

An ethical analysis of ADHD patient experiences on diagnostics and pharmacological treatment

– a scoping review

Version 2

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Abstract

Introduction

Attention deficit hyperactivity syndrome (ADHD) is a neuropsychiatric disorder that is characterized by three core symptoms: inattention, hyperactivity, and impulsivity. The prevalence of ADHD is estimated to be 3-10 %. The number of ADHD diagnosis and prescriptions of central stimulants that are used to treat the disorder have been steadily growing which has led to debates about the diagnostic process and pharmacological treatment. The ethics of the diagnostic process and treatment have been discussed, and it has been pointed out that there's a lack of knowledge about how the ADHD patients experience the diagnosis and treatment.

Aim

The aim of this study is to review the existing knowledge of the ADHD patient experiences concerning the diagnosis and the medical treatment, and to examine this knowledge in the light of medical ethics.

Method

This is a scoping review. Eight studies were included in this study. The inclusion criteria were that the participants of the studies were interviewed by using semi-structured interviews, both genders were included, and that the interviews covered both diagnosis and medical treatment. Material was analysed by using qualitative content analysis.

Results

Four main themes emerged from the material: *access*, *diagnosis*, *treatment*, and *impairment*. All the main themes include several sub-categories.

Conclusion

In the light of the principles of biomedical ethics the diagnostic process and the treatment measures of ADHD are not ethically trouble-free. Studying the patient experiences does evoke ethical question of patients' autonomy and the justification of distribution of needed services.

Keywords: ADHD, biomedical ethics, patient experience, qualitative content analysis

ABBREVIATIONS

| | |
|--------|--|
| ADHD | Attention deficit hyperactivity syndrome |
| ADD | Attention Deficit Disorder |
| CPRS | Conners' Parent Rating Scale |
| DSM | Diagnostic and Statistical Manual of Mental Disorders |
| ICD | The International Classification of Diseases |
| MBD | Minimal Brain Damage/Minimal Brain disorder |
| QCA | Qualitative Content Analysis |
| PRISMA | Preferred Reporting Items for Systematic Reviews |
| SBU | Swedish Agency for Health Technology Assessment of Social Services |
| WHO | World Health Organization |
| WMA | World Medical Association |

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1 INTRODUCTION

Attention deficit hyperactivity syndrome (ADHD) is a neuropsychiatric disorder that is characterized by three core symptoms: inattention, hyperactivity and impulsivity [1]. In American Psychiatric Association's diagnostic manual the disorder is categorized as neurodevelopmental disorder and in World Health Organizations (WHO) diagnostic manual ICD-10 it is classified as a hyperkinetic disorder [1][2].

In the 1910's and 1920's ADHD like behaviour was diagnosed as minimal brain damage (MBD) referring to children who developed similar behavioural problems after an encephalitis. In the sixties it was renamed as minimal brain dysfunction since children without encephalitis were also observed having these kinds of symptoms. The concept of attention deficit syndrome first appeared in DSM-III manual that was published 1980. Back then the disorder was called attention deficit disorder (ADD) with or without hyperactivity. The revised version of DSM-III was published 1987 and the disorder was named ADHD [3]. Still in the DSM-IV (1994) it was required that the ADHD symptoms had existed before the age of seven [4]. The DSM-V recognizes the older adolescent and adult ADHD [1].

The prevalence of ADHD is estimated to be 3-10 percent depending on how the diagnostic process is performed. Boys are diagnosed 3-5 times more often than girls. Prevalence amongst adults is estimated to be 3-4 percent [5].

The diagnostic process is executed by a specialist and it aims to map the extent of patient's symptoms and the effect the disorder has on different parts of their lives [6][7]. Diagnostic process of children includes an interview with a parent to survey the course of the disorder [6]. When diagnosing adults this course is mapped by discussing with the person under process. An interview with parents or other significant people in person's life is also included [7].

According to a directional guideline of ADHD management released by the National Board of Health and Welfare (Socialstyrelsen) the treatment of ADHD should be based on supportive measures that are planned taking into consideration the person's whole life situation. The supportive services should be directed to the different fields of life such as school, work and

family life. Both children and adults with ADHD should be offered psychological and educational measures that can eventually be completed by pharmacological treatment [8].

Swedish medical product agency (Läkemedelsverket) released its treatment recommendation for ADHD 2016. They state that the pharmacological treatment needs to be a part of a treatment protocol that includes psychosocial and educational measures. The primary pharmacological treatment is methylphenidate that is a central stimulant [9].

Swedish National Council of Medical Ethics published an ethics report of ADHD in 2015. This report highlights several ethical issues and questions that remain unanswered. One of the concerns is the lack of knowledge about ADHD patients' experiences of the diagnosis and the medication [3].

There are several ethical guidelines and rules, and at least as many variables that exist in the clinical and research situations. The history of medical ethics starts from the Hippocratic oath, which principles build the base of the declaration of Geneva that was first published 1948 and have since then been revised five times, the latest being 2006. The World Medical Association (WMA) recommends that this document is read parallel with WMA's more detailed policy, the International Code of Medical Ethics that has also been revised several times [10]. The national medical associations have their own ethical rules and guidelines. The Swedish Medical Association (Läkarförbundet) has updated their ethical rules 2017 [11].

The Principles of Biomedical Ethics was published in 1979 to create a structured way of resolving ethical issues in clinical medicine. The seventh edition was published 2013. Four ethical principles are introduced in this book: *respect for autonomy*, *nonmaleficence*, *beneficence*, and *justice* [12].

At a minimum, *autonomy* is understood as self-rule that is not affected by interference by others or by limitations that might prevent the individual from doing meaningful choices, such as inadequate understanding. Theories of autonomy name two essential conditions for autonomy: liberty and agency. Liberty means that the individual is "independent from controlling influences", and agency means that the individual has "capacity for intentional action". The respect for autonomy includes acknowledging the individuals' "right to hold views, to make choices, and to take actions based on their values and beliefs". This respect consists of

acknowledging the individual's decision-making and enabling the autonomous agency. For a health care professional this respect means an obligation to inform and to ensure that the individual has understood the information before proceeding with decision making. The respect for autonomy is to be withheld if the individuals' autonomous decisions don't endanger public health, harm others or require resources that are not available. The obligation to respect autonomy does not apply to the individuals perceived as less autonomous such as people who are immature, ignorant, coerced, or exploited. This however does not mean that these individuals are treated morally inadequately, but more so that they have a significant moral status and are to be protected from harm [12].

Nonmaleficence means intentional avoidance of harmful actions. The obligation of not harming others can be more stringent than the obligation of helping them, but it also works the other way around. For example, we may be causing some risks of surgical harm, creating social costs to protect public health or being burdensome on some research subjects but these harms can be justified by the gained benefits in some cases. The concept of nonmaleficence can be explained by the concepts of harm and injury. Harm can be understood widely to include disbenefit on property, emotions, or privacy. In health care the risk of physical harm is widely acknowledged, but the importance of mental harm is not to be forgotten. The principle of nonmaleficence supports other more specific moral rules such as do not kill, do not cause pain or suffering, do not incapacitate or cause offense [12].

"The principle of *beneficence* refers to a statement of moral obligation to act for the benefits of others." This principle is sometimes combined with the principle of nonmaleficence. Beneficence means helping others by preventing harm, removing harm or by promoting good, whereas nonmaleficence is intentional avoidance of harming. Nonmaleficence is avoidance of harmful actions, while beneficence requires active agency to contributions on individuals' health and wellbeing. The principle of beneficence does not stand for altruism which includes an obligation of doing good even if it means sacrificing one's own wellbeing. There is no moral obligation to benefit individuals on all occasions. The principle of beneficence is idealistic yet obligating to some extent. This principle supports some obligatory rules such as protecting and defending the rights of others, preventing harm from occurring to others, removing conditions that will cause harm to others, helping individuals with disabilities, and rescuing individuals in danger [12].

The principle of *justice* requires fair distribution of goods and services [13]. In its core this principle carries the ideal of equal cases being treated equally. From the human rights point of view all citizens should have equal rights and equal access to public services. How equality is understood can be divided to smaller concepts of principles. For example, according to the principle of need the essential resources are to be distributed with the individuals in biggest need [12]. Defining a need and determining whose need is the biggest is not easy. It's suggested that following criteria can be used to determine medical needs: likely benefit to the patient, urgency of need, change in quality of life, duration of benefit. The questions of social justice can be observed on three different levels: national, institutional, and individual. The national level includes economic considerations whereas the institutional level can be thought of as consisting among other things the medical triage [13].

2 METHODS AND MATERIAL

2.1 Aim and research question

The aim of this study is to review the existing knowledge of the ADHD patient experiences concerning the diagnosis and the medical treatment, and to examine this knowledge in the light of medical ethics.

The research questions are:

- How do the ADHD patients experience the diagnosis and the effect the medication has?
- Do these experiences give new perspectives on the ethical discussion about the disorder and its treatment?

2.2 A Scoping Review

This study is a scoping review which is an overview study with a broad research question. This study type is used to map the existing evidence of the studied subject, to identify the central parameters or to define the aim and research question for a systematic literature study. It is a convenient method when there are little or no randomized controlled studies available or the whole field of study is new and still under development [14].

A scoping review aims to survey the existing evidence and not to seek only the best evidence to answer the research question. Therefore, a specified quality analysis of the included studies is generally not performed [15] [16]. However the consequences of not doing a quality analysis can be discussed [17].

There are no randomized controlled studies of patient experiences because of the qualitative nature of the subject. Therefore, a scoping review with its broad research question, flexible quality criteria and loose inclusion and exclusion criteria is an optimal tool for data collection in this study.

2.3 Search of Literature

A preliminary data search was performed in PubMed database (PubMed Central [PMC] and MEDLINE) and in Google Scholar. The search term used was "ADHD AND ethics". This was done to gain an overview of the existing knowledge and to map the subjects that need to be studied further. One article was included to the final pool of articles already during the preliminary search.

The next stage of data search was performed in PubMed database (PubMed Central [PMC] and MEDLINE). The search words used were "ADHD patient experiences" and "ADHD experience". At this point the search was limited to include the studies published during the last 5 years until 10.02.2019. Other restrictions were not used. These two searches led to a total of 459 articles. The abstracts of the articles were scanned through and 11 articles were included to the next stage. Articles not including ADHD or patient experiences were excluded. One article was included already during the preliminary search. The reference lists of the included studies were searched, which led to the inclusion of five more studies. Total of 17 studies were included based on the study's aim and the method used. These 17 studies aimed to reach the patients' experiences and had used semi-structured interviews as a method.

The inclusion criteria were re-formed at this point. Articles older than five years were reviewed as eligible. These articles were identified through reference lists. The studies not mentioning pharmacological treatment, studies including only one gender, and studies including other methods than semi-structured interviews were excluded. The studies with more specific aims were excluded. For example, there were studies focusing on women's occupational experiences or experiences at leisure activities, but these were too narrow to describe the patient experience on diagnostics and pharmacological treatment. A total of 8 articles were included to the study. The search process is described in Figure 1.

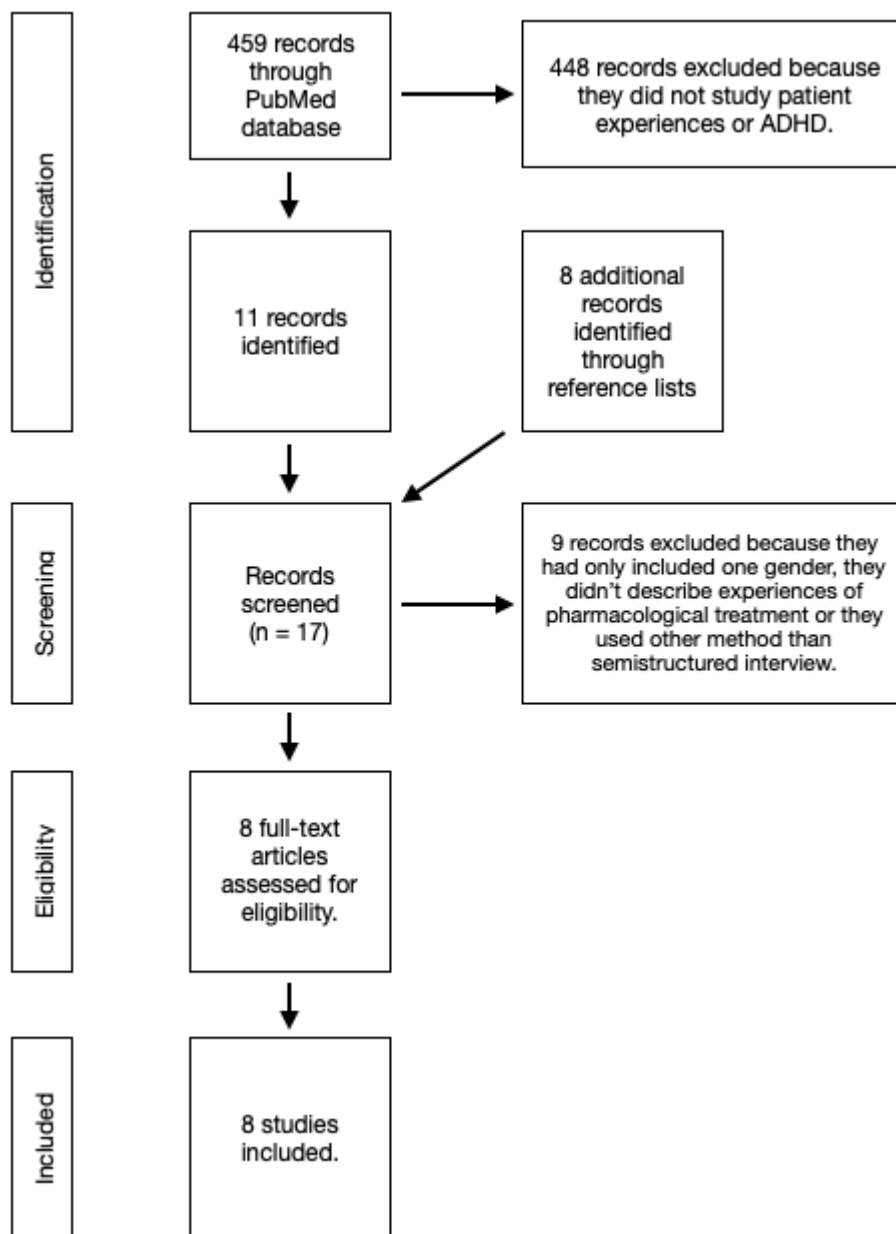


Figure 1. PRISMA flow chart showing inclusion and exclusion of retrieved studies. Adapted from [14] and [15].

2.4 Qualitative content analysis

The data retrieved was analysed by using the qualitative content analysis (QCA). This method is generally used to describe a phenomenon. It is an appropriate method when there is a limited amount of research literature or existing theories on a phenomenon [18]. QCA is suitable for this study where the data consists of studies of experiences instead of the actual lived experiences, since the QCA aims to research what do these experiences consist of.

QCA can be executed inductively, deductively, or most often by a combination [19]. This study was performed as inductively as possible, but it was partly deductive since the structure of the studies steered the composition of the material. The way the studies were executed created a certain categorizing of the data, which made the classical inductive analysis difficult to do. This led to analytic induction. This approach starts with a deductive analysis where a certain theory or existing framework is steering the process. After this deductive phase the data is looked at to find "undiscovered patterns and emergent understandings" [19].

The analysis was executed by adapting the inductive analysis model [19][20]. In the preparation phase the data was read and the units of analysis were selected. In this study the units of analysis are the results of the included studies. The organizing phase consisted of coding data and finding patterns. The next step was abstraction: the patterns were grouped in sub-categories and thereafter to main categories. This process is described in Figure 2.

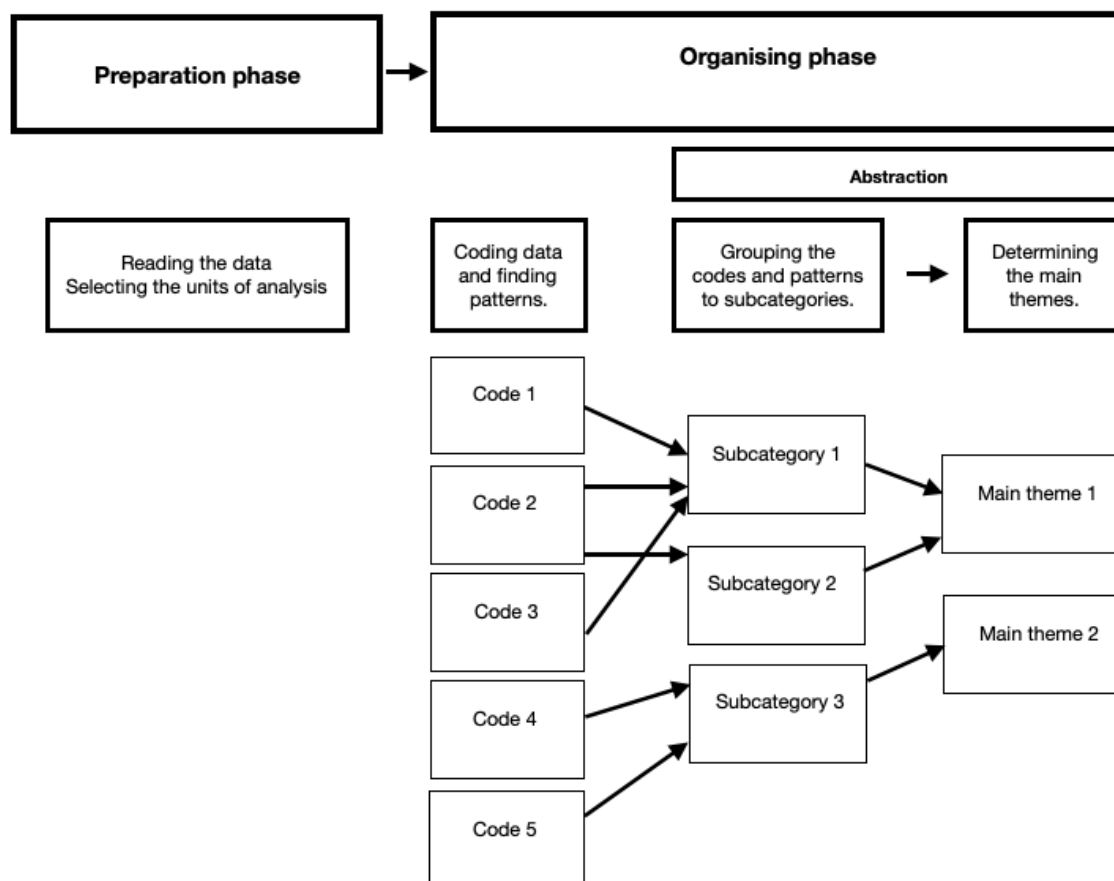


Figure 2. Qualitative content analysis process. Adapted from [19] and [20].

2.5 Ethics

Four of the included studies mention an ethical approval. In the remaining four there is no mention of such approval. It is unclear whether this approval exists even though it is not mentioned. If not, it can be questionable if these kinds of studies should be included in scoping reviews. Since this study does not aim in creating clinical guidelines but tries to reach the existing patient experience, and there was no sensitive personal information that could be linked to any specific person, it was seen acceptable to include these studies.

3 RESULTS

8 studies were included in the analysis. Cheung et al interviewed participants with ADHD about their experiences of treatment services and clinical management in Hong Kong [21]. In their study about ADHD experience and management in college Lefler et al interviewed college students in the USA [22]. Matheson et al discussed adults with ADHD about their experiences of ADHD impairment, access to services and the clinical management of the disability [23]. Singh et al interviewed young people about their experiences of ADHD and stimulant medication [24]. Young et al had their study participants answering questions about the experiences of receiving an ADHD diagnosis and treatment [25]. Another study about college students with ADHD was done by Meaux et al [26]. Walker-Noack et al interviewed participants about the difficulties they face because of their ADHD, how they cope and how they perceive the pharmacological treatment [27]. Jones & Hesse asked adolescent participants about their experiences of having ADHD diagnosis and how it affected their self-image and identity [28].

3.1 Study population

The total number of participants in the eight studies was 179 with a wide age range from 9 years to 57 years. The age of the participants was more specifically defined only in part of the studies which made it impossible to count a mean or median age for this study. 108 (60 %) participants were male and 71 female (40 %).

There was a variety in the reporting of the use of pharmacological treatment: five of the studies reported the number of participants using some kind of pharmacological treatment at the time of the study, and the number of participants who had used pharmacological treatment but discontinued the treatment at the time of the study. One study reported only the total number of participants who had at some point used medication. The remaining three studies did not report participants who had discontinued medication. It is unclear whether this is because this population does not exist among the studied participants or because of an active choice to not report the use of pharmacological treatment this way. The reported number of participants using medication during the time of the studies was 116. Seven of these however self-reported taking the medicine only when they "had a lot of work to do" [26]. Lefler et al reported 33 participants who had "used medication for their ADHD at some point in the past" [22]. These 33 are included in the total number of participants using pharmacological treatment in Table 1. The reported number of participants who had discontinued their pharmacological treatment at the time of the studies was 16. The eight studies were executed in five different countries. Three in England, two in the United States of America, one in Canada, one in Denmark and one in Hong Kong. The study population is described in Table 1.

Table 1. Study population and the study features.

| | Published | Nation | Amount of participants | Age | Male | Female | Using medication | Discontinued medication |
|------------------------|-----------|-----------|------------------------|---------|------|--------|--------------------------------------|-------------------------|
| 1. Cheung et al. | 2015 | Hong Kong | 40 | 16 - 23 | 27 | 13 | 33 | 7 |
| 2. Lefler et al. | 2016 | USA | 36 | 18 - 39 | 24 | 12 | 33 had at some point used medication | - |
| 3. Matheson et al. | 2013 | England | 30 | 18 - 57 | 13 | 17 | 25 | 5 |
| 4. Singh et al. | 2010 | England | 16 | 9 - 14 | 14 | 2 | 16 | |
| 5. Young et al. | 2008 | England | 8 | 21 - 50 | 4 | 4 | 7 | 1 |
| 6. Meaux et al. | 2009 | USA | 15 | 18 - 21 | 9 | 6 | 10 (3 on regular basis) | - |
| 7. Walker-Noack et al. | 2013 | Canada | 25 | 10 - 21 | 15 | 10 | 19 | - |
| 8. Jones & Hesse | 2018 | Danmark | 9 | 15 - 21 | 2 | 7 | 6 | 3 |
| Total | | 8 | 179 | 9 - 57 | 108 | 71 | 149 | 16 |

3.2 Main themes

Four main themes were created based on the themes that emerged in the original studies:

- Access
- Diagnosis
- Treatment
- Impairment

These main themes steered the forming of sub-categories as well as the coding process. Sub-category *stigma* appears both under the theme *diagnosis* and the theme *impairment*. This is because of the context: both the diagnosis and ADHD related impairments were experienced stigmatizing.

3.3 Access

Five of the eight studies had the theme *access* emerging from the material. Three sub-categories emerge under the main theme of access: *access to services*, *access to medication*, and *doctor-patient relationship*. The sub-categories and the related codes are presented in the Figure 3.

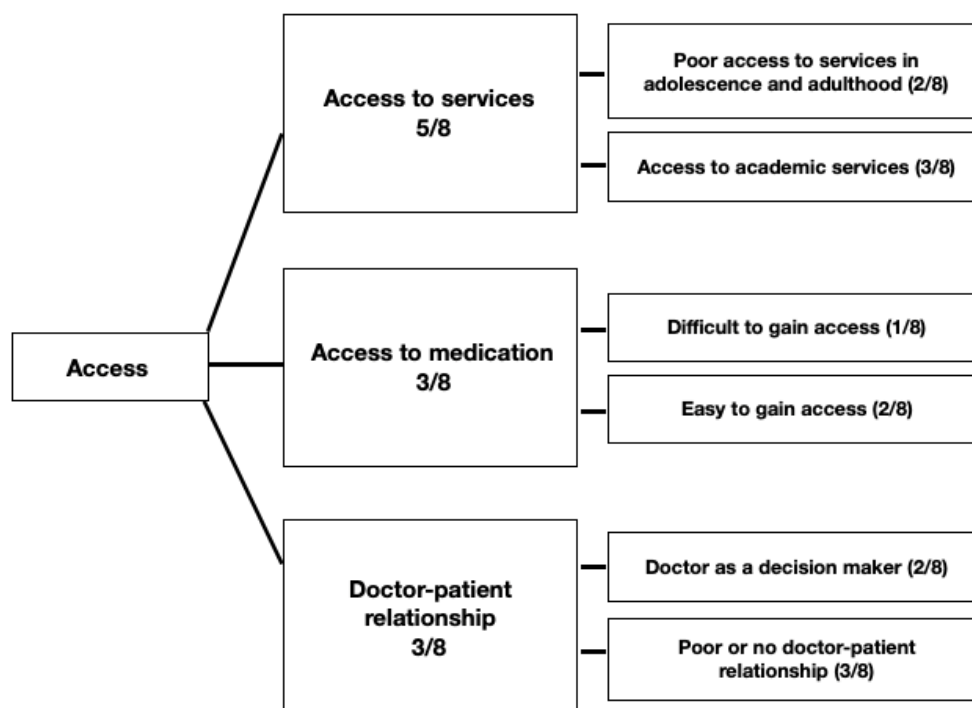


Figure 3. Access. The amount of studies bringing up the certain sub-category or code is mentioned in the parentheses.

3.3.1 Access to services

This sub-category appears in five of the eight studies. There were several codes under this sub-category but only the ones that appeared more than once were included in this study.

The code *poor access to services in adolescent and adulthood* appeared in two studies. In one of these studies the participants told that they had only occasional access to psychological treatment and this was experienced as insufficient. It was however indicated that having access to private health care made it easier to gain these services but that it is expensive. The participants in the other study experienced the process of getting diagnosed and accessing the ADHD services as long and burdensome. This was experienced especially by the participants diagnosed in adulthood. One of the barriers the participants named was health care professionals' negative and sceptical attitudes towards ADHD. Those with access to private services or those diagnosed in childhood had more positive experiences. The long waiting times were mentioned which led to distress and impaired functioning: "Putting somebody with ADHD through a bureaucracy is torture...It's like treating a diabetic in a bakery" [23].

Access to academic services was brought up in three of the eight studies. The participants were expressing interest in academic accommodations but telling that they don't have knowledge about the existing services. Some students were aware of the services but experienced that pursuing these was too difficult. Several students received accommodations or disability services such as tutors and extra time on exams. Many students didn't want accommodations because they didn't perceive ADHD being severe enough disability to deserve accommodations. "I wouldn't really consider myself disabled" [22].

3.3.2 Access to medication

This sub-category was found in three of the eight studies. In one of the studies the participants reported *problematic access to medication* since the doctors were unwilling to prescribe or the pharmacist were "reluctant to stock or to dispense ADHD medication" [23]. Some participants also experienced that the health care professionals were reluctant to help patients to adjust the dosages or the type of medicines. The lack of support led to negative beliefs towards drug effectiveness. Some perceived the access to services necessary only because they wanted the prescription. Getting the prescription was experienced *easy* since the health care professional

they had contact with didn't really invest time on discussing the participants but just gave the prescription after a few routine questions.

3.3.3 Doctor-patient relationship

The relationship with doctors was brought up in three of eight studies. In two of these studies the *doctor was the main decision maker* when it came to medication. Many participants had worries that medication would have harmful effects on their health, but they trusted the doctors' decisions. "I worry that it will cause harm to body but doctor said it won't" [21]. Participants started to take bigger responsibility as they matured. Those having a stable contact with their doctor trusted their judgement. Some participants reported lacking the access to prescription because their doctors refused to renew it.

Poor or absent doctor-patient relationship was reported in three of the eight studies. Participants experienced the changing doctors and routine questions as negative and as counterproductive to meeting patients' needs. The previously mentioned inaccessible prescription renewal was the reason for negative doctor-patient relationship experience for a few participants. Some participants saw their doctor regularly and got their prescriptions renewed but felt that the contact was superficial and only aimed on the renewal.

3.4 Diagnosis

The theme *diagnosis* appears in six of the eight studies. This theme has four sub-categories: *stigma/embarrassment*, *desire for an earlier diagnosis*, *relief*, and *part of self*. Figure 4 describes the main theme, sub-categories and the codes.

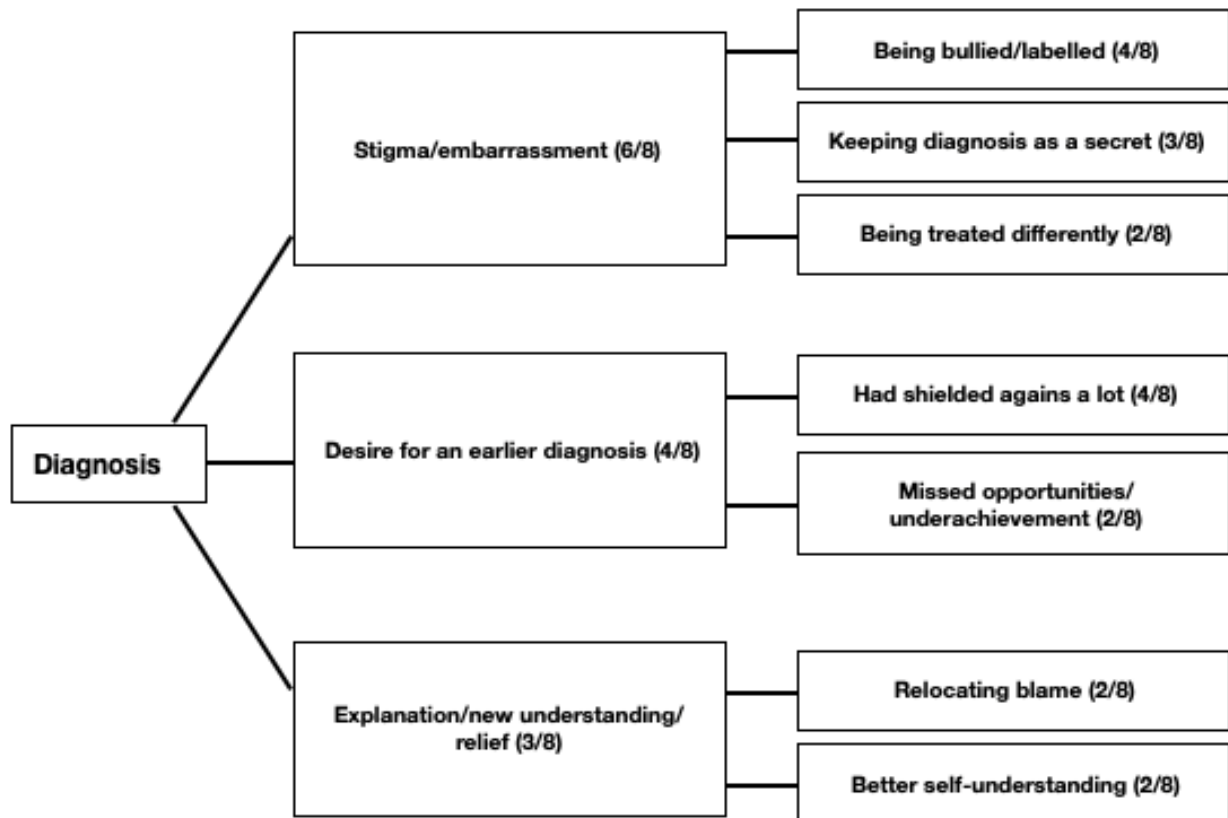


Figure 4. Diagnosis. The amount of studies bringing up the certain sub-category or code is mentioned in the parentheses.

3.4.1 Stigma/embarrassment

Six of eight studies had this sub-category. The most common code emerging under this sub-category was *being bullied or labelled*. Some participants felt that they had been discriminated or teased because of the prejudices general public had of ADHD. In another study the participants reported being bullied about the ADHD behaviours and/or diagnosis. It was also reported that knowledge of one's diagnosis led to differential treatment and bad reputation. Awareness of the existing stigma made some participants worrisome for being seen differently if people got to know about their diagnosis. General public was experienced having overall negative thoughts about ADHD: people with ADHD perceived as "bad", "weird", "freaks", learning disabled, mentally handicapped or stupid.

In two studies participants expressed that they had *kept their diagnosis as secret* from others than family or close friends. Participants hiding their diagnosis were afraid of being judged or labelled because of it. In one of the studies participants told that their parents had kept their diagnosis a secret but they later in life felt good about opening about it.

In two studies the participants told about *being treated differently* than their peers because of their diagnosis. Participants felt that they were completely ignored by their teachers and that the teachers had given up on them. Other participants expressed similar experiences of differential treatment.

3.4.2 Desire for earlier diagnosis

This sub-category appears in four of the eight studies. The participants felt that an earlier *diagnosis had shielded them against a lot*: they had had a chance to have a happier childhood, their families had had a better understanding towards them, they would have been punished less and they hadn't have to go through all kinds of negative emotions such as feeling as a failure. "If I received treatment earlier, at least I wouldn't suffer from emotional problems that much. I could have had a happier childhood" [21].

Two studies bring up the experience of *missed opportunities or underachievement*. The participants felt that an earlier diagnosis had made it easier for them to get a hold of their problems and to gain their full academic potential. A delayed diagnosis also led to greater impairment since the participants experienced that the feelings of missed potential or a sense failure had been a part of their life so long that it was difficult to overcome those. "I think that's probably the biggest thing...is the accumulation of shame and failed whatever, education, jobs, relationships, there's sort of an accumulation" [23].

3.4.3 Explanation/new understanding

Receiving the ADHD diagnosis was experienced as a relief in three studies. It offered participants *a new understanding or an explanation* to the difficulties they had been experiencing during their lives.

Some participants felt that the diagnosis helped them to *relocate the blame for* the difficulties from themselves to the diagnosis. This helped to associate the problems with ADHD not with their personal characters. "Before I knew about this condition, I assumed that everything was part of my personality. And I guess one of the things it gives you is an awareness of how many things that you convince yourself are conscious decisions are in fact nothing of the kind" [25].

Receiving ADHD diagnosis helped participants also to gain insight into themselves and to eventually reach a *better self-understanding*. This new understanding helped them to develop a better self-understanding which affected their self-identity and self-worth positively.

3.5 Treatment

The third theme treatment appears in all studies included. It has three subcategories emerging: *pharmacological treatment - positive*, *pharmacological treatment- negative*, and *non-pharmacological treatment*. The theme, its sub-categories and codes are presented in Figure 5.

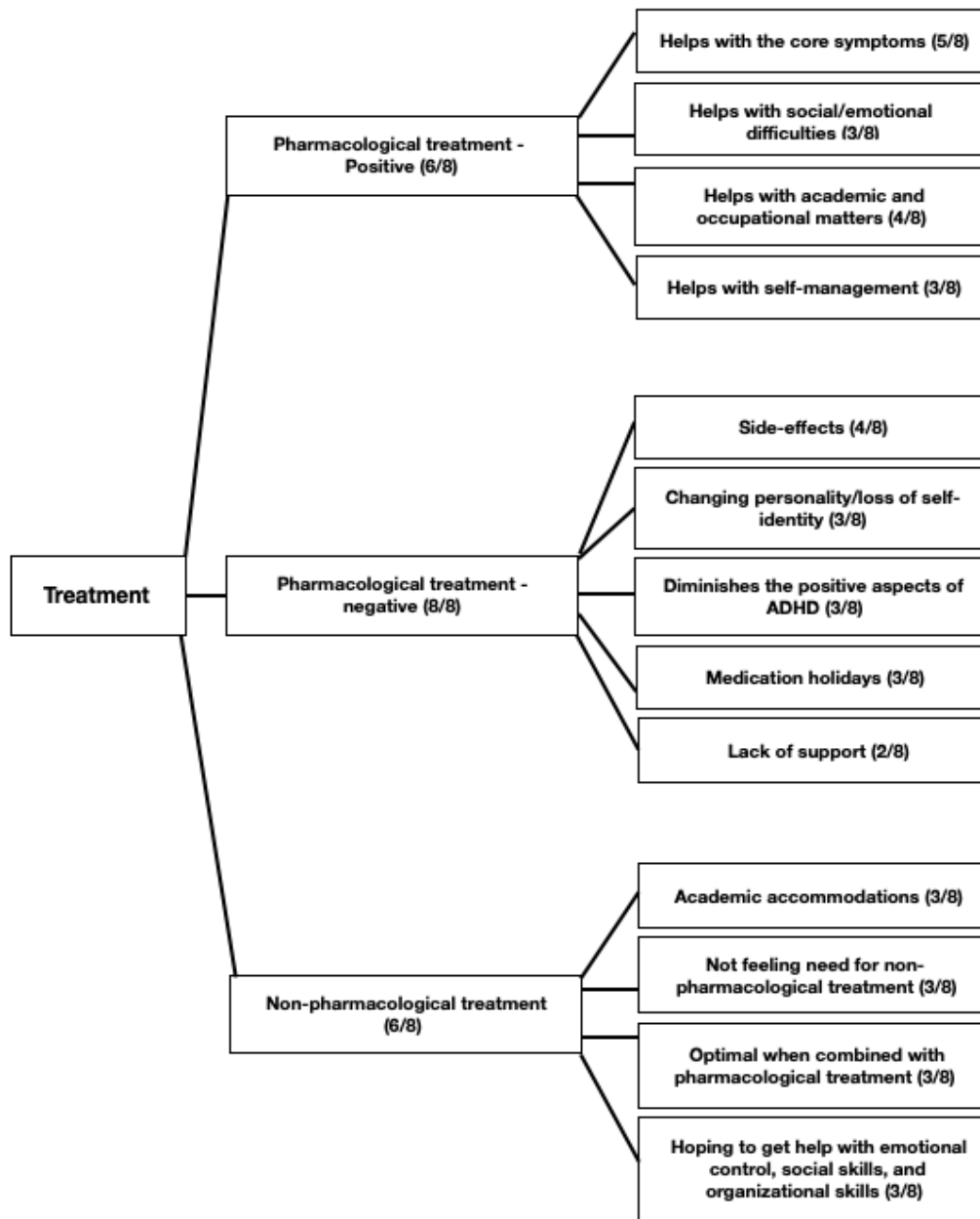


Figure 5. Treatment. The amount of studies bringing up the certain sub-category or code is mentioned in the parentheses.

3.5.1 Pharmacological treatment - positive

This sub-category emerged in seven studies. In five of these studies the participants felt that the pharmacological treatment was *helping them to deal with the core symptoms* of ADHD: inattention, hyperactivity and impulsivity. The pharmacological treatment was experienced to increase the attention span, helping to be more organized, to stay calm, and follow the rules.

Participants of four studies felt that the pharmacological treatment *helps with academic and occupational matters*. Medication made it easier to focus on homework, and some improved their grades significantly. It was also experienced that it was easier to manage the routine tasks at work. It was also reported helping with reading comprehension and writing.

The positive effect of pharmacological treatment on *social and behavioural difficulties* was also reported. Participants experienced that medication helped them to function better in social situations. In one study the participants reported that the impact on social behaviour was the primary way the medication helped. It was experienced to help with emotional control which then helped in social interactions and made it easier to make friends with peers. The participants described that they had easier to discuss with people without interrupting them and to keep calm during interactions.

The positive effect medication had on participants *self-management* was also mentioned. The participants felt a general responsibility for their behaviour, feeling that medication helped them with this. Having medication helped the participants compare their behaviour on- and off-medication which helped them to gain better understanding of the disorder and to adopt greater responsibility for their behaviour.

3.5.2 Pharmacological treatment - negative

This theme was mentioned in all studies. The most common negative experience was the *side effects* of stimulant medication. The most common side effects were loss of appetite, negative effect on sleep quality and withdrawal symptoms. Some participants also name having antisocial feelings when on medication.

The pharmacological treatment is experienced as *changing personality or leading to loss of self-identity*. "It was a pill I took and it changed who I was so I didn't like it" [23]. The impulsive traits of ADHD were experienced as positive by some participants since they felt that it made them more fun to interact with. They felt that medication diminished this fun side in them, but they were also aware of the negative consequences this kind of impulsive behaviour can have and thus accepted the medication.

Participants felt also that medication had a *negative effect on the positive sides of ADHD* such as sociability. "When I'm on my tablets I'm totally different person. I can't socialize. I am socially awkward" [23]. The previously mentioned effect on impulsivity can also be included in this sub-category. Some participants felt that medication depleted the extra energy they felt they had thanks to ADHD. It was also reported that ADHD helped with multitasking since there were several thoughts running at the same time, and that the medication stopped these thoughts.

Some participants reported taking *medication holidays* without discussing with their doctors. The medication was taken only when they felt a specific need for it such as a difficult school assignment or an approaching deadline. Some participants were medication-free during the weekends and holidays. These holidays also occurred because of forgetfulness or because the participants felt *lack of guidance or support by their doctors*.

3.5.3 Non-pharmacological treatment

Non-pharmacological treatment was discussed in six studies. The participants in three studies felt that the non-pharmacological treatments are good but that they are more effective *combined with medical treatment*.

Academic accommodation as a form of non-pharmacological treatment was also brought up. There were both positive and negative experiences of these accommodations. Participants with positive experiences were very satisfied with the institution's disability services and felt that they were encountered well by the professors and staff members. The ones having negative experiences felt that it was too difficult applying the accommodations or that the professors had a bad attitude towards the accommodations. Some participants experienced having the need for accommodations or having to go to disability centre as stigmatizing or embarrassing.

Not wanting non-pharmacological treatment was mentioned in three studies. For some this thought was initiated by the treating doctor who had informed that these kinds of measures are not needed, or they simply didn't offer those. Participants who were studying expressed not wanting additional help because they wanted to manage themselves. Many declined the academic accommodations because they didn't think ADHD as a disability that requires specific accommodations or that their disability is not severe enough.

Several participants felt that the non-pharmacological treatment was optimal when *combined with pharmacological treatment*. Young participants expressed suspicion towards the non-pharmacological treatments but felt that the combination of these two would give the best effect. The older participants were more open to the idea of non-pharmacological treatments and were hoping to get more of those. Participants hoped that they would get counselling in, for instance, *stress management, organizational skills and social interactions*.

3.6 Impairment

The ADHD related impairments were discussed in all studies. The most obvious impairments were *the core symptoms* of ADHD. The impairments regarding *academic and occupational matters* as well as interpersonal relationships were also brought up. There was also a subcategory including *other* impairment related difficulties such as stigma, addiction and feeling of being different. The theme, sub-categories and codes are described in Figure 6.

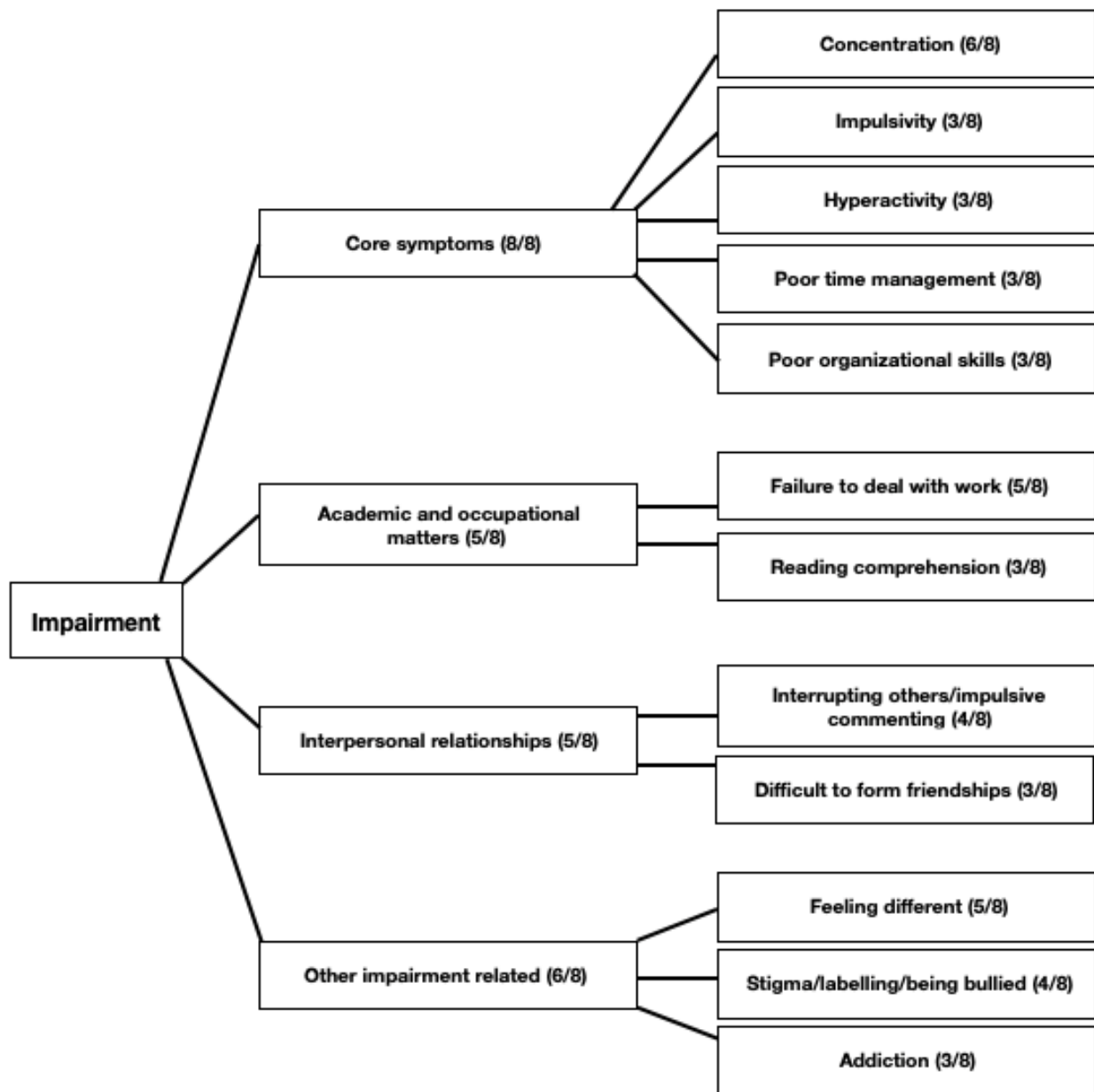


Figure 6. Impairment. The amount of studies bringing up the certain sub-category or code is mentioned in the parentheses.

3.6.1 The core symptoms

The core symptoms were mentioned in all studies. The most common core symptom discussed was *inattention*. This symptom had a negative effect on academic and occupational performances. The *impulsivity* and *hyperactivity* were less discussed. Symptoms related to or ascending from the core symptoms were *poor time management* and *poor organizational skills*.

2.6.2 Academic and occupational matters

Academic and occupational impairments emerged in five studies. The core symptoms were the reason for *failing to deal with the given tasks or homework*. Getting distracted was mentioned most often as the reason of failure with work. The participants told that they had difficulties with *reading comprehension*. It is however unclear whether or not these participants have a comorbidity, or the reading incomprehension is ADHD related.

2.6.3 Interpersonal relationships

Impairments leading to difficulties in interpersonal relationships were brought up in five studies. Of these impairments the impulsiveness was mentioned most often. Impulsiveness led to *disturbing commenting or interrupting others during discussions*. *Difficulties in forming friendships* was mentioned separate from these communicative complications. Participants expressed difficulties also in maintaining long-term friendships.

2.6.4 Other impairments

This sub-category contains three codes that emerged in three or more studies and were therefore seen worth including. The participants expressed having been *stigmatized, labeled or bullied* because of their ADHD related impairments. The negative criticism and labelling based on their behavioural features was on-going: "I was told more or less daily, that it was just naughtiness, being disruptive purely out of seeking attention and so forth" [25]. This was closely related to the participants' *feeling of being different*. To some participants this feeling was present even before they became aware of their ADHD diagnosis. Some were aware of their behavioural problems and the impact those had on their interpersonal relationships. Some couldn't point out a certain behavioural feature that made them feel different, but they felt that they stood out and were bullied or left out because of this.

In three studies the participants told about their *addictions*. The discussed addictions were to computer games, drugs, alcohol and nicotine. It was experienced that the impulsivity made it harder to deal with drugs and alcohol. Nicotine was experienced as symptom relieving.

4 DISCUSSION

Participants' experience of doctors being the main decision makers in their treatment can be seen to interfere with the respect of *autonomy* since the patient does not feel agency, yet it can be seen to fulfil the principle of beneficence since the doctors are helping people with disabilities and trying to prevent the harm the impairments can cause in these individuals' lives. The respect for autonomy does not apply to less autonomous individuals who can be seen to have reduced ability to make decisions. It is questionable whether an individual with ADHD can be seen as someone with this much reduced autonomy. This principle also includes an obligation to enable the individuals' autonomous agency, which in this case could be done by thoroughly informing the patients about the effects and side effects of the medication. This informative contact was expressed to be insufficient or lacking by some participants since they didn't get support with their prescriptions or dose adjustments. The feeling of being poorly informed led to mistrust of pharmacological treatment which then led to unplanned medication holidays and independent dose adjustments. The poor compliance can be seen to interfere with the principle of beneficence.

It was also experienced that the access to non-pharmacological treatment wasn't provided because the treating doctors didn't inform about the possibilities or because they didn't see that the patient needed these kinds of services. Hence the participants' right to autonomous agency was denied. It must however be noted that many participants experienced that they had a good relationship with their doctor and trusted their decision making, which can be seen as an act of autonomous agency.

Interestingly it was also expressed that the knowledge of the non-pharmacological treatments existed but that the participants used their autonomous agency to decline these services in order to feel self-sufficient in their disorder management.

The results do not indicate that there would be intentional harming of patients with ADHD, hence the principle of *non-maleficence* can be seen fulfilled to some extent. Yet the lack of intentional avoidance of harmful actions can be discussed. Some participants experienced that they didn't have access to pharmacological treatment because of the health care professionals' bad attitude towards the diagnosis or the medication.

This principle includes the concept of harm which includes harm on emotions. Participants experienced that the pharmacological treatment changed their personality or lead to loss of self-identity which per se can be seen as emotionally highly harmful. The side effects of ADHD medications seem to be experienced by some as interfering with one's identity. This kind of harm is difficult to measure since the concept of identity is philosophical and difficult to define. The medication offers a great variety of benefits such as diminishing the impairments disturbing individuals' lives but for some it seems to be suppressing some qualities that are experienced as beneficial or as part of one's identity. Is the emotional harm of losing parts of one's personality or self-identity to be seen as a cost of treating the impairments and is this cost reasonable?

The pharmacological treatment was experienced as highly beneficial by several participants. It was even described as lifesaving. This indicates that the principle of *beneficence* is fulfilled by offering the treatment to the patients, since the aim is to prevent harm and promote good. Also, the diagnosis per se was beneficial for many since it helped them to self-manage their disability and lives and thus even increased their autonomy. The benefits of the diagnosis can also be seen to reduce some of the emotional harm the disorder has on one's personality since it helped some participants to relocate the blame of their underachievement or struggles from their personality to the disorder. Hence it was experienced that their personal traits were not the reason to their failure, which helped to build a better self-understanding and even better confidence.

This principle also supports the idea of removing conditions that will cause harm to others. ADHD impairments can be experienced as disturbing at the academic or occupational situations and to some extent, they can even be seen as harming the working environment. It can be discussed if the interference with ADHD-individuals' autonomy and causing emotional harm in form of suppressing the personality traits is necessary in order to make them more functional in social situations, at school or at work place, and thus helping a bigger group of people to manage their daily tasks.

Participants in some studies experienced that they had poor access to mental health services. This was experienced both when seeking diagnosis and when trying to get access to pharmacological treatment. The participants who were diagnosed in adolescence or adulthood

had more negative experience of the service access than the participants who were diagnosed in childhood. Also, the participants with access to private health care had more positive experience about the diagnostics and treatment. The ones with delayed diagnosis felt a greater impairment in their daily lives and they felt that the impairment had already left its mark on them and it was difficult to overcome the underachievement that had accumulated during the years. According to the principle of *justice* the public services are to be distributed fairly and equally. The individuals in biggest need are to be prioritized. Are the adult and adolescent ADHD individuals treated equally when it comes to access to services?

The medical need can be defined by judging, among other things, the likelihood of benefit to the patient, the urgency of need, change in quality of life and duration benefit. ADHD was originally a children's diagnosis which has understandably led to the diagnostic efforts and treatment services being invested on children. Children can also be seen as a group with lesser autonomy and therefore as a group with significant moral status. Therefore, the youngest population can be seen as the most urgent and as the one to prioritize. However, the adult and adolescent population with the undiagnosed and untreated disability can experience an accumulation of suffering. The earlier the diagnosis and treatment are achieved the lesser the accumulation is. Investing in children's services seems to be more justified from this point of view. Then on the other hand the individuals with accumulated burden may be suffering more than the individuals without this accumulation. This is a question of social justice on an individual level.

From the national point of view the effect on economics can be viewed as serving the principle of justice. The ADHD impairments led to underachievement both academically and occupationally which has a direct effect on personal and national economy. If the individuals can be helped to reach their potential by treating their impairments a certain emotional impact can also be achieved since these individuals can be included to the society more fully. This can help to alleviate the feeling of differentness the participants in studies bring up.

As pointed out earlier in this study it is important that the ADHD diagnostics and treatment are not only to be evaluated by the economic benefit viewpoint, but the individual benefits and disadvantages are to be carefully analysed.

4.1 The limitations of the study

Studying experiences through a literature study is not an optimal way of reaching the actual lived experience. More unified studies that are performed with similar interviews and even more coherent aims had offered a better chance of performing an inductive analysis, and thus given a better overview of the lived experiences of ADHD patients.

The limited amount of studies with coherent content can also be a limitation. A greater number of studies could have offered a greater variety of experiences and reinforce the experiences that emerged from the included studies. In QCA the saturation of the data is suggested to indicate the optimal amount of material [29]. In this study the evaluation of data saturation was challenging since the studies included were not totally coherent. This problem was solved by including the most saturated parts into the final analysis and by leaving out the more diffuse findings.

QCA always includes some degree of interpretation of the texts [29]. To diminish the effect of interpretation the coding was reaffirmed twice during the process: during the abstraction the codes were revalued and during the writing process another revaluation was done. For example, it can be discussed whether the stigma/embarrassment over the diagnosis and over the impairments can be categorized under a same theme.

5 CONCLUSION

The patients had both positive and negative experiences on ADHD diagnostics and pharmacological treatment. According to the patient experiences the benefits of both diagnosis and treatment are undisputable, but there are negative aspects as well. The pharmacological treatment was for example experienced as changing personality, and the participants experienced lack of support in treatment related issues.

From the ethics point of view the questions like the impact the medication has on one's personality, the autonomy of the ADHD patients in treatment related decision making and the distribution of services and treatment should be studied and discussed further. These questions need to be answered in the future in order to make the process of ADHD diagnostics and treatment more humane and ethically sound.

Future studies on patient experiences in Sweden would give a valuable view of the current situation. A wider and more detailed discussion of the philosophy of treating the neurodevelopmental disorders such as ADHD would be necessary in order to understand concepts such as personality traits, self-image, impairments and symptoms. This is essential to make it clearer what we are actually treating with the pharmacological measures, and to respect the human value of these patients.

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APPENDIX

Appendix 1: Cover letter

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Dr. Martin Balslev Jørgensen
Editor-in-Chief
Nordic Journal of Psychiatry

May 25th 2019

Dear Dr. Balslev Jørgensen,

I am pleased to submit an original research article entitled "An ethical analysis of ADHD patient experiences on diagnostics and pharmacological treatment" by Hanna Hirvonen for consideration for publication in the *Nordic Journal of Psychiatry*. There has been an on-going debate about the diagnostics and treatment of ADHD, and in this manuscript I take a deeper look into the ethical perspectives the patients' own experiences foreground.

In this manuscript, I show that diagnosing and treating ADHD is ethically challenging, and the patients' voices have to be heard in order to discover these challenges.

I believe that this manuscript is appropriate for publication by *Nordic Journal of Psychiatry* because it discusses a diagnosis that is currently widely debated. My manuscript emphasizes the patients' perspective and discusses the biomedical ethics from this point of view, and therefore creates a base for future development of ethics diagnostics and treatment.

This manuscript has not been published and is not under consideration for publication elsewhere. I have no conflicts of interest to disclose.

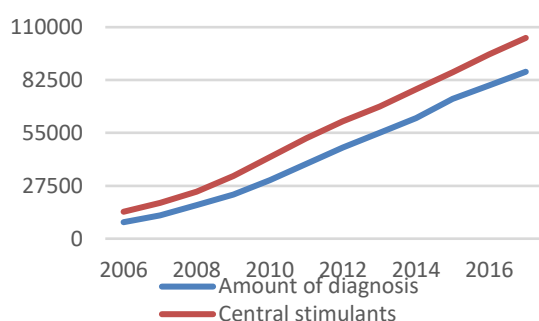
Thank you for your consideration!

Sincerely,
Hanna Hirvonen, Bachelor of Medicine
University of Örebro, School of Medical Sciences

Appendix 2: Populärvetenskaplig sammanfattning

Attention deficit hyperactivity syndrome (ADHD) är ett neuropsykiatriskt tillstånd. Det uppskattas att 3-10 % av svenska befolkningen har ADHD. Mängden ADHD diagnoser och recept på centralstimulantia som används för behandling av tillståndet har ökat successivt under det senaste decenniet. Denna ökningen har lett till ökad debatt kring diagnosen, dess diagnostisering samt läkemedelsbehandling. Statens medicinsk-etiska råd har gjort en etisk rapport om de etiska utmaningar som finns kring detta tillstånd. Det pekas ut bland annat att vi har bristande kunskap om ADHD patienternas erfarenheter om diagnosen och behandlingen.

Figur 1. Mängden diagnoser F90.0 och mängden recept på centralstimulantia i Sverige 2006-2011, alla åldrar, båda könen.



I denna litteraturstudie forskades hur ADHD patienternas erfarenheter har kartlaggats i andra studier, och hur dessa erfarenheter resonerar med de etiska principerna vi har som guide inom medicin. Det visar sig att många patienter upplever att diagnosen har varit befriande för dem, men att det finns brist på resurser när det gäller tillgång till diagnostiseringsprocess. Framförallt upplever patienter i vuxenålder att de inte har tillräckligt bra tillgång till psykiatriska tjänster.

Läkemedelsbehandlingen upplevs väldigt hjälpsam speciellt när det gäller de grundsymtomen av ADHD. Många negativa erfarenheter dyker dock upp i patienterfarenheter. Bland annat upplever vissa att ADHD medicineringen dämpar deras personlighet, och att de inte får tillräckligt mycket stöd med deras behandling.

Forskning av patienterfarenheter lyfter fram viktiga synpunkter om bland annat patienternas autonomi. Det är också viktigt att överväga delning av resurser inom psykiatri för att minska det mänskliga lidandet. Det är inte enkelt att lösa dessa problem och därför vidare forskning och etisk diskussion om neuropsykiatrisk diagnostik från patienternas perspektiv behövs.

Appendix 3: Etisk reflektion

Etisk övervägande

I studier om patienterfarenhet kan finnas en risk för att känsliga personliga erfarenheter kommer att beröras. Detta kan leda till personligt lidande. Neuropsykiatriska tillstånd är kopplade till personliga egenskaper och genom att analysera dessa tillstånd kan man få en känsla av att ens personlighet blir attackerad. Det är viktigt att dessa studier utförs av erfarna forskare, och att det finns ett etiskt tillstånd.

Att studera ADHD patienternas erfarenheter kan lära oss mycket om patientgruppens särskilda behov vilka kan hjälpa oss rikta både farmakologiska och icke-farmakologiska behandlingar bättre. Genom att diagnostisera och behandla patienterna tidigare kan vi minska det mänskliga lidandet.

ADHD kan leda till svårigheter på skolan och i arbetslivet. Bättre behandlingar kan hjälpa patienter att vara mer produktiva inom dess områden. Detta kan bidra till både personlig och nationell ekonomi. Det är däremot viktigt att den etiska diskussionen värderas inte bara för att den kan hjälpa att bidra till ekonomiska aspekter, men också för att den kan hjälpa oss att förstå människonatur, människovärde och individuella behov av sårbara grupper bättre.

Oklarheter i etiska tillstånd i inkluderade studier noterades för att detta är etiskt oacceptabelt. Det tycktes vara osannolikt att dessa studier hade fått genomföras och publiceras om tillstånden inte fanns. I scoping review metodiken man ofta inte gör en kvalitetsbedömning, men det är viktigt att notera att sådana brister i inkluderade studier fanns. Denna studien syftade inte till att bygga nya riktlinjer, och det sågs att inga känsliga patientuppgifter kunde länkas till existerande patienter.