Chapter 6

The burden of ADHD in older adults: a qualitative study


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ABSTRACT

Objective: To explore how ADHD may have affected the lives of older adults who meet the diagnostic criteria of ADHD, but are unaware of their diagnosis. Our second aim was to examine whether the reported symptoms change over the life span.

Method: A qualitative study was conducted following a thematic approach. Seventeen Dutch older people (>65 years), diagnosed in this study with ADHD, but unaware of their diagnosis, participated in in-depth interviews. Data were analyzed according to techniques of coding and constant comparison.

Results: Seven themes emerged from the analyses. Four themes correspond to ADHD symptoms: being active’, ‘being impulsive’ ‘attention problems’ and ‘mental restlessness’. In addition the themes ‘low self-esteem’ ‘overstepping boundaries’ ‘feeling misunderstood’ emerged. The impact of ADHD symptoms seems to have declined with age.

Conclusion: ADHD has a negative impact late life and older adults with the disorder may benefit from treatment. Moreover, this study’s findings call for an early detection and treatment of ADHD in children and adults. Effective treatment at younger age may prevent much hardship over the life span.
INTRODUCTION

Attention Deficit/Hyperactivity Disorder (ADHD) is a psychiatric disorder with symptoms of inattentiveness, impulsivity and/or hyperactivity. Individuals with ADHD often experience forgetfulness, difficulty planning, restlessness and mood instability (1,2). ADHD negatively affects children and adults in their functioning in several fields, such as in friendships (3,4), relationships (5), education (6) and work (7). For a long time ADHD has been viewed as a child disorder, but in the last decades research has shown that the disorder persists into adulthood (8). Studies showed that overt signs of hyperactivity/impulsivity seem to decline in adulthood, while inattention continues largely unchanged (9–11).

Only recently studies started focusing on the disorder in late life. First, a few case studies appeared in the literature describing the disorder in late life (12–14), followed by quantitative studies showing that the disorder may also persist in old age (15,16). Furthermore, quantitative studies based on the Longitudinal Ageing Study Amsterdam (LASA) data showed that ADHD in old age is associated with loneliness (17), depressive and anxiety symptoms (18), lower self-esteem and sense of mastery (19) and lower self-perceived health (20).

So far, two qualitative studies have investigated the impact of ADHD in late life. The first (pilot)study, examined the experiences of 27 older men and women, aged 60-77 years, diagnosed with ADHD (21). The most important theme that emerged was “the burden of ADHD across the life course”. Most respondents reported a tangible, accumulative impact of their ADHD on their finances, reflecting missed career opportunities, reduced income and retirement funds due to impulsive spending, and reported that their ADHD symptoms alienated friends, family, and co-workers (21). The other qualitative study examined the experiences of older adult women with ADHD (22). Several main themes were found, such as “peer rejection”, “feeling different” and “family and marriage experiences” the latter reflecting in some cases marital problems and conflicts with children.

These two studies provide a first insight in the experiences of older adults diagnosed with ADHD across the life span. However, the two studies included diagnosed older adults in a clinical sample, while it is unknown how older adults with this disorder in the general population have experienced their lives. It is more likely that the disorder has not been recognized and treated among the majority of older adults in the general population. It is unknown how older adults who are unaware of their diagnosis experience their symptoms and how ADHD may have affected their lives. Older adults who are unaware of their diagnosis will interpret their experiences without any iatrogenic or other bias due to diagnosis and this “unclouded” view of their self and life experiences may give new insights in the possible
experienced problems in later life. In addition, little is known how the disorder affected the lives of older adults who received their diagnosis in late life, but never received treatment before and after the diagnosis. Therefore, the aim of this study was to explore how the symptoms may have affected the lives of older adults who meet the diagnostic criteria of ADHD, but have never in their lives been diagnosed with ADHD and/or have never been treated for the disorder. Since studies showed that overt signs of hyperactivity/impulsivity seem to decline in adulthood, while inattention continues largely unchanged (9–11), we additionally explore whether the reported symptoms change over the life span.

METHODS

A qualitative interview study was conducted from October 2013 to November 2014, encompassing in-depth interviews with 17 older adults with a (research)diagnosis of ADHD.

Respondents and sampling

Respondents for the in-depth interviews were selected from the Longitudinal Aging Study Amsterdam (LASA), an ongoing study of changes in autonomy and well-being with aging in The Netherlands that started in 1992 with 3-year follow-cycles (23). In 2008-2009 an ADHD side study started. Full details of the ADHD side study on sampling, measurements and non-response are described elsewhere (24). In short, on the basis of the results of an ADHD screening list (25), participants were invited for a diagnostic ADHD interview (DIVA 2.0) (26). For the ADHD diagnosis the cut-off point for current symptoms suggested by Kooij et al. (27) and Barkley et al. (28) was used: it was required to have four or more symptoms of either inattention and/or hyperactivity-impulsivity during the 6 months prior to the interview (27), and to have had six symptoms of either inattention and/or hyperactivity-impulsivity in childhood (DSM-IV criterion A).

LASA has the protocol not to inform the respondents when they fulfill the requirements of a diagnosis. The respondents were asked for their informed consent to participate in an “attention and concentration study”. For the present study they approved to participate after they received written information in which more information was given, i.e. that we were interested in the possible changes in attention and concentration capacity when ageing; how they dealt with their attention and concentration problems during their life, and whether the impact of the attention and concentration problems was different at an older age than younger age. Therefore the participants remained unaware of their (ADHD) diagnosis. In total 23 respondents fulfilled the criteria for ADHD.
Data collection and analysis

Semi-structured in-depth interviews took place in the homes of the respondents and lasted between 90-150 minutes. All interviews were conducted one on one, except for one interview where the partner was present. Before the session, written informed consent and approval for recording of the interview was obtained. Since the respondents were not aware about their diagnosis, respondents were asked how they would describe their personality characteristics and whether these characteristics had changed over their life span. The interview guide, based on literature and clinical expert opinion (29), consisted of the following topics: daily structure, personality characteristics, changes in personality characteristics over the life course and feeling different/misunderstood.

Five interviews were conducted by two interviewers, four by MM and SvM and one by MM and JdK. All the other interviews were conducted by MM. Except for one interview where only the first 16 minutes were taped due to recorder failure, all the other interviews were fully audiotaped. Directly after the unrecorded interview a summary was made and sent to the respondent, who agreed with the summary. The sampling stopped when saturation of data was reached, which was defined as an understanding on the most relevant themes.

To foster validity, member checks were used. The respondents were asked to give feedback on a summary of the most important findings.

Interviews were transcribed verbatim and to ensure anonymity, numbers were allocated to the participants and no names were mentioned in the transcriptions. Thematic analysis was conducted based on comparisons within and across respondents using ATLAS.ti 5.2 software, into which all interview transcripts were imported.

Data analysis of the first interviews was done by two researchers (MM) and (SvM) so that they could agree upon a method of coding. The analyses of the remaining interviews were performed by the most experienced qualitative researcher and consisted of three steps and discussion with JdK.

First, the transcripts were read several times. The texts were divided into fragments, and codes (labels) were assigned to these fragments (open coding). Subsequently, codes were assigned to themes and finally, the categories of the several transcripts were related to one another (axial coding). These codes were all organized into a mind map, using the computer program MindManager (Mindjet, 2012). The preliminary conclusions based on this mind map were thoroughly discussed between MM and JdK. The last phase of the analysis was selective coding. This implies that we identified the essence of what each theme is about, searched for relations through constant comparison across cases (individual interviews), looked for deviant cases, and analyzed variation within and between cases. Finally the
different themes were fit into the broader overall ‘story’ that the data told us, to gain insight into differences and similarities between the findings from previous quantitative analyses and current qualitative analyses. All findings were discussed in the project team.

Table 1 Demographic characteristics

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<th>Respondents N=17</th>
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<tr>
<td><strong>Sex</strong></td>
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<tr>
<td>Female</td>
<td>10</td>
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<tr>
<td><strong>Partner status</strong></td>
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<td>Partner, previous</td>
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<td>divorced</td>
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<tr>
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<tr>
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<td>3</td>
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<td>Divorced</td>
<td>4</td>
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<td><strong>Children</strong></td>
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<td>67-69</td>
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<td><strong>Age (at interview)</strong></td>
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<td>5-6</td>
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<td>9-10</td>
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<td>11-12</td>
<td>5</td>
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<tr>
<td><strong>Years of education</strong></td>
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<td>5-6</td>
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<td>9-10</td>
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<td>11-12</td>
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<tr>
<td><strong>(Physical) Comorbidity</strong></td>
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<tr>
<td>(previous) Heart Disease</td>
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</tr>
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<td>Hypertension</td>
<td>5</td>
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<tr>
<td>Dyslexia</td>
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RESULTS

Subjects

In total 17 respondents were interviewed. Their demographic details are presented in Table 1. All respondents lived independently. One respondent turned out to be diagnosed with ADHD a couple of years before the interview.

Themes

The emerging themes corresponding to ADHD symptoms are ‘being active’, ‘being impulsive’ ‘attention problems’ and ‘mental restlessness’. Three other themes emerged: ‘low self-esteem’ ‘overstepping boundaries’ and ‘feeling misunderstood’.
Being active

The respondents found the question, “how would you describe yourself (your personality characteristics)?”, difficult to answer. One of the first things being mentioned was ‘being active’ or being busy. ‘Being active’ can be divided in the subthemes ‘being busy’, ‘talkative’ and ‘physical restlessness’. This theme corresponds to the hyperactivity symptoms of ADHD described in the DSM-5. Not only would they describe themselves as busy, sometimes others did too:

“Busy. I am always busy. I am always on the go. Sometimes they say ‘what is it you have to do?’ I have a lot of things to do.” (f, 74 years); “Friends tell me ‘I get tired because you are so busy.’” (f, 83 years).

Respondents mention doing lots of physical activities, such as playing sports, cycling and walking, the latter two often for hours on end. Their agendas are often full, and some mention being short on time due to their hobbies and activities. ‘Being active’ also meant ‘being talkative’ as the following respondent mentions: “I can be really active, like I am talking now.” (f, 73 years). ‘Being talkative’ was often observed by the interviewer(s).

Two respondents thought that being active might derive from psychical restlessness. Some respondents felt they were driven by a feeling or an urge in childhood and adulthood that they ‘must do things’, or felt an urge to do things, as one lady told us: “After 15 minutes [reading] I have to do something.” (f, 68 years). Physical restlessness was also reflected in head scratching or moving with their feet.

The respondents recognized themselves as being active their whole lives. They mentioned finding it difficult to sit still in primary school, others were talking lots and being very active at young age, such as this older man: “After school, I ran everywhere, I would always run... I think it was a way to relax, that was the reason.” (m, 72 years). ‘Being talkative’ sometimes resulted in punishment at school.

In adulthood they mentioned being hard workers, some working more than 50 hours per week (mostly men). ‘Being active’ was mostly described as something that suited them, being a part of them, in contrast to sitting quietly in their homes.

Ten respondents did not experience negative consequences of being active at an older age. It was often mentioned that it was good to be active at an old age: “it keeps me young” and “I think it delays deterioration”. But some negative consequences were mentioned. ‘Being talkative’ sometimes has a negative impact in social interactions at older age: “Well, I can be
overly present and some people find that a bad thing.” (f, 73 years). It was also mentioned that ‘being active’ resulted in not having enough time for oneself or for the housekeeping and it was also brought up that it could be annoying not being able to sit still “Jeez, why do I have to go now. Why do I have to get up again?” (f, 68 years). One respondent, who takes care of his sick partner and is therefore more homebound, mentioned not being able to get rid of his energy and missed being active.

Nine respondents said that ‘being active’ or being busy became less as they became older. In addition, ageing and diseases were mentioned as reasons why they were less active. Only two mentioned that they became more active. One respondent mentioned that she was a bigger ‘chatterbox’ than before. She is often on her own, and when she is with someone, she talks more than she used to. One respondent said she became even more active since her husband died. She could not stand the quiet Sunday mornings and joined a walking club, now walking 12km every Sunday.

**Being impulsive**

Eight of the respondents reported ‘being impulsive’. Mostly they reported being impulsive in saying things, which results in humorous, but also hurtful situations, the latter they often regret. Being impulsive in buying things such as clothes was mentioned, but this does not necessarily result in debt. Only one respondent is ‘really poor’ due to impulsive money spending in earlier years.

Being impulsive is what the respondents have been throughout their lives. Throughout their lives their impulsiveness had positive and negative consequences. Positive consequences of their impulsivity were mentioned, such as having had interesting experiences and being in for fun; “I see an ad in the newspaper for a hiking trip in Lapland, I said “great”. It was two days later; I quickly packed a bag.” (f, 76 years). However, wearing their hearts on their sleeves, expressing opinions too quickly and immediately reacting to a row had a negative influence on (intimate) relationships, where family members, partners, neighbors or friends got upset. In two cases it resulted in ‘dropping out’ of friends. In their younger years it resulted in problems with the teachers and detention at school.

Except for one respondent, all respondents said they learned not being verbally impulsive, due to the negative consequences. They are more careful in what they say although it cannot always be prevented. One respondent said he got more direct (and blunt) with saying things and not always thinking it through. “Across the street there is a supermarket. In my opinion, they can bomb the place. The way they treat you. And sometimes I go there and say ‘just act normal with your big mouth’ while actually, it does not have anything to do with me.” (m,
He was not able to explain the reason why he became more impulsive in saying things.

**Attention problems**

The theme attention problems can be divided into the subthemes ‘chaotic’, ‘concentration problems’ and ‘difficulty structuring’. Some respondents described themselves as being ‘chaotic’ or sloppy, meaning having a messy, chaotic house. In their seemingly disorganized house some respondents know exactly where their belongings are, while others are often searching for things. Being ‘chaotic’ could also mean being easily sidetracked by other chores or thoughts, sometimes leading to forgetting what they were going to do. Overall, being chaotic did not change over the life course, although for some it now took longer to find things around the house. Being easily sidetracked by other chores did not change for some, but became less by others due to physical illnesses. Most respondents did not mind being chaotic, but their partners did.

“If I have forgotten something, it will come back to me later, ‘oh yeah, I was going to do this or that’. I have to do things immediately. If I walk to the shed, take of my shoes...than for sure I come out of the shed calling my wife. I’ve already forgotten it, I am already busy with something else.” Partner of the respondent: “It bothers me, not him. It bothers me.” (m, 67 years).

‘Concentration problems’ were mentioned, such as difficulty reading a book, difficulty reading official letters from the local government, difficulty doing two things at a time, forgetting things (in social relationships) and difficulty concentrating on conversations (when boring). Forgetting things was mentioned as something that was present throughout their lives. Respondents learned to cope with their forgetfulness by immediately writing things down, for example at their work or doing daily chores. However, forgetfulness did lead to some distress; it led to feelings of annoyance and one respondent mentioned having difficulty maintaining friendships because he continually forgets to call friends. ‘Concentration problems’ were also reported in early childhood. Respondents mentioned being easily distracted by their own thoughts (being a “dreamer”) and/or by external stimuli. This sometimes led to difficulty absorbing information in class, resulting in poor performance at school. Dreaming was often a way to escape boring lessons or situations.

“I was a bit of a dreamer then [primary school]. Absorbed too little, and then later, in later phases you have a lot of catching up to do....I had to work in the evenings to get my high school diploma.” (m, 73 years).
“With my fantasy and with my thoughts I was far far away...my mother used to say to me ‘you look like a sail dancer’. I said, ‘What do you mean?’ ‘You balance on a thin sail, you do not see what happens on your right, or on your left, you are in a parallel universe.’ Or she would say ‘somehow nothing happens to you, I don't know how you do it, but you are a dream dancer.” (f, 74 years).

Being a dreamer and being distracted became less over the years, but was still present. One respondent mentioned that dreaming had sometimes a negative consequence; time passed away more quickly than estimated and her daily tasks had to be done in less time.

Seven of the respondents reported to prefer a loose day or week structure and half of them preferred a organized week(day), which suited them better. A couple of respondents reported ‘difficulty structuring’ their days: “I have difficulty with that [structuring her days], I am not one to have a program. On the one hand, I say I should be able to do it, but I just can’t.” (f, 73 years). After retirement, the majority of the respondents enjoyed structuring their days as they pleased. For some it meant a change into a looser day structure where not a lot of things were planned. However, for three respondents the changes in their lives at old age resulted in difficulty structuring their days. Work, children and partner gave structure to their lives, when this ‘disappeared’ they found it difficult to give structure to their lives. In addition, for one respondent, giving informal care to a family member had a large influence on her weekly schedule. She found it difficult to plan her week efficiently and it resulted in stress and physical complaints. For three respondents the day-night rhythm became reversed and due to lack of structure lunches were missed, and they “muddled along” through the day.

Mental restlessness
Closely related to the previous themes, another theme that emerged was ‘mental restlessness’. Respondents mentioned their minds being restless and having constant thoughts: “There are too many things in my mind to do. Then I think yes, I still have to vacuum my bed, check my computer, make coffee...then you’re busy with two things and that is not good. Then I catch myself and I think ‘take it easy, you have all day.” (f, 83 years). Mental restlessness is also expressed by getting easily agitated, being impatient and feeling nervous. Most respondents see their restlessness as a part of themselves and described themselves as nervous in primary school. One respondent mentioned she probably needs some tension to be able to do things. One respondent explained that her mind became more restless due to the complexity of the modern world. She found it more difficult to structure her thoughts when dealing with bank and health insurance issues.
The feeling of many respondents that they ‘must do things’ became less over the years. Before, things had to be done as soon as possible, respondents felt they were in a hurry, impatient, but in later life respondents were able to perform their tasks in a more relaxed manner, e.g., dividing their tasks over more days. The change in restlessness was mostly explained by retirement, when work pressure disappeared and more time became available. In addition they learned to deal with the restlessness:

“My mind is always restless hahaha. Yes, that is probably the reason why I have to get up so early, the day is pressing…. it makes me nervous, all the things I have to do and then I just start….it does not create as much tension anymore in me…. it is less, but I don’t think it will disappear… I have had countless yoga lessons, I learned to cope with it, but to let it go completely, I cannot do that, it is here to stay.” (f, 76 years).

Low self-esteem
Eight of the respondents mentioned low self-esteem in childhood and at present. It is unclear if having attention problems, restlessness and/or impulsivity was related to low self-esteem. Respondents mentioned they often were told by their parents or teachers in their childhood that they could not do anything right. For two respondents their parents were not only negative about them, but about all their siblings. Another reason mentioned for having low self-esteem was ex-partners who were physically abusive and degrading. However, experiences such as sitting in a row where all ‘the dumb kids’ had to sit, difficulty learning, being slow, having bad grades, and often being punished at school were mentioned. These negative experiences may have had a role in developing poor self-belief.

Low self-esteem had several consequences in adolescence and adulthood, such as being shy or uncomfortable around others. Overall, self-esteem improved when getting older. Positive experiences (e.g. getting a good job, raising a family well) and having good friends and an accepting partner increased self-esteem. In addition, one respondent decided at age 65 years to sign up for assertiveness course, from which he benefited.

Overstepping boundaries
‘Overstepping boundaries’ is another theme that emerged. ‘Overstepping boundaries’ is reflected in difficulty saying no and working too hard. Reasons why they had difficulty saying no were being too fast in saying yes without thinking things through; out of insecurity and wanting to take care of others. One respondent mentioned that overstepping boundaries runs in the family. Difficulty saying no resulted in doing tasks they did not want to do, associating themselves with people they did not want to be with and sometimes resulting in having too much on their plate. Due to working too hard and not saying no they tended
to step over their physical boundaries, resulting in physical ailments due to too much stress, such as stomach ulcer or shingles.

“I worked too hard. The doctor even told me to stop working.” (f, 84 years).
“I am always busy...I was always very busy. I wanted to do everything....Back then, than, oh boy, once I started... the boat, I made it in one and a half year. I was completely nuts, too crazy...I was totally burned-out.” (m, 67 years).

While working too hard during working life, nine respondents seemed to slow down after retirement. One respondent explained, “I am consciously slowing things down. I became more aware of my body. If something is going on with my body I respond to it now. Earlier I would have thought that it would disappear by itself.” (m, 76 years).

Although the respondents try to slow down it is not always easy to them. A respondent who herself has difficulty walking and bending over, visited her neighbor lately. The neighbor asked her to get her shoes from underneath her bed. “I said to her: “take it easy, I also can not crawl underneath the bed”. But in the end I do it anyway.” (f, 84 years).

Feeling different/misunderstood
Feeling different and/or misunderstood were included in the topic list based on literature and/or clinical expert opinion (22,30). The majority of the respondents did not describe themselves feeling different from others. However, seven respondents mentioned feeling misunderstood in their childhood by their family members and/or teachers. Problems at school were often not understood by parents and teachers. The respondents were often the first ones in the family to rebel against religion and were more outspoken against parents than their siblings. The respondent who received an ADHD diagnosis previous to this study, said he did not feel understood by his teachers and parents regarding his learning problems at school. He sees that his grandchild, also diagnosed with ADHD, receives better counseling at school for his problems than the respondent did when he was young. Only three respondents still mention feeling misunderstood by others, mainly peers.

DISCUSSION
This study aimed to explore how ADHD symptoms may have affected the lives of older adults, aged 65 and over, who meet the diagnostic criteria of ADHD, but were not diagnosed with the disorder, and whether the reported symptoms had changed over the life course. Seven master themes emerged, four corresponding to ADHD symptoms and three corresponding with descriptions of behavior in the literature and clinical practice in children and adults.
with ADHD. The emerged themes ‘being active’, ‘being impulsive’, ‘attention problems’ and ‘mental restlessness’ correspond with the two basic clusters of ADHD symptoms inattention and impulsivity/hyperactivity described by the DSM-5 (31). ‘Classic’ ADHD symptoms were mentioned such as being talkative, being impulsive, feeling restless and being easily distracted by inner thoughts or external stimuli. These symptoms were experienced as being a part of their personality, as a part of their lives.

The theme ‘low self-esteem’ is in line with our previous quantitative study among the same older adults (19) and is in concordance with the literature and clinical observations in children and adults with ADHD (32–34). Safren,(35) developed an theoretical model for adult ADHD, explaining how adults with ADHD may develop a negative self-image. Negative experiences from a young age adversely affect the formation of an individual’s self-esteem (36). A vicious circle may arise of ongoing stressful events and disappointments where the ADHD patient sees his low self-esteem confirmed. Although only a few respondents linked reporting having low self-esteem to their ADHD symptoms, all of them had a history of difficulties at school and at home, which may have played a role in developing low self-esteem. ‘Overstepping boundaries’ is a result that is in line with clinical observations but has been described little in scientific literature. Clinical observations show that some adults with ADHD become workaholics and have trouble relaxing (37), others work many hours overtime to keep up with the workload (38). Working too hard may be one of the pathways in developing a burnout. Research of Brattberg (39) among adults with a burnout showed that 24% met the diagnosis of ADHD. ADHD may be a risk factor for developing a burnout; more research on this subject is recommended. ‘Feeling misunderstood’ is also a theme that is in line with clinical observations (30). Children and adults with ADHD may feel they are constantly being criticized by others, and as a consequence feel misunderstood. Therefore, psycho-education is an important component in treatment that will help family members as well as the individual with ADHD to develop an understanding of the potential disabling effects of ADHD. In addition, group therapy providing the opportunity to meet people with similar problems may diminish the feeling of being misunderstood (30).

In contrast to the study of Henry and Jones (22), this study did not replicate their most important themes ‘peer rejection’ ‘feeling different’ and ‘family and marriage experiences’. The majority of the respondents in our study also reported marital problems, but in the perception of the respondents the problems were caused by their physically and/or mentally abusive (ex) partners. Another reason for the different findings may be the dimensional manifestation of the symptoms and impairments. Respondents varied in intensity of the symptoms and impairments, ranging from hardly any impairment to severe impairments in several fields such as marital conflicts and peer rejection. In addition, a subclinical cut-off
score was used in this study. Since all the respondents in the study of Henry and Jones were in treatment in a mental health care organization, it is likely their respondents experienced more severe impairment than respondents in our study.

The ADHD symptoms seem to have had a more negative impact in the younger years than in the current lives of the respondents. Most respondents experienced primary and high school as the worst time of their lives. Punishment due to impulsive and/or hyperactive behavior and difficulty learning due to attention problems made the school period an unpleasant time. Throughout their lives they experienced conflicts with others due to impulsiveness, distress and physical ailments due to overstepping their own boundaries and low self-esteem. Although the respondents still experience negative effects of having difficulty concentrating and being impulsive, the consequences are less disturbing than in earlier life. There may be several explanations for this.

First, respondents learned to cope with the symptoms throughout their lives. For example, respondents mentioned developing tricks and trained their memory to cope with forgetfulness as a consequence of inattentiveness and they learned to ‘think before they act’ since being verbally impulsive had a negative influence on relationships. In the literature there has been little attention for the coping strategies commonly employed by adults with ADHD. One study found that adults with ADHD positively reappraised stressful situations, a coping strategy reflecting the effort to create positive meaning by focusing on personal growth (e.g. changed or grew as a person in a good way) (Young, 2005). This positive reappraisal of situations may mean, according to Young, that adults with ADHD have “the ability to reframe the problems they face in their lives which causes them to be resilient to disappointments”. In addition, there are two explanations for resilience of older adults regarding distress in later life (41). First, the inoculation hypothesis argues that exposure to mildly stressful events in earlier life may make an individual more resilient to adverse events later in life.

Second, the maturation hypothesis argues that older adults may be less reactive to stressful events in later life. Increased psychological maturation, including more mature coping styles may protect older adult against stressors (41). Many respondents were able to have families, complete an education and have careers, all while living with undiagnosed ADHD. Learning to handle the symptoms along with positive coping strategies may have helped the respondents being resilient throughout their lives. Second, normal neurobiological ageing processes may lead to diminished manifestations of certain symptoms. There is converging evidence from behavioral and neurobiological studies showing that impulse control improves between childhood and adolescence, as well as between adolescence and adulthood (42). Third, the later life stage seemed to play a role in the expression of certain symptoms. After retirement the pressure of work disappeared. Being able to do things in
their own time made especially the hurried feeling or the urge to do things less prominent. In this later stage of life respondents are more often confronted with illnesses, which ‘forced’ them to be less active or impulsive. Tasks in which they were easily distracted in earlier life, for example tasks at work or cleaning the house, were no longer present or were done by others.

Even though the ADHD symptoms seem to lead to less impairment in older age, there are potential problems that may arise specifically in later stages in life. In older age it is more likely that one becomes an informal caregiver. Organizing the extra care may be much harder for an older adult with ADHD, since it heavily relies on executive functioning, such as planning, keeping an overview and purposive action. Older adults with ADHD may be more vulnerable of being overburdened by the care giving than older adults without ADHD. Further research is needed to examine the potential psychological burden of older informal caregivers with ADHD.

In recent years there has been a steep increase in the public debate concerning the validity of ADHD. It has been argued that ADHD is not a real disorder but a mere cultural construct (43) or a symptom of weak parenting (44,45). Although it was not an aim of the study to validate the disorder, the lifelong ADHD symptoms reported by the respondents who are unaware of their diagnosis correspond with ADHD symptoms and experiences of younger adults with ADHD seen in outpatient care, give an indirect validation of the ADHD diagnosis.

**Limitations and conclusion**

Since little research has been done among older adults with ADHD, our study gives first insight in the experiences of older adults with ADHD who are unaware of their diagnosis, but the results should be interpreted in the context of several limitations. In this study information about other psychiatric disorders were unknown and the presence of potential comorbid disorders renders it difficult to determine the effects of ADHD versus those of other disorders. Since the respondents mentioned lifetime persistence of the symptoms and mentioned impairment due to the symptoms, it should correctly reflect the experiences of older adults with ADHD, even when they are suffering from a comorbid disorder, such as depressive disorder, at present. Another limitation is that we did not ask the respondents whether they would have liked to receive help for their inattention and or impulsivity problems. In addition, the sample included only Caucasian respondents; in future research a more culturally diverse sample is needed. Lastly, since we did not ask the respondents directly whether they have ever received a diagnosis of ADHD. Therefore we cannot be certain that they were all unaware of their diagnosis.
ADHD manifests throughout the life span and the respondents were unknowingly suffering and coping with this disorder. Their stories reflect hardship and struggle as well as resilience. The disorder has a dimensional manifestation of the symptoms and impairments in old age, and older adults with more severe impairments may benefit from treatment. Moreover, this study’s findings call for an early detection and treatment of ADHD in children and adults with severe impairments. Effective treatment at young age, with the aim to learn to live well with ADHD, including psycho-education, coping strategies and skills training, and to enhance self-esteem and improve insight of their (physical) limitations, may potentially prevent a lot of misery over the life span.
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