a public child and adolescent psychiatric clinic in Stockholm, work which includes conducting neurodevelopmental evaluations and clinical diagnostic procedures. This position may have had an impact on the research process. In order to increase the validity of the data collection and analysis, repeated meetings were held between the authors in order to discuss data collection and different possible interpretations of the data. In addition, the data interpretation has also been checked and discussed with two different panels of researchers in the field.

### **Results**

The data analysis identified five conceptual categories, which together can be understood as components of a process of adaptation. The first category, representing the parents' experiences of the child's behaviour as challenging and difficult to understand and manage, is seen as a starting point for an adaptive meaning-making described by the four last categories: 'Having an explanation and understanding child's needs', 'Adjusting oneself', 'Processing emotions', and 'Negotiating an integration of ADHD with everyday life'. Typically, the meaning-making is influenced by the parents' perception of the child's ADHD diagnosis. In fact, the adaptive character of the parents' meaning-making seems to be closely connected to their understanding of the diagnosis. In the course of the process, the parents' adaptive meaning-making follows the experience of the child's difficulties with the diagnosis as a kind of mediating factor. However, this does not mean that, at the moment the parents first receive information about the diagnosis, the process is divided into a phase before the diagnosis dominated by the parents' experiences of difficulties and a phase after the diagnosis when the adaptive meaning-making takes place; on the contrary, both the parents' experience of difficulties and their adaptive meaning-making seem to take place over and over again during the course of the process, but the adaptive meaning-making seems to receive much of its power from the parents' gradual appropriation and understanding of their child's diagnosis.

### ***Experiencing Difficulties***

This category describes parents experiencing difficulties in relation to their role as parents, in relation to their child, and in managing demands and expectations, with regard to both self-expectations and expectations from others. The parents' experiences



of difficulties varied, but all were related to their child's disruptive behaviours, and can be described by the following subcategories:

### *Difficulties in Managing Everyday Routines*

This category included experiences of not being able to manage everyday family procedures that the parents believed were necessary in order to have a functioning family life. Such difficulties included, for example, preparing the child for school, having family dinners with the whole family sitting at the table, and performing the child's hygiene. Feelings related to such difficulties were overwhelming and confusing, and were associated with a lack of control.

### *Struggle to Manage Demands From Others Outside the Family*

All parents expressed having difficulty managing other people's expectations and demands. Perceived expectations from teachers included, for example, that the parents should ensure that the child would sit still in the classroom, would not create a disturbance, and would not come into conflict with others. Many of the parents experienced that it was difficult to manage such demands as they were not at school during the day and had no control over the potentially problematic situations. Liam's Mother talked about the expectations she perceived from his teachers:

I think the school's goal the whole time has been to try to be able to handle it, and when they didn't feel like it was working anymore they spoke up. And that's why, as a parent, there were quiet periods and then here comes a huge problem. And then you think...now we've figured out what we're going to do, but then there are problems again...And that's why it's hard as a parent to know what you're supposed to do. You feel powerless. You don't have a solution either.

Demands from other children's parents, which the parents were confronted with when the child ended up in conflict with those children, were particularly difficult to manage emotionally. All parents described that they perceived demands 'to foster their child'. This struggle with others' demands was often related to the experience of shame and a lack of control.

### *Difficulties in Implementing Personal Values*

All parents had a clear picture and expectations of how they would like to have things in their family, how they would like to be as parents, what values they had, and what they considered important. Such values included, for example, the ideas 'I should have positive emotions towards my child', 'my child and I should be like each other', 'I should make my child happy and satisfied', 'siblings should be nice and generous to each other', and 'I'm responsible for my child's safety'. When they were not able to implement such personal values, parents experienced sorrow and guilt.

### *Not Being Able to Understand and the Search for Explanations*

All parents expressed having difficulty understanding the reasons for their child's disruptive behaviours. Parents described this experience of lacking understanding, not being able to 'categorise' the child's disruptive behaviours, as frustrating and distressing. By continually testing and evaluating alternative explanations, the parents hoped to find

one valid, stable and useful explanation. The repertoire of parents' possible explanations for their child's disruptive behaviours was prominent.

Several parents also tried to explain their child's behaviours in terms of 'I'm doing something wrong', looking for personal responsibility in the child's difficulties, explosive behaviour and dissatisfaction. Others explained the situation in terms of family processes such as conflicts between parents, the arrival of a sibling, being the only child, or being young parents. Some parents used themselves as a reference in order to understand their child, trying to recall how they were as children, to find an explanation based on their own experience. August's Mother articulated this process of searching for explanations:

You have a lot of thoughts when you see that your child has deviating behaviour in certain things. So I had a lot of criticism for myself, or tried to search within myself.

Other parents applied explanations related to factors in the child's social environment, such as school circumstances and social norms involving different expectations for girls and boys and what is right and wrong. This situation of not being able to understand was characterised by parents actively searching for knowledge about their child's behaviours in other contexts such as at school or when they were with other adults. Parents also sought knowledge by talking with other adults, such as partners, friends or other family members, and seeking information in books and on the Internet. This process of searching for a valid explanation, obtrusively bearing in mind different hypotheses, was described by parents as exhausting and confusing.

### *Having an Explanation and Understanding the Child's Needs*

All parents experienced the diagnosis as a clear threshold to a new way of interpreting their child's behaviours and needs – beyond this threshold, the validated explanation for the child's problematic behaviours ought to be a biological disability: my child's ability is qualitatively poorer than that of other children, and it has a biological explanation. In addition, the diagnosis has been used as a standard for anticipating the child's needs as special, qualitatively different than those of other children. This change in interpretation of the child's needs and difficulties led to changes in parents' perception of self, becoming that of a parent of a child with a disability. Many of the parents had been introduced to this new explanation model at the neuropsychiatric assessment or when their child received the diagnosis. Some parents had learnt about the new way of understanding their child's needs and behaviours via courses organised by the healthcare clinic. Actively searching for information in books and on the Internet was also a source for learning about the new standard of interpretation. This process of learning about the new 'model of understanding' was more frequently expressed by parents of children who were relatively newly diagnosed, or when describing the time during and just after the neuropsychiatric assessment. As Arthur's Mother described:

It's quite important that it's about a diagnosis. That's important to me...I think it has great significance. It has greater weight and credibility. Because if you say about someone that he's forgetful, or he has problems remembering things, then you think yeah, just straighten up...it's just a matter of focusing. But here I understand it's not his fault, if you can put it that way. It's not just that he's not concentrated; he just isn't able to take in more than one thing at a time.

## ***Adjusting Oneself***

This category, describing behavioural changes in parents following the diagnosis in order to manage their child's ADHD symptoms, consists of four subcategories:

### ***Adjusting Proactive Behaviours Towards Their Child***

All parents experienced using the diagnosis as a guideline for regulating their own proactive behaviours towards the child in situations such as planning and preparing everyday activities. Parents described conscious decision-making with regard to everyday activities, such as presenting new activities to the child and making demands. By explicitly thinking about the diagnosis, parents adjusted their way of speaking to their child, the content of what they said, and the use of assistive pedagogical tools. Liam's Mother describes how she adjusts her proactive behaviour towards her son by thinking about the diagnosis:

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

### ***Adjusting Reactive Behaviours Towards Their Child***

Parents also used the diagnosis in regulating their reactive behaviours towards their child when the child's behaviour needed to be adjusted or corrected. Reactive behaviours included, for example, explaining to the child instructionally, in a pedagogical manner, what he or she should do, or even taking a conscious decision not to react.

### ***Acquiring Knowledge and Becoming an Expert***

Many parents described an ongoing process of actively searching for knowledge about the diagnosis. This search for knowledge was done mainly in order to find help in how to manage everyday life challenges. The knowledge parents referred to was mainly theoretical and specifically related to ADHD in children, in the form of self-help books and formal courses.

## ***Processing Emotions***

This category describes processes of parents' emotional reactions towards their child related to receiving the diagnosis.

### ***Regulation of Negative Emotions Towards Their Child***

The diagnosis played a role in parents' regulation of negative emotions towards their child in three ways. Firstly, by interpreting their child's behavioural problems in terms of his or her disability, they could replace their feelings of anger and irritation with feelings of empathy and compassion. Secondly, by having a diagnosis, a separation emerged between the 'child' and the 'symptoms', making the diagnosis a legitimate scapegoat towards which to target negative emotions. A third way the diagnosis was used in the regulation of negative emotions was by shifting feelings of frustration and the inability

to solve problematic situations towards feelings of decisiveness and action. This last process can be labelled 'acquiring a pedagogic distance', meaning that when the parents focus on the pedagogical components of problematic situations, the problem takes on a theoretical dimension and the emotional component in the parents' reactions decreases. Being able to regulate negative feelings towards one's child was expressed by parents as a relief and as potentially empowering.

### *Feelings of Guilt*

With regard to the diagnosis and the new explanatory model of understanding the child's disruptive behaviour as a result of a biological inability, parents retrospectively evaluated the way they had managed their child's behaviours prior to the diagnosis. For several parents, this process of self-revaluation had led to self-criticism, and feelings of guilt and regret.

### *Managing Shame by Using the Diagnosis in Relation to Others*

In social situations in which parents felt criticised and blamed by other adults, situations often coupled with feelings of shame, the diagnosis was perceived as a communicative tool for minimising or even preventing such criticism. Parents believed that by informing other adults about the child's diagnosis, they were positioning themselves as parents with different parental prerequisites, on which different standards should be applied when being evaluated. By communicating that 'under the circumstances' they were 'doing a pretty good job', feelings of shame transformed into feelings of pride and self-worth. However, it was not always that parents chose to inform people about their child's diagnosis, even when they were met with blame and disapproval. Informing people about the diagnosis was done only in circumstances in which the parents experienced trust towards the other adult and believed the reaction would be understanding and empathetic. August's Mother tells us about her experience of telling other parents about her son's diagnosis:

...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. It feels like everybody's against you...It felt like they have no idea...then I suggest that I call the people I want to talk to...now I can move freely... now I can say hi to the parents I've told about his ADHD, I mean say "Hi" like normal...I don't have to hide or make excuses for myself or for him. And that feels damned good.

### *Negotiating an Integration of ADHD with Everyday Life*

This category describes the process of negotiating the meaning of ADHD within the family's everyday context and demands, the parents' personal values, and life events. This category refers to 'negotiating' as parents reflected upon these experiences as if they were engaged with an 'inner dialog' in order to reach a compromise between personal aspects of life that conflicted with the diagnosis. Finding a balanced integration of ADHD with life was the process parents were mostly engaged with, and was often characterised by rumination, insecurity and distress. In this category, three subcategories were found:

### *Seeking Normalcy in the Relationship With Their Child*

A common theme expressed by all parents was the wish to maintain a 'normal' relationship with their child and be a 'regular' parent. The meaning of being a 'regular' parent varied between the parents, and consisted of experiences of 'not thinking too much', 'being less conscious about their behaviours', 'being spontaneous', and 'being less pedagogical'. One way of doing this was by limiting the validity of the diagnosis to unproblematic situations. In situations in which children did not behave in a deviant way or in a way the parents perceived as problematic, the parents did not think about or reflect upon the diagnosis. In these situations they regarded their children as quite ordinary, making them any kind of parent to any kind of child. Another way of reaching normalcy in their relationship with their child was by making a conscious decision not to adjust themselves to the diagnosis, even in more vulnerable situations, and instead 'take the consequences'. Oliver's Father described this experience:

Right now we're playing a strategic game, a kind of card game, 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 going to hope he loses because I want to win.

*Integrating ADHD with everyday demands and parenting values:* Interpreting the child's behaviours and needs in terms of biological disability sometimes came into conflict with everyday demands and other parenting values such as the importance of getting ready for school on time, being well-mannered, doing homework, being generous, and maintaining equality between siblings. This subcategory reflects parents' attempts to negotiate between their parenting values, everyday demands and ADHD.

### *Integrating ADHD With Life Circumstances*

Several parents experienced attempting to integrate ADHD with life circumstances, such as sickness, divorce, and moving to a new place. This subcategory reflects parents' attempts to integrate their understanding of ADHD, their child's needs and the management of disruptive behaviours, and such life circumstances.

## **Discussion**

The aim of the current study was to explore parents' meaning-making processes in relation to their children's ADHD, specifically with regard to the impact of the diagnosis on parents' perceptions of both their children's challenging behaviours and of their ability to manage these behaviours in the context of everyday life.

As described in the result section, the child's diagnosis can be seen as an important mediating factor in a process of adaptation that the parents entered as a result of experiencing challenging everyday problems. These problems were all related to their children's behaviours, and were of different types. The first type was more practical and was related to the parents' perceived ability to manage daily routines and demands. The second type involved the parents' perception of not being able to understand and categorise their own child's behaviours. These two problems were of course mutually related: lacking a valid explanation and having difficulty understanding, according to the parents, led to the experience of not knowing how to deal with their child's challenging

behaviours or how to manage everyday routines. These two types of difficulties led to extensive distress caused by the cognitive endeavour of seeking out and testing different explanation models for the child's challenging behaviours, and the emotional distress of failing to manage one's parenting role with regard to daily family routines and being a parent who does not understand his or her own child. The third type of problem was related to the experience of not being able to manage others' demands or deal with criticism from others. This type of difficulty also meant a great deal of distress for the parents, cognitively in terms of problem-solving procedures and emotionally by causing them to feel ashamed and blamed.

Upon receiving the child's diagnosis the parents' meaning-making seems to have drastically changed and taken an adaptive turn. One aspect of this was that the parents' experience of having received a valid and stable explanation for their child's challenging behaviours and needs. The diagnosis was perceived as a clear threshold, a border-crossing as one of the parents described it, to be able to interpret their child's problematic behaviours in terms of biological disability. This new explanation model was useful not only in terms of understanding but also in terms of predicting potentially challenging situations. Parents' perceived ability to manage everyday problems increased, and they established attempts to adjust their behaviours towards their child. They perceived that, together with the diagnosis, they had received tools to manage their parenting roles. The 'biological disability' explanatory model also had consequences for parents' emotional processing. Negative emotions and irritation towards their children, which had been present prior to the diagnosis when they had interpreted disruptive behaviours as unwillingness, were transformed into positive feelings of compassion and empathy. Since irritation and other negative emotions towards the child were in themselves a source of psychological distress and guilty feelings, this change meant a decrease in distress for the parents. In the same way, feelings of shame and distress related to the parents' perceived criticism from others became more manageable when they used the diagnosis. This manageability has two parts. Firstly, parents perceived their parenthood as more challenging in terms of preconditions, which allowed them to evaluate themselves in relation to other standards than for parents of typically developed children. This led to the parents perceiving themselves more positively and as doing the best they could under the circumstances. The second part of this manageability relates to parents' possibility to communicate the situation to others. By having the option to talk to others about the diagnosis, they felt less distressed when facing the risk of being criticised and blamed for the child's behaviours.

However, the parents' experience of distress had entered a new arena, and now after the diagnosis the distress shifted to the challenge of incorporating ADHD into everyday life. A major challenge and source of distress was related to the parents' attempts to achieve normalcy in their relationship with their child; 'normal' being defined by how they themselves believed parenting should be. It seems that they strived to reach a balance between being the parent of a child with a disability and being a 'regular' parent. To them, being the parent of a child with ADHD meant being conscious and rational, analysing behaviours, understanding mechanisms, and needing to adjust themselves to the child's special needs. On other hand, the 'regular' type of parenthood meant being less theoretical or rational, being spontaneous, using their intuition and relying on their gut feeling. Integrating these two kinds of 'parenthood' was perceived as challenging and distressing, as they had to learn that merely intuitive parenting was not sufficient.

Integrating the new model of interpretation of the child's challenging behaviours as a result of biological disability with the demands of everyday life was also a source of psychological distress. Although the parents now perceived that they understood the reasons and had knowledge about how to adjust themselves, they still had other parenting role demands and life circumstances to negotiate.

As mentioned earlier, the parents' perception and understanding of the ADHD diagnosis appeared as quite a dramatic moment of change to them. However, the importance of the diagnosis in their meaning-making most likely took place over a long time, during which they gradually discovered new aspects of distress and life challenges and consequently searched for new ways of understanding their parenthood and responsibility for their child, drawing on new reflections on what the diagnosis could mean. There seem to be characteristics of the meanings of the diagnosis that the parents perceived quite similarly, for example the fact that the child's difficulties appeared as a biologically based problem against the background of the diagnosis. At the same time, we also found differences in the parents' concrete use of the diagnosis in explaining the particularities of their child's problems and resources.

The categorisation of the results presents a pattern that may perhaps be better understood against the background of Lazarus and Folkman's transactional theory of stress and coping (1984). According to this theory, people constantly engage in interpreting their environment in order to evaluate its threatening or harmful potential on their well-being. Every time a transaction (encounter) between an individual and external environment occurs, two types of appraisals take place: primary and secondary. Primary appraisals are those interpretations the individual makes in order to evaluate the significance of the event for his or her well-being. Primary appraisals entail two aspects. The first is related to the nature and characteristics of the environmental event, for example how familiar or ambiguous the event is to the individual. The other aspect primary appraisals are based on is the individual's personal agenda, which includes aspects such as his or her values, goals, beliefs, desires, expectations, and personal needs. The outcome of a primary appraisals could be a judgement of the external event as insignificant, positive, or threatening. Interpreting the event as threatening to the individual's personal well-being results in emotional and physical reactions in the form of negative emotions such as stress, anxiety, frustration, and anger. In order to deal with these aversive reactions, the individual engages in secondary appraisals, which are based on interpretations of his or her own ability to deal with the threatening event. In other words, secondary appraisals aim to evaluate the possibility of coping with the situation.

Following Lazarus and Folkman's theory, a possible interpretation of the findings presented in this study is that the diagnosis influences parents' interpretation of their child's behaviours (the external event) in several ways. Firstly, by receiving the diagnosis, unlike the multiple explanations the parents had applied to their child's challenging behaviours, they could now apply a single interpretation model, which made the behaviours less ambiguous and easier to perceive. Secondly, explaining their child's behaviours in terms of biological inability, as opposed to interpretations of these behaviours as a lack of motivation and disobedience before receiving the diagnosis, was less threatening to the parents' beliefs about themselves and their parenting values. A third way the diagnosis may have had an effect on the parents is by increasing their perceived ability to solve problems. If prior to receiving the diagnosis they had been overwhelmed by the many different ways to deal

with their child's behaviour, the diagnosis allowed them to focus on a more specific repertoire of coping (parents' proactive and reactive behaviours towards their child). In addition, the diagnosis made it possible for a more efficient search for and acquisition of knowledge about the specific condition of ADHD.

The implications of the results here concern both parents of children who have received an ADHD diagnosis, as they increase our understanding of the possible impacts of the diagnosis on their everyday life, and for practitioners who work with these families. As the results suggest, the process of meaning-making of a diagnosis is a long-term process which changes its focus from searching for understanding to making adjustments and integrating the diagnosis into everyday family life. Understanding these processes may allow for more integrative help after receiving the diagnosis.

However, considering the homogeneity of the research participants in terms of educational level, all of them being highly educated, further research is needed in order to investigate processes related to meaning-making of the diagnosis among parents across different demographics.

## Acknowledgments

The authors are grateful to all the participants who shared their experiences, thoughts and feelings.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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