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'Do I need to become someone else?' A qualitative exploratory study into the experiences and needs of adults with ADHD

Samuel J. C. Schrevel MSc,* Christine Dedding PhD,† Jeroen A. van Aken MSc‡ and Jacqueline E. W. Broerse PhD§

*PhD Candidate, †Assistant Professor, ‡former intern and §Professor, Athena Institute for Research on Communication and Innovation in Health and Life Sciences, Faculty of Earth and Life Sciences, VU University Amsterdam, The Netherlands

Correspondence
Samuel J. C. Schrevel, MSc
PhD Candidate
Athena Institute for Research on Communication and Innovation in Health and Life Sciences
Faculty of Earth and Life Sciences
VU University Amsterdam
de Boelelaan 1085
1081HV
Amsterdam
The Netherlands
E-mail: s.j.c.schrevel@vu.nl

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Abstract

Background Attention deficit/hyperactivity disorder (ADHD) is a common psychiatric disorder in childhood which has recently been acknowledged to persist into adulthood in two-thirds of cases. However, the problems faced by adults with ADHD in their daily lives remain largely unexplored.

Objective To assess the perspectives, problems and needs of adults with ADHD.

Design and Participants In this exploratory qualitative study, adults (n = 52) with a primary ADHD or ADD diagnosis, aged 21 years or older, participated in eight focus groups in five cities in the Netherlands.

Results Although core symptoms of ADHD were perceived as a problem, participants placed greater emphasis on social problems that arise from living with ADHD and their subsequent effects on self-image. Accompanying problems were feelings of powerlessness, lack of acceptance by their social environment and poor self-image. Adults with ADHD would like to see greater acceptance of ADHD and its accompanying problems, together with appreciation for personal competences and strengths in certain domains, such as creative or associative thinking.

Conclusion Our study adds to previous research by providing insight into how these problems are interrelated and their strong link to the social environment. Perceived powerlessness, failure and negative reactions of the social environment lead to a persistent low self-image. This merits substantial attention in future research, particularly when considering on-going care options.

Introduction

Attention deficit/hyperactivity disorder (ADHD) is a common psychiatric disorder in childhood which persists in adulthood in two-thirds of cases.[1,2] The prevalence of ADHD in children has been estimated to be 5.29[3] and 2.5%[4] in adults. According to the fourth edition Diagnostic and Statistical Manual of psychiatric disorders, text revision (DSM-IV-TR), there are three different ADHD subtypes: the mainly inattentive type better known as attention deficit disorder (ADD), the mainly hyperactive/impulsive type and the combined type.[5] The classical symptoms are clustered in the three categories of inattention, hyperactivity and impulsivity.[1,6] However, these symptoms have been defined for children, and there is no consensus regarding the applicability of these criteria to adults.[1,7]

Adults with ADHD often additionally suffer from a wide range of social, emotional and psychological problems.[8] For example, on average, adults with ADHD experience higher rates of unemployment and underemployment; underachievement in academic careers[9,10]; and relational, marital and family problems.[10–13] Thus, adult ADHD negatively affects multiple facets of life and is responsible for considerable impairment in social functioning.

Although the diagnosis and treatment of ADHD has been extensively studied from a clinical or a psychiatric perspective, the perspectives and experiences of adults with the disorder remain largely unexplored with the exception of three qualitative studies.[14–16] First, Brod *et al.*[15] compared the burden of disease of ADHD in seven Western countries using focus group discussions, demonstrating that core ADHD symptoms cause substantial dysfunction in the lives of adults and that the burden of disease did not significantly differ between countries. Second, Young *et al.*[14] explored the experience of receiving a diagnosis and care for adult ADHD, establishing that participants had to reframe their past in the light of their ADHD diagnosis and went through a period of emotional acceptance to form a vision of their new future with ADHD. Additionally, they found that most of the interviewed adults recognized the positive impact of stimulant medications on their functioning. Finally, Fleischmann and Fleischmann[16] analysed online accounts of adults with ADHD and found that some adults can see the positive side of their disorder if they have had successful therapy to address the problems resulting from ADHD. Although these studies provide valuable insights into the burden of symptoms, the diagnosis and treatment of adult ADHD, there remains limited insight into the perspectives, problems and needs of adults with ADHD in daily life. In an effort to fill this knowledge gap, this study explores the perspectives of adults with ADHD with respect to the following questions: (i) What are their experiences of living with ADHD? (ii) What problems do they face in daily life? and (iii) what are their current needs and wishes for the future with regard to their life with adult ADHD?

Methods

Due to the exploratory nature of this study, a qualitative approach was employed. The focus group discussion (FGD) method was chosen as a means of data collection because it is a suitable method for understanding the perceptions and concerns of groups of people, and exploring diverse views, values and attitudes.[17] From the perspective of social psychology, perspectives and opinions are individually constructed but can be further explored through interaction with others.[18] A FGD therefore makes shared and conflicting ideas more visible through participant interaction.[18–20] The moderator used a protocol with questions and exercises to guide the discussion, aiming to create a balance between encouraging participant interaction and staying on topic[18].

Two overlapping FGD protocols were used for a total of eight focus groups. The first five focus groups explored the daily life experiences and problems of adults with ADHD. Activities in these focus groups were structured as follows: (i) a brainstorm session to identify a

broad variety of topics and problems considered important in living with ADHD; (ii) a discussion phase to further elaborate two central topics and their effects on daily life; and (iii) a discussion phase in which possible solutions to the problems were considered. The second FGD protocol, used in three focus groups, also consisted of three phases: (i) a reflection phase in which a summary of the findings of the previous five focus groups was discussed; (ii) a creative phase in which participants were asked to visualize their current situation and their desired situation, and how they could achieve their desired situation; and (iii) an exercise to identify real-world solutions for reaching the desired situation. Focus groups were held at five different locations throughout the Netherlands to ensure diversity in participants. Substantial saturation was reached as no new topics emerged in the third focus group for both designs which suggests that the full variety of themes relating to the research topic have been observed in the study. Consequently, no additional FGDs were planned.

In the FGD design, initial time was allocated to give the participants the opportunity to become acquainted with each other. Participants quickly discovered that they had much in common and they often recognized each other's perspectives. This enabled in-depth and personal discussions. In many cases, participants were eager to stay longer than the planned duration of the sessions discussing their experiences of ADHD and related problems.

Participants were recruited through two channels: a notification e-mail to a national forum for adults with ADHD; and an announcement on the website of the Dutch patient organization for adults with ADHD. In both cases, potential participants were also asked to invite peers. Contact information of the researchers was provided, and adults interested in participating could seek further information from the researchers. Respondents with a primary ADHD diagnosis were eligible to participate given that comorbid disorders are common among people with ADHD.[1] Only respondents aged 21 years or older were eligible so that all participants would have experience with employment or higher education.

During the recruitment phase, 138 potential participants responded to the announcements of the study. Subsequently, 73 participants were excluded because they did not meet the inclusion criteria ($n = 3$), did not reply to invitations for particular dates and locations ($n = 68$), or were unable to attend the planned focus group sessions ($n = 2$). In total, 65 participants were assigned to one of the eight focus groups. There was a no-show rate of 20%, leaving a total of 52 actual participants. On average, there were seven participants per FGD, with the exception of one focus group which only had three participants.

All FGDs were recorded and transcribed verbatim; summaries of the individual discussions were sent to FGD participants for respondent check. Additionally, after the analysis, the main findings of the study were sent to all respondents for member check to support the validity of the conclusions. The reactions of the participants were positive, indicating that reporting was consistent with the views of the study participants; no amendments were necessary.

To ensure rigour, two researchers were involved in the analysis of the data; their reflections were regularly discussed with a third researcher. The coding process followed the structure of conventional content analysis as described by Hsieh and Shannon.[21] Transcripts were read and re-read to develop familiarity with the data. In the first phase of coding, the two researchers read the transcripts independently and developed two separate coding schemes. The two coding schemes were then compared and discussed prior to developing a final joint coding scheme based on agreement in terms of the code name, definition and description. This was subsequently discussed with a third researcher. All transcripts were then re-coded using the final coding scheme in Atlas.ti software. Relevant quotes to underpin the analysis and results were checked and discussed within the research team.

Ethical considerations

Given the non-invasive nature of the study, medical ethical approval was not required. All participants received verbal information about the aim and scope of the research; anonymity was ensured using pseudonyms in the reporting of the research; and participants were informed that they could withdraw from the study at any time without penalty or questions. During the recruitment phase, contact information of the researchers was provided so that potential participants could enquire after eligibility and study procedures. Verbal informed consent was acquired for recording, transcribing and analysis of the FGDs.

Results

Demographic characteristics of the participants are presented in Table 1. Some (52) participants took part in eight focus group discussions. 54% of the participants were female, and the mean age was 43 (range: 23–55) with a median number of 2 years since receiving an ADHD diagnosis. Problems identified during the focus groups were divided into three categories: powerlessness, perceived lack of understanding from the environment with regard to specific ADHD problems, and poor self-image. In the next subsections, these categories are discussed from the perspective of the participants. Finally, future visions and desires are described.

Powerlessness: 'I want to but I can't'

The vast majority of participants felt limited in their ability to undertake everyday activities. The word 'powerless' was often used to describe their inability to control their thoughts and emotions. Thoughts and emotions were out of their control and could change abruptly, almost like they had 'lives of their own'. As Alice explained:

> Sometimes you wake up and you're on top of the world, and only one thing happens which is actually quite small, and suddenly you're down as hell.

Table 1 Demographic variables of the study participants

	No. of participants (n = 52)
Age[1]	43 ± 9.5
Male	24
Female	28
ADHD subtype	
Predominantly hyperactive-impulsive type	33
Predominanty inattentive type	14
Combined type	**5**
Current treatment[2]	
Pharmacological	37
Psychosocial	17
Other	4
No treatment	7
Education and employment	
College	7
Higher vocational education	27
Intermediate vocational education	11
High school	5
Other	2
Unemployed	10

[1]Years, mean ± SD.
[2]Because there was overlap in treatments, the sum of these numbers exceeds the number of study participants.
The DSM-IV-TR distinguishes three types of ADHD based on the symptom categories of inattention, hyperactivity and impulsivity.

In addition to the perceived inability to control thoughts and emotions, participants explained that they felt unable to behave in the way that they would like to. This mainly revolved around the inability to perform behaviours that are considered necessary or desirable in social situations, such as tidying the house, and refraining from behaviours perceived as inappropriate, such as speaking loudly in public places. Participants attributed the cause of poor behavioural control to the gap between the intention and the performance of a behaviour, and to a lack of interest in performing certain tasks or activities. Participants explained that they understood socially acceptable behaviours, felt that they had the competencies and attributes to behave in socially acceptable ways but nevertheless felt unable to act or change behaviour patterns. Some participants explained that they were able to modifying their behavioural patterns but that these efforts were short-lived:

> And every time you start again with the idea 'this time I am going to do it right', and you start off in the right way, but in the end it doesn't work out that way. (Peter)

> I can talk on and on, and there is a little voice in my head telling me to shut up, but I just can't stop, I just can't stop [talking]. (Margreet)

Maintaining focus on uninteresting tasks or activities was perceived as difficult by most participants, often leading to postponing, forgetting and not finishing tasks. Novel tasks and activities were perceived as interesting to participants but, with increasing familiarity, focus dwindled. Novelty was perceived to be advantageous by some participants because it stimulated interest in undertaking new and multiple activities simultaneously. For others, novelty had negative connotations because it contributed to avoidance behaviour or served as an escape from uninteresting, annoying obligations. Interestingly, this behaviour, both positively and negatively formulated, led to postponing, forgetting and not finishing other more important or urgent things:

> If I don't see use and necessity, even for the simplest things, then it just doesn't happen. The necessity will be there surely, some things need doing, but the simplest things become the biggest barriers. (Mark)

Some participants described that they find it more difficult than people without ADHD to 'filter out' irrelevant stimuli or thoughts that spring to into their mind. This was also described as the inability to control ones internal filters. As a result, every new stimulus, emotion or thought needs immediate attention and action, making it hard for them to focus on one task:

> If too many stimuli enter your head, you are unable to filter them which makes it impossible to prioritize them. (Ingrid)

Lack of understanding: '[They think] you can but you don't want to'

Participants were of the opinion that their immediate social environment (family, colleagues and friends) expects that they should be able to perform simple tasks, such as housekeeping or bookkeeping, whereas these are precisely the tasks that participants found difficult to focus on and complete. For some participants, this was further complicated by the ease with which they could perform highly complex tasks. This paradox of the inability to do easy tasks, and the ability to do highly specialized tasks, for example process engineering, was difficult for their social network to grasp and accept:

> On the one hand, in some things you are a real perfectionist …on the other hand, you don't understand the most simple things. Then you have to ask for help all the time and then people think that you are a complete idiot. (Anna)

In response to mismatched societal expectations, participants felt forced to adapt to meet these societal expectations, such as having a tidy house or being structured and organized. Participants explained that they were convinced that something was wrong with them and that they were expected to act in a different way. In a sense, they felt they had to be someone else:

> Well, adaptation really is a big one [problem] for me. For thirty years, I have tried being a blue square while I actually am a red circle. I try very hard to be like everybody else. (Cees)

The pressure to adapt and perceived high expectations often gave participants the feeling of having to perform to the highest standards at all times, inevitably leading to disappointment and failure when these standards could not be met. Participants frequently made statements like 'I want to but I can't' where they felt judged by their social environment as people that 'are able [to do certain things] but don't want to'. This spiral of failure and lack of understanding from their social environment led to feelings of low self-worth and to low self-image.

Low self-image: 'I come from a different world'

The perceived inability to think and act as they would like to, coupled with the lack of understanding from social networks, has a

negative impact on the self-image of many participants. Many explained that the phrase 'you can do it but you don't want to' was carved into their minds, reinforcing repeated feelings of not being good enough and of underachievement:

> Continuously trying so hard, and then you feel disappointed in yourself, because by trying so hard all the time, sooner or later, you get a setback; you can't do your best all the time. And then people tell you: you are worthless or you are no good. (Mark)

Mark, quoted above, wanted to behave optimally all the time and in all circumstances, an aspiration which was unrealistic, easily leading to a sense of failure and lack of acceptance by his social environment. Although social influence was important in shaping the feeling of having to perform optimally, many participants admitted that they had high expectations of themselves, were frequently unsatisfied with their achievements, and always thought they could do better. Moreover, they explained that the feeling of striving to be perfect becomes compulsive with time:

> I am such a perfectionist with what I want, because I really want everything to be tidy and I am continuously looking for the structure to do so, but I can't give myself that. (Margreet)

Expectations ranged from the every mundane tasks (e.g. having a tidy house) to professional and employment expectations (e.g. being the best at a very specialized job). Regardless of the type of task or life event, the negative impacts on self-esteem were similar. In most cases, not living up to one's own expectations led to a sense of underachievement and experience of failure. The continuous, common feeling of underachievement, in turn, contributed to low self-worth:

> For me, perfectionism is different from procrastination… No, not always, sometimes my targets are too high and then it is difficult to get started with my tasks and the consequence of this procrastination is shame: shit, I've done it wrong again… A vicious circle. (Karin)

Participants explained that, regardless of the repeated experiences of failure, they tried to start again 'the right way' and make a 'new start' for themselves, but they were often confronted with the inability to maintain this new way of doing things. This was often perceived as proof of inability to change or to do things better. In this 'cycle of failure', it was difficult to start challenging tasks due to the fear of continuous failure:

> I don't have faith it will work out but I try every time. And that causes my self-image to stay low because you keep on failing all the time. (Yvette)

Some participants explained that they felt they 'came from a different planet' as they continuously try to adapt to their environment. This, sometimes, led to feelings of alienation such as illustrated by Masha and Peter respectively:

> It seems like you can't be yourself in this world

> I already said it, we are beavers in the world of squirrels!

Not all participants interpreted the feeling of being different as a bad thing. Being different was described as a reflection of human diversity, including different qualities, competences and weaknesses. Some participants indicated they even perceived ADHD as an advantage, arguing that they were, for example, able to think faster, more creatively and more 'out of the box' than people without ADHD. Participants explained that they felt gifted in certain areas that are less developed in individuals without ADHD, for example as associative and creative thinkers and, to lesser extent, as faster thinkers as can be illustrated by the discussion excerpt:

> Martijn: You just understand, or see through, a lot of things more quickly than other people. For example, in a meeting when you come up with a certain solution, then people say: Huh where does that come from? And then, two weeks later, those people come up with exactly the same solution.!
> Peter: That is because we can think out of the box!

This was often extrapolated to the ability to be extremely powerful in designing more creative solutions for difficult problems. Associative and unconventional thinking was linked to successful careers requiring such traits, such as entrepreneurship.

Needs and future desires: 'We are a beautiful colourful world'

When future aspirations and desires were discussed, many participants visualized a world of harmony in which everyone is accepted for who they are, including shortcomings, and appreciated for their gifts and competences. To achieve this harmonious world, four steps were identified by participants: self-knowledge; acceptance and understanding; two-way communication; and appreciation.

Many participants explained that self-knowledge is an essential step to enable people with ADHD to function better in daily life. Self-knowledge would allow individuals to see their own weaknesses and understand where others might have problems with their behaviour. Ultimately, self-knowledge would make it possible to deal with or circumvent one's own behaviour:

> It is just like shooting with a gun at a fair. If you know the inaccuracy of your gun, it is possible to hit your targets. (Alice)

Moreover, several participants explained that awareness of their own weaknesses means that they know when to ask for help from others and how to instruct people in their social network to deal with their behaviour in specific situations. Asking for help, in turn, prevented failures and also lack of understanding from the social environment:

> Well, that understanding increases, the more you know who you are, the more your environment positively reinforces that and the more you find the setting in which you function best. (Jan)

Another important benefit of self-knowledge was that it helps to find an environment that best fits an individual's personality. If you know yourself, they explained, it is possible to find the people that accept you for who you are and that give you energy, instead of draining energy. Additionally, knowing yourself enabled participants to look for jobs that better aligned with their desires and competences:

> It is a quest. For example, last year I had a job, I have a new job every year, and I thought: 'Oh no, I am going to die here, I have to leave or I will kill myself!' And every time I think: and now I am going to find a job that suits me better, and I am not there yet, but I made one step in the right direction and I won't jump off my roof that soon anymore. (Anna)

Two pathways to acquiring self-knowledge were described: professional therapy and coaching; and having a 'mirror', namely contact with other people with ADHD. Indeed, the focus groups themselves were seen as an example of the latter. They helped the participants to reflect on their behaviour, how they function and the extent to which they are similar or different to others. Moreover, it sometimes helped them to gain self-knowledge as they saw their behaviour through the eyes of others. This, in turn, made them realize how difficult it can be for their own social environment to live with someone who has ADHD:

> You know how you can get that extra self-insight? By looking around in this [focus] group, for me it was really nice to recognize my own behaviour in others. It enables me to see when I behave in this way. Just what you said [other participant]: a lot of thoughts and immediately start talking, no matter who is talking at that moment. So, we see, from each other, how we behave, and that is very nice for self-knowledge. (Peter)

Most participants also wanted adults with ADHD to be accepted by their social environment as individuals with strengths and weaknesses. For this to happen, society should first accept that 'ADHD is a real thing and can cause real problems' for people with the disorder. One particular difficulty, according to participants, is that ADHD is not something which can objectively be proven to exist by, for example, a photograph or a scan:

> Because you can't see it [ADHD], that makes it so difficult. You can't see it. If you break your legs they think: well, that's sad, we'll help you with that. And if you have something wrong in your head, that they can't see, that they think what a freak. (Angelique)

Third, participants stressed that open, non-prejudicial communication with people in their social networks was crucial. This communication should be mutually open: person with ADHD could explain openly how they feel or what they are experiencing; and people in their social network could identify their boundaries or describe their feelings about living with someone with ADHD. In this way, an open and accepting environment could be created and this, in turn, would enable adults with ADHD to function better socially.

Finally, the greatest desire of the participants was concerned with their need for appreciation. Many participants explained that their characters also have positive, worthwhile characteristics from which the world could benefit and for which they would like to be appreciated. This goes beyond their desire to be accepted for their weaknesses:

> Well, I like to paint sometimes, and then I think: 'What if you have a painting where all colours blend into each other because we actually are a beautiful colourful world.' Then I think: 'Beautiful, that is where our strength is, that is where we complement each other.' If there is a little acceptance and everyone can live to his or her own competences, then together we stand strong. That not only the other is different but we see we are all different. (Johan)

Discussion

In this exploratory study, focus groups were conducted to better understand the problems faced by adults with ADHD in their daily lives, and their visions and needs for the future. We found that there were three interrelated categories of problems that the participants perceived to be particularly detrimental, namely the inability to control their thoughts, emotions and behaviours; the lack of understanding of their social environment; and the combination of high self-expectations and poor self-image. Their visions and desires for the future included improving self-knowledge, increasing social acceptance of the individual and his or her shortcomings; and appreciation of one's own gifts, talents and competences. Although symptoms, such as inattention, impulsivity and hyperactivity, were mentioned, priority was given to the social implications of these symptoms and the effect of these social implications on self-image. Few participants wanted to get rid of the symptoms completely because that would mean that they were not themselves anymore. Instead, they wanted the world to accept them for who they are and to appreciate them for their gifts and competences.

Adults with ADHD appear to consider that nothing works out the way they want and that even the easiest tasks will, for them, result in failure. This underperformance is often misinterpreted by those in their social environment, such as colleagues or spouses, as unwillingness. This leads to a lack of understanding, which, in turn, results in feelings of poor self-image and feelings of rejection. In other words, daily life with ADHD becomes problematic in relation to the broad social context, rather than ADHD and its symptoms being a problem in themselves.

Our study confirms findings that have been reported earlier. Experiences of adults with ADHD were comparable with those identified here, namely problems with interpersonal relations and feelings of being different from normal people; and repeated experiences of failure, and their effects on the self-image[1,14–16]. However, our study adds to previous research by providing an insight into how these problems are interrelated and strongly linked to social context. We hypothesize that it is the repeated and reinforcing interaction between problems with self-image and typical ADHD symptoms and the negative or even rejecting reactions of the environment that creates the tremendous impact of ADHD has on the daily lives of adults with the condition. Additionally, this is the first study to provide insights into the desires of adults with ADHD with regard to

the future, namely their desire for more societal acceptance of ADHD, for support from within their social environment and for appreciation of personal strengths.

The findings of this study reinforce the importance of person-centred care for people with ADHD. From the person-centred care perspective, therapies and 'doctor–patient' communication need to look beyond the disorder and consider the individual as a whole, including his or her context, emotional needs and life issues[22,23]. Our study highlights the need to pay more attention to problems specific to adult life with ADHD, particularly in relation to the social environment. Moreover, participants expressed the need for more positive acceptance of adults with ADHD and a stronger focus on personal strengths. Currently, neither of these perspectives have an explicit place in standard practice for the treatment of adult ADHD, as recommended by Kooij *et al.*[1] or the guidelines from the National Institute of Health and Care Excellence[24].

In this context, and also reflecting Brod *et al.*'s[15] proposal of the need to further investigate the role of social stigma on wellbeing of adults with ADHD, we propose that future research should investigate the role of the social environment and social stigma on the quality of life of adults with ADHD. Future research should investigate how therapeutic interventions can be adapted or supplemented to address the role of the social environment. Moreover, participants highlighted the need for positive acceptance and recognition of personal strengths, possible paths for research which focuses on person-centred therapies.

This study has two limitations. First, most participants had received their diagnosis relatively recently with a median of 2 years, which may indicate that they were still coming to terms with their condition. Second, groups were heterogeneous with respect to diagnosed type of the disorder, namely ADHD, ADD or the combined type, and comorbid disorders, which could have disguised differences between these groups of adults with ADHD.

Conclusions

The symptoms of ADHD in themselves were not seen as a problem by most of the participants. Although coping with ADHD was a struggle for some, ADHD appears to become most problematic in the social environment with symptoms, self-image and social environment all playing central roles. Adults with ADHD appear to have low expectations of what they can achieve and expect failure. This underperformance is often interpreted by those in their social environment, such as colleagues or spouses, as unwillingness. This lack of acceptance results in feelings of not being good enough and feelings of rejection. The role of the social environment should be investigated in future research so that suitable therapeutic strategies can be developed to integrate the environment in the treatment process.

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