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## Being Different but Striving to Seem Normal: The Lived Experiences of People Aged 50+ with ADHD

Anne Nyström, RN, MSc<sup>a</sup>, Kerstin Petersson, RNT, MSc, PhD<sup>b</sup>, and Ann-Christin Janlöv, RNT, MSc, PhD<sup>a</sup>

<sup>a</sup>Faculty of Health Sciences, Department of Nursing and Health Sciences, Kristianstad University, Kristianstad, Sweden; <sup>b</sup>Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden

### ABSTRACT

This qualitative study explored the day-to-day life of people aged 50+ diagnosed with ADHD. A phenomenological-hermeneutical method was chosen for the analysis. Two themes including sub-themes were revealed. The first theme, *Being different and trying to handle my inner self*, concerned emotional self-regulation, emotional resilience, social skills, and personal resource management. The second theme, *Trying to adapt to fit in with people around me*, concerned relationships, work, and personal finances. The comprehensive understanding was interpreted as *Being different but striving to seem normal*.



### Background

Attention Deficit Hyperactivity Disorder (ADHD) is a condition affecting different areas of life ranging from school and work to personal relationships. Our knowledge of ADHD has increased, but mostly in areas affecting children and younger adults. Children with ADHD grow up, but how their day-to-day life is affected as they grow older is less known. Adult ADHD can be found in the research literature since 1976 (Wood, Reimherr, Wender, & Johnson, 1976). Subsequent research shows that ADHD persists into adulthood (Fayyad et al., 2017; Semeijn et al., 2016), and old age (Torgersen, Gjervan, Lensing, & Rasmussen, 2016).

Depending on diagnostic criteria and methods for data collection, reported prevalence of ADHD may vary. The prevalence of adult ADHD has been estimated to 2.8–4.4% worldwide. World Mental Health (WMH) surveys from 11 countries (USA included) estimated adult ADHD (18–44 years) to averaged 3.5% (Fayyad et al., 2007), and later in 20 other countries the prevalence was estimated to be averaged 2.8% (Fayyad et al., 2017). The National Comorbidity Survey Replication in USA estimated the prevalence to 4.4% (Kessler et al., 2006). Populations diagnosed with ADHD are known to often report other mental co-morbidities (Brod, Schmitt, Goodwin, Hodgkins, & Niebler, 2012a; Kooij et al., 2019; Silva et al., 2013) and heritability is estimated to 70–80% for adult and childhood ADHD (Kooij et al., 2019).

People with ADHD may get diagnosed at different times in their lives (Brod, Pohlman, Lasser, & Hodgkins, 2012b), or not at all. Hansson Halleröd, Anckarsäter, Råstam, and

Hansson Scherman (2015) interviewed 21 adults in Sweden diagnosed with ADHD about the perceived consequences of being diagnosed with ADHD as an adult. It was mostly regarded as positive to be diagnosed. About half of them acknowledged some negative consequences with being diagnosed, but none regretted going through the neuropsychiatric evaluation. Brod et al. (2012b), with the aim to understand the burden that ADHD posed on diagnosed adults (aged 18–62, mean age 36), made a comparison across seven countries in North America and Europe. Focus groups (N = 14, total 103 participants) and telephone interviews (N = 5) revealed that ADHD (i.e. burdening symptoms, impact of ADHD through life, work life, personal finances, relationships and mental health) affected peoples' lives similarly across these countries, regardless socioculture and health care systems. Later, adult ADHD was focused by Schrevel, Dedding, van Aken, and Broerse (2016). Adults aged 21 years and older (N = 52, mean 43 years) participated in eight focus groups in five cities in the Netherlands. While they did record being affected by their ADHD symptoms, they expressed suffering more from the negative social consequences of ADHD, which led to poor self-image. A literature review with European focus on young and adult people with ADHD indicated that their life circumstances got worse as they grew older (Ginsberg, Beusterien, Amos, Jousselein, & Asherson, 2014). Moreover, Das, Cherbuin, Easta, and Anstey (2014) conducted an Australian study that compared different age groups (20–24, 40–44, 60–64) with ADHD, which suggested that ADHD symptoms persist but decrease with age.

**CONTACT** Ann-Christin Janlöv  ann-christin.janlov@hkr  Faculty of Health Sciences, Department of Nursing and Health Sciences, Kristianstad University, Kristianstad, SE-291 26 Sweden.

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**Table 1.** The demographic data of the participants.

Gender	Female	7
	Male	3
Age	50–55	5
	55–60	4
	60–65	0
	65–70	0
	70–	1
Marital status	Married/in relationship	0
	Single (unmarried or divorced)	10
	Children	9
Housing	Apartment	6
	House	4
Education	Compulsory school	2
	Secondary school	3
	Adult education	1
	University	4
Occupation	Unemployed/pension	3
	Sick-leave	3
	Retired	1
	Self-employed	1
	Working part time/pension	2

A growing number of people age 50 years and older are diagnosed and treated for ADHD worldwide (Torgersen et al., 2016). In Longitudinal Aging Study Amsterdam (LASA), Michielsen et al. (2012) by a random sample of men and women ( $N = 231$ ) aged 55–85 years, concluded that 2.8% of older adults had full-blown syndromatic ADHD and 4.2% symptomatic ADHD.

In research conducted on older adults with ADHD, participants reported that ADHD had had a negative impact on their life circumstances. A German study by Philippe-Wiegmann, Retz-Junginger, Retz, and Rösler (2016) explored if the burden of ADHD is the same after 50 as at younger ages. Out of 296 respondents (mean age 69.55 years), 11 had ADHD and answered a questionnaire. They reported the negative impact of ADHD remaining stable across their lifespan in family life, social relationships, dealing with money, and organization of daily life. In The Netherlands Michielsen et al. (2015) from the LASA study explored the association between an ADHD diagnosis and social functioning and participation in older adults. Of 231 people aged 60–94 years, 23 was diagnosed with ADHD. Among the effects of ADHD greater participation in recreational activities was reported, which could be a result of a need “to do something” as a result of hyperactivity or impulsiveness commonly observed with ADHD. However, life remained difficult, especially social life resulting in such as getting divorced/never marrying, having less social interaction with family members, and a higher level of perceived loneliness.

Qualitative studies focusing on life with ADHD in old age are few. In the United States, Brod et al. (2012b) conducted telephone interviews with 24 older adults aged 60–77 years diagnosed with ADHD to study the burden of the illness. The interviewees stated that aging had little impact on the experience of ADHD symptoms and the impairments did not appear to be different from when they were younger. Positive effects of ADHD were also found. Half of the individuals in the study perceived themselves as being more creative, more enthusiastic, aware of the multiplicity of things and able to be hyper-focused and multitask when interested in a topic. Based on the LASA study on the

sample of older people aged 55–85, Michielsen et al. (2018) conducted a study with the aim to explore how ADHD affects the lives of older adults. They interviewed 17 people who, according to the researchers, met the criteria of ADHD but were unaware of the diagnosis themselves. The participants reported doing lots of physical activity and having full agendas but struggling with low self-esteem, impulsivity, and attention problems.

Adults aged 50+ with ADHD may have been diagnosed late in life and may or may not have been treated for it. The question is how they manage their day-to-day life with the disorder. Few qualitative studies have been published giving insight to the day-to-day life of people over 50 years of age with ADHD and this study may provide additional insight into their experience.

## Aim

The aim of the study was to explore the lived experience of the day-to-day life of people aged 50+ diagnosed with ADHD.

## Method

A qualitative lifeworld approach was deemed most appropriate to explore the lived experiences of people with ADHD. Since the lifeworld is central in both hermeneutic and phenomenological philosophies, a phenomenological hermeneutical method based on those philosophies was used. The method developed by Lindseth and Norberg (2004) is inspired by Paul Ricoeur (1976) to interpret the lived experience of 10 people’s narratives obtained through individual interviews.

## Participants

The participants, aged 50+ diagnosed with ADHD, were identified and recruited via personal contacts, through social media platforms such as Facebook, and by using “snowball sampling.” Attention, a Swedish special interest group for people with neuropsychiatric disorders, was contacted and asked to reach out to their members. E-mails were sent to Attention districts in four counties in southern Sweden. Personal phone calls were made to people in these counties to spread the information. E-mails were sent to lecturers who had spoken at conferences about ADHD. Invitations to participate were also extended to members of an ADHD Facebook-group. Ten people agreed to participate in the study: three men and seven women. One person was reached via the lecturer, two via Attention, five came from the Facebook group and two from personal contacts. The participants were distributed throughout four different counties in Sweden. Prior to the interview, none of the subjects were known to the author. Their ages varied between 51 and 74 years of age (mean 57 years of age). All participants spoke Swedish. Nine out of 10 were native Swedes. For demographic information, see Table 1, and for factors about ADHD diagnosis, see Table 2.

**Table 2.** Background factors related to ADHD diagnosis.

Age when diagnosed	–40	1	
	40–50	4	
	50–60	4	
	60–	1	
Awareness of being different	Early in school	4	
	Entire life	4	
	After assessment (age >40)	2	
Medication	No medication for ADHD	3	
	ADHD medication	7	
	Antidepressants	4	
	Treatment for sleeping disorder	2	
	For other psychiatric conditions (antipsychotics)	3	
	None	0	
Effect of ADHD medication (7 of 10)	Non-specific	1	
	Better self-regulation, calmer	6	
Support (respondent may have several types of support)	Subsidized housing	3	
	Occupational therapist	3	
	Psychologist	3	
	Doctor	4	
	Employment services	1	
	Day care	1	
	ADHD support group	2	
	Psychiatric outpatient unit	1	
	Drug treatment program	2	
	Social services	1	
	None	1	
	Psychiatric comorbidity (several possible options)	Burn out syndrome	3
		Depression	6
		Sleeping disorder	4
		Alcohol/substance abuse	3
Anxiety/panic disorder		4	
Bipolar		2	
Physical comorbidity (several possible options)	None	0	
	Obesity/risk of obesity	2	
	Hepatitis C	2	
	Arthritis/pain problems	3	
	Parkinson's disease	1	
	Hyperthyroidism	1	
	None	1	
Family with ADHD/psychiatric disorder	Grandparent/s	2	
	Parent/s	5	
	Sibling/s	4	
	Child/ren	6	
	Grandchild/ren	1	
	None	0	

### Data collection

Individual interviews were conducted using Mishler's (1986) ideas of jointly created dialogue to facilitate mutual understanding. An interview guide containing a few overarching questions was used to ensure that the same approach was applied during the interviews. The guide was tested but didn't require any adjustments after the pilot interview. The interviews started with the author introducing herself, followed by small talk to achieve a relaxed atmosphere, and thereafter the focus of the study was stated. The informants were asked the open question, "Could you please share openly what it is like to live with ADHD at your current age?" The informants were encouraged to share about feelings, thoughts, and challenges in their day-to-day life, how they handle them, what has changed over the years, and if anything has been better/easier with age. Questions about demographics, factors related to the ADHD diagnosis, and complementary questions were asked at the end of the interview. The informants were allowed to choose where and when their interview were to take place. They were asked to set aside approximately 1 hour for the interview. Seven of

the informants chose to be interviewed in their home, one at their work place, one at a treatment facility, and one in a public area. The interviews were conducted by the first author in November and December of 2016, lasted from 45 to 88 minutes (median 68 minutes). The informants were very talkative and fast-speaking and rich information was provided during the interview. They expressed sadness and anger about the struggle and difficulties they had experienced, but also relief about being given this opportunity to vocally express themselves. After 10 interviews, data saturation was reached since no new information was observed in the data. The interviews were recorded and transcribed verbatim. Notes were not taken during the interviews, but after.

### Ethical considerations

Ethical considerations followed the Swedish law for human research—the Ethical Review of Research Involving Humans Act (SFS, 2003, p. 460). None of the subjects were known to the author prior to the interview. Permission was granted by

**Table 3.** Example of meaning units condensation processed into sub-themes and themes.

Meaning unit	Condensation	Sub-theme	Theme
Me and my family, we are a bunch of intelligent, highly educated totally useless individuals. There is nothing really wrong with us, we are smart and sharp, creative, but we get nothing done (IP1)	In my family we are intelligent and highly educated, but we don't get things done.	Managing feelings of being different, disorganized and forgetful	Being different and trying to handle my inner self
Another thing I've been talking about is about having a strategy for knowing when to start, what to do, and what to do next. But I don't stick to it, I take out things in advance, and that's not good. (IP10)	I need a strategy to know what to do and when, but I don't adhere to it.	Developing strategies to handle the difficulties of being different	Being different and trying to handle my inner self
I've conquered myself. This thing about controlling my temper and making things work, making every day work. Nothing works if you are angry, or get angry (IP2)	I need to take control over my temper and make things work in everyday life without getting angry.	Having to control impulses and energy	Being different and trying to handle my inner self
I talk too much, or not at all, too emotional, say things I shouldn't, no balance (IP1)	I don't have any balance in what I say or how	Struggling to adapt in social relationships	Trying to adapt to fit in with people around me
I struggle. Everyday tasks like paying bills and keeping my home clean. The things other people do easily I can't handle at all (IP6)	I struggle with everyday tasks such as paying bills and keeping my home clean. Others handle these things, but I can't.	Dealing with work and personal finances	Trying to adapt to fit in with people around me

the operational supervisor to include one informant currently in treatment. Information about the study was offered both orally and in writing: orally during the initial phone call were informants agreed to participate in the study and in writing through a consent form sent prior to the interview. The form stated that participation was voluntary and that informants could terminate participation at any time. Confidentiality was ensured by coding collected data to avoid identification of participants. All personally identifiable information was kept in a locked file cabinet in the personal possession of the first author.

There was a risk of bad memories resurfacing during the interview. The first author, with psychiatric nursing experience, was present to handle any such negative reactions, and could, if necessary, refer the subject to professional caretakers for further assessment.

### Analysis

The interpretation of the text was conducted according to the phenomenological hermeneutical method by Lindseth and Norberg (2004), inspired by the theory of Paul Ricoeur (1976), meaning that interpretation of a text is carried out through a three-phase process. It starts with an initial reading of the text, through which the meaning of a phenomena are naively understood. Subsequently, an explaining structural analysis is conducted that validates or invalidates this naive understanding. In the third phase, the individual phases (parts) are interpreted and summarized in relation to the text as a whole. According to Ricoeur (1976), interpretation of texts is not about understanding the intentions of the narrator but about uncovering the meaning of the text. The reader's pre-understanding has influence on this interpretation.

This analysis started with reading each interview individually, and then all together, giving the author a first naive

sense of the meaning of the informants' personal lived experiences with ADHD. Meaning units related to the aim were then identified and condensed, kept in everyday language, edited for brevity, scanned for similarities and differences, and finally sorted into sub-themes and themes based on congruence. Themes were validated since evaluation of the naive understanding revealed a similar meaning. Examples of the structural analysis process can be found in Tables 3 and 4.

To capture the comprehensive understanding of the interviews with these individuals aged 50+ diagnosed with ADHD, sub-themes and themes were reflected on in light of the meaning of their day-to-day life. According to Gadamer (2004), pre-understanding is an intentional structuring, activated when we regard something. He further explains that the hermeneutical task is to be aware of one's own bias, so that the text can present itself and thereby assert its truth against one's fore-meanings. Regarding pre-understanding, the first author (AN) has over 40 years of experience in psychiatric nursing and personal experience with ADHD in the family. The third author (KP) has participated in a study of developing an instrument for screening infants with development disorders or autism. The second author (ACJ) has experience in psychiatric nursing practice and research, research in elder care, and also ADHD in the family.

### Findings

The naive reading revealed that the informants appeared to have many functioning areas in their lives, but struggled severely areas such as personal finance and taking care of the household. They felt sad that had suffered for so many years without help or a good understanding of why or how to cope. Feelings of restlessness and lack of impulse control created problems in their social life. A sense of relief was found when functional strategies were identified. They felt

**Table 4.** The sub-themes and the themes of the structural analysis.

Being different and trying to manage my inner self	Trying to adapt to fit in with people around me
Managing feelings of being different, disorganized and forgetful	Struggling to adapt in social relationships
Developing strategies to handle the difficulties of being different	Dealing with work and personal finances
Having to control impulses and energy	

alone by choice or forced into loneliness. Excessive intake of alcohol, food, and drugs were also revealed as well as other physical and mental problem areas. Major problem areas were forgetfulness, uncontrollable racing thoughts, difficulties with time management and an inability to focus on tasks. Informants with creative work, challenging tasks, a work situation with changing locations, and late work hours seemed to have less work-related problems than others. Protective factors seemed to be having an understanding family, friends who stayed no matter what, work with suitable structures, and coworkers who understood. It seemed that when protective structures fell apart as by a divorce or having a child with problems, a functional breakdown emerged and assessment for a diagnosis was done. For the mostpart, there were several types of help and assistance around every informant and this help gave them better control of everyday life. Work- and study ability seemed to be negatively affected by the disorder. Taking medication for ADHD or other related conditions was common and medication was not experienced to have caused any significant harm or bad side effects.

#### ***Being different and trying to manage my inner self***

This theme is about the inner dimension, about how the informants lived their day-to-day lives with ADHD and how they coped with the problems they faced. The subthemes were, (1) Managing feelings of being different, being disorganized and forgetful, (2) Developing strategies to handle the difficulties of being different, and (3) Having to control impulses and energy.

#### ***Managing feelings of being different, disorganized and forgetful***

The text revealed that living with ADHD meant feeling different from other people, feeling inferior, and that something was wrong. Feeling of shame and embarrassment of were common and this persisted over time—especially in areas where performance was measured. To face facts and be forced to accept how life has been (past and present) was difficult. “About studying (with tearful eyes): I didn’t understand fast enough. I need to know exactly what to do. I don’t understand. I get blocked in my mind and it feels shameful... I got such anxiety that I hid in the bathroom. What am I to do?” (I:3). Even though they were aware of their problems, they had trouble asking for help, and to accept that help was needed. Informants who seemed to have higher cognitive functions received their diagnosis late in life, because they could manage the difficulties they faced longer than others. The diagnosis provided a sense of relief. These problems became less severe with age and life became

a bit easier. They felt safer as they grew older and could understand life better. They became less afraid and, little by little, life got progressively better.

#### ***Developing strategies to handle the difficulties of being different***

The text revealed different strategies of how difficulties were managed in day-to-day life. But having strategies did not eliminate the difficulties, it simply made them easier to manage. Having strategies could also mask a need for help. Physical activity was a good way to cope with restlessness; i.e. jogging in the late evening so getting to bed would be easier or eating and sleeping on a regular schedule to feel better during daytime, even if they weren’t feeling hungry or tired. It was easier to keep the home clean, or at least less messy, when they were forced to take care of the household, i.e. living with dependents or a partner. Having a positive relaxing environment and very structured and detailed instructions seemed beneficial to their well-being. On the other hand, subjects who didn’t live with children or a partner had fewer interpersonal conflicts. Those who struggled with shopping and couldn’t tolerate standing in line, found that shopping early in the morning was the best solution. The sense of having to find strategies was expressed in: “I didn’t fail 10,000 times, I simply found 10,000 ways that don’t work. I’ll never give up, I’ll find a solution. That’s my strategy. I am street-smart. If there will be another war, I’m one of the survivors. Even if it takes time to find solutions, I will... I’ll never give up” (I:6).

Poor working memory seemed to have caused the informants a lot of suffering in their day-to-day life. Problems with making plans were also perceived to be a common challenge. The expectation from others to organize and take care of things was a major struggle and things easily got chaotic. One informant described the shame and embarrassment of arguing with someone about something only to find out that the things they argued about did not happen in the way she remembered. Everyday trivial things that they had to remember to take care of, like taking care of pets, seemed to need a strategy to be remembered. Most of the informants were using memo notes and calendars to avoid forgetting about important things. Taking care of the household seemed difficult to manage for the informants. All the informants were misplacing things over and over again, and their homes were generally not clean enough to have people come over to visit unannounced. They felt ashamed of the mess and blamed themselves for it.

There was a difference between men and women in that mothers (cf. fathers) seemed to create structure around their children. When the children had left home it got worse and more chaotic for many of the mothers. A need for help with

the household was common. “I need my community shelter assistant to help me out with all my paperwork, to know what to do with it. Otherwise, I’ll be sitting with it in my lap, not knowing whether to store it or throw it away” (I:3). Medication also seemed to be of good help in reducing negative feelings, calming down, slowing down thoughts, and allowing some time to think before acting.

### **Having to control impulses and energy**

Inability to control impulses seemed to be a factor that caused a lot of trouble. Negative consequences from lack of impulse control were, for example, getting speeding tickets, driver’s license suspensions, car accidents, running away from home, getting in sexual relations too quickly, and getting pregnant early. The impulses arising from restlessness are described as “... an itch in the bone marrow” (I:6). The positive side of low impulse control was the sense of being very creative to start up new projects, being super focused, and the feeling of having an engine that makes things happen. Informants expressed having less energy than required, feeling unable to do things they needed to, having a greater need for recovery than others, and feeling exhausted. They couldn’t work full-time. Excessive amounts of energy were spent pretending to be normal. Meeting one’s own needs required doing things in the early mornings; there was no energy left in the afternoons and evenings. Even nice things, like a friend calling, could ruin the day if it wasn’t accounted for in how energy was planned to be used for the day.

### **Trying to adapt to fit in with people around me**

This theme addresses the social dimension of having ADHD in the company of others. The subthemes were (1) Struggling to adapt in social relationships and (2) Dealing with work and personal finances.

### **Struggling to adapt in social relationships**

Social situations were of major concern to the informants. They struggled with understanding social norms, with behaving in accordance with situational expectations, with adjusting communication to the person they were talking to—talking too much or too little, being too emotional, saying things they shouldn’t, or coming off as imbalanced. Choosing to be alone was a way to avoid social problems. Even social media was avoided, “I don’t invite people to my home, I don’t call my friends, I don’t get this thing about Facebook and I’m not active on other social media platforms. I end up outside of everything. I feel like a quitter. Other people have a social life, I’m behind closed doors, I don’t exist” (I:1). Saying things without thinking about consequences was common. Lack of social skills resulted in adverse effects on quality of life, i.e. one subject who couldn’t communicate clearly with a contractor had to put up with a nonfunctioning kitchen in their house for a long time. Relations with family and friends were affected. They

were really grateful for family relationships that still were healthy and functioning. Contact with family and relatives seemed to often deteriorate due to feelings of not been understood and hurt feelings on both sides. One informant told about not being well-received in contact with health care staff. Informants had no clear sense of how to address or mitigate their social challenges. It seemed to persist.

### **Dealing with work and personal finances**

For informants that actually were employed, the text revealed ongoing struggles with achieving a functional work-situation, combined with a fear of being excluded from workplace groups. Inability to control impulses seemed to be a factor that caused a lot of social problems, both at work and in personal relationships. Failing to pay bills and their household expenses was especially difficult to handle because it had serious financial consequences. When deciding between insurance, phone carriers, and other service providers, informants found it difficult to understand terms, conditions, and prices. This often led to less favorable deals and agreements which in turn led to even worse financial outcomes including higher costs for subscriptions and fees. All the informants had already experienced problems in primary and/or secondary school. Higher education was difficult to cope with; lack of concentration being the major issue. However, even post-secondary degrees didn’t spare them from problems, including financial problems. Lower income due to less education, underpaid jobs, working part-time, unemployment, and not being able to handle money or pay the bills were still all common obstacles. The most effective solution was to create routines, get help with making plans, and accepting help from support systems in society. In spite of these challenges, there was hope for a better future: “I must cope until retirement and then I’ll be free. Keep myself healthy and be able to enjoy my pension and think about how to provide support for our child when I get old. In a way I feel free the day retire. I won’t have to make such an effort trying to be normal. It’s going to be great” (I:1).

### **Comprehensive understanding and reflection**

Swedes over 50 years of age sharing what it is like living with ADHD was interpreted to *Being different but striving to seem normal*. The study reveals a lot of problems for people with ADHD. These people have lived a big part of their lives without understanding and knowing what was wrong and how to make their lives work better. There was bitterness and sorrow expressed over this fact. Nowadays, ADHD is often spoken of in the media as being a superpower. There was little evidence of that in this study, with participants mostly struggling. Only in a few cases was “the ADHD-way” of handling life—with more creativity and speed—possibly perceived to be advantageous. Generally it had negative drawbacks such as lack of impulse control and instilling a sense of chaos, and in specific areas problems persisted (social problems, chaotic homes, and inability to handle the

household finances). But with age, and through finding strategies, life got easier in some areas (i.e. fewer mood swings and a greater acceptance of one's shortcomings); as supported by a study by Das et al. (2014), which found that older adults (68–74 years) reported fewer/less severe ADHD symptoms than middle-aged adults (48–52 years). They surprisingly found that older adults benefited from their hyperactivity by performing better in cognitive activities.

The participants' sense of being different but striving to seem normal is a question about who sets the standard. Maybe we are in a transition toward a new normality, where the ability to think fast and cope with multiple tasks at the same time is not only desired but perhaps even required? It's clear from the participants' narratives that participants having the "right" kind of life also would feel quite normal, so context seems important in order to feel accepted and self-confident. Most people try to be normal and to live a life as close to normal as possible, but we all reserve the right to define our own standards for "normal life." Normative behaviors considered adaptive during one time-period may well turn out to be disastrous during another. According to Émile Durkheim (in Fricke, 2015), in *The Rules of Sociological Method* (1895), society—and the habits adopted by the majority of its members—change over time. Most adopt new and more advantageous behaviors, which eventually become the norm. The conclusion is that there is no reason to be normal in a statistical sense of term. We all have reason to live our lives as well as possible and to acquire as much knowledge of the world as possible (Fricke, 2015). Given the problems with social norms that subjects detailed in this study, perhaps the "grammar" of norms is a different and difficult set of rules for people with ADHD to learn. The participants desire to be accepted is expressed, however they could feel that their desire seldom was fulfilled. Lack of acceptance and understanding by their social environment was also found in the study by Schrevel et al. (2016), which focused on the problems and needs of adults with ADHD (N = 52, aged 21 and older, mean age 43 years). This kind of social misunderstanding resulted in feelings of not being good enough, feelings that likely remain when getting older. Social norms, according to Bicchieri and Muldoon (2014), are the unplanned and unexpected result of individuals' interactions and ought to be understood as a kind of grammar of social interactions showing what is acceptable and what is not in a society or group. When norms are internalized (a need or motive to conform to a set of shared norms), norm-abiding behavior will be perceived as good or appropriate, and people will feel guilt or shame at the prospect of behaving in a deviant way.

Another important part of human life is to belong and confirmed by this study, being a part of and belonging to a group was found to be essential and all participants had some social contacts; no one was completely socially isolated. It was revealed that the participants who chose social withdrawal simply to avoid social rejection suffered loneliness as a consequence. Similarly, feelings of social rejection was found in the previous mentioned study by Schrevel

et al. (2016). That adults with ADHD suffer from loneliness was also identified in a study by Stickley, Koyanagi, Takahashi, Ruchkin, and Kamio (2017). The more severe the ADHD symptoms, the higher risk of feeling lonely; a finding that warrants further attention in future research.

In this study all participants had some social contacts, no one was completely isolated. Some had also chosen to minimize contact with relatives to avoid conflict. Several participants had difficulty accepting needing help as well as accepting help with everyday tasks. The modern phenomena of seeking belonging through virtual communities was not discussed in the study, and may be an interesting aspect for people with ADHD to explore. It could be easier to interact with people at distance. According to Baumeister and Leary (1995), we need to belong and to form and maintain a minimum quantity of interpersonal relationships, but this could differ by individual in both strength and intensity. To satisfy the need to belong, a person must believe that the other cares about his or her welfare and likes (or loves) him or her. Feelings of loneliness can result either from insufficient social contact (social loneliness) or lack of meaningful, intimate relatedness (emotional loneliness). Absence of close social bonds is strongly linked to unhappiness, depression, and other woes. Being single, divorced, widowed or being unemployed carries higher rates of suicide. Simply being a part of a supportive social network reduces stress, even if the network doesn't provide explicit emotional assistance. The quality of friendships is far more important than quantity. When a person fears rejection, the tactic seems to be to engage socially as little as possible, thereby minimizing risk of rejection (Baumeister & Leary, 1995). In Newark, Elsässer, and Stieglitz (2016), they found that despite having difficulties in relationships, their capacity for love seemed unaffected. It also seemed that courage and ability to love may be protective traits for people with ADHD. This study the participants narrated that being a part of a social community and interacting with others in different situations was very difficult, and simply being alone felt better in some sense; not having had to feel any pressure to be social and not break any of the unwritten rules of being a friend, colleague, family member, or partner. Keeping the family together over time seemed difficult and getting friends was easier than keeping them. Self-esteem and self-efficacy was highly affected.

To manage to handle a periodically chaotic life, the participants found strategies to assist them. A study by Kysow, Park, and Johnston (2017) found that adults suffering inattention symptoms frequently use compensatory strategies because they find these symptoms impairing in the workplace and at home. The ability to find working strategies was a creative process and provided a feeling of satisfaction. Findings by Newark et al. (2016) in a Swiss study revealed that resourcefulness was lower in people with ADHD, explained by the multitude of impairments and their longstanding history of negative experiences starting in childhood.

External resources like family and friends can assist and improve work performance (Newark et al., 2016). For

participants in this study working and being a part of the social work-life scene seemed to work best for those who had jobs befitting their traits and needs, such as working late hours, having creative challenging jobs, having understanding colleagues, or working alone. The fact that only one person in this study worked full time (being self-employed) and the others worked part time or not at all, is similar to findings by Halmøy, Fasmer, Gillberg, and Haavik (2009). Results from a Canadian study suggest that if conditions are put in place—helping people with ADHD succeed and earn higher incomes—they may not experience above-average levels of psychological distress, meaning that high income may serve as a protective factor for psychological distress (Pond, Fowler, & Hesson, 2019).

All the participants were affected by some illness or condition—physical or mental. Generally speaking, sleeping disorders can have a major impact on many areas of day-to-day life. Insomnia alone was found in 66.8% of ADHD patients (Brevik et al., 2016; Snitselaar, Smits, van der Heijden, & Spijker, 2017), and could add even more stress to the lives of anyone with ADHD. According to the participants psychiatric comorbidity such as burnout, depression, anxiety, panic attacks, bipolar disorder, and sleeping disorders were described, as well as abuse or overconsumption of drugs, alcohol and food. Physical conditions were often the result of self-neglect such as not resting enough or ignoring bodily symptoms (e.g. back pain). According to Pineiro-Dieguez, Balanzá-Martinez, Garcia-Garcia, Soler-Lopez & the CAT Study Group (2016), women were more likely to have eating and mood disorders, while men had more substance use disorders. Instanes, Klungsøyr, Halmøy, Fasmer, and Haavik (2018) point out a consistent correlation between ADHD and obesity, sleep disorders, asthma, migraine, and celiac disease. A number of studies confirm the findings of both psychiatric and physical comorbidity, i.e. Caci et al. (2015), Kooij et al. (2019), Fayyad et al. (2007), and Kessler et al. (2006).

In this study, forgetfulness appeared to be a major problem in day-to-day life. Even the simplest tasks were forgotten, unless strategies were employed to remember them. The inability to keep things in mind and fulfill one's obligations as promised caused shame and embarrassment. According to a study by Skodzik, Holling and Pedersen about long-term memory in adult ADHD, this kind of forgetfulness, where verbal information is only partially encoded, is due to impaired encoding processes in the brain and should be considered a learning deficit (Skodzik, Holling, & Pedersen, 2017).

Mental restlessness was described as thoughts constantly flying like ping-pong balls in the brain and never stopping. Physical restlessness was a feeling of “itching in the bone-marrow” and impossible to ignore. This restlessness led to a constant urge to move body parts or to go jogging at any time of day. This restlessness, in combination with having very limited energy reserves, caused problems. When energy reserves were empty, they could not perform any more, no matter what.

In Swedish media there is an ongoing debate about what ADHD is; bad behavior, disorder, disease, or super-power? The participants in this study have strived and struggled, they have had their difficulties and sometime strengths all their lives, and they achieve improved functioning when taking medication. However, problems occur mostly in social situations, and when daily life is organized according to the person's needs, problems diminish. Almost all of the participants had ADHD in their families, ranging from older to younger generations. So, we may discuss what it is and isn't. A philosophical discussion is held by Murphy (2015) about scientific and common sense concepts about medicine and we may ask which concept should be adopted. Poor assumptions might lead us to believe that a condition is not a disease, but scientific inquiry might conclude that people with the condition are suffering from a biological malfunction. Constructivists tend to say that health and disease medicalize behavior that breaks norms or fails in some way to accord with our values. The chief problem with constructivism is that it makes a distinction between illness and the deviant—pathological conditions and those we just disapprove of. A good example is about whether or not homosexuality or masturbation should be considered a disease. We may think that something is a disease but that may be incorrect. Constructivists strive to uncover the role that moral and social values have played in medical diagnoses and argue that our disease categories often aren't sufficiently naturalistic (Murphy, 2015).

### **Methodological considerations**

To ensure trustworthiness, the research must be evaluated in relation to the procedures used to generate the findings. Credibility is about how well data and processes of analysis address the intended focus. Dependability is the degree to which data stays the same over time and alterations made in the researcher's decisions during the analysis process. Transferability refers to the extent to which the findings can be transferred to other settings or groups (Shenton, 2004). The informants were recruited mostly by help from Attention and from the Facebook group for persons over 30 years with ADHD. The findings could be affected by this selection.

Efforts were made to strengthen the *credibility* by ensuring that the person who conducted the study is a capable person with professional competence and awareness of the sensitivity of the study. The age span was 23 years, the background of the participants differed by education and occupation and these factors give a variation of the phenomena under study. To strengthen the *credibility*, description of the steps of the research process were made. To strengthen the *dependability*, the analysis process of the themes was described and illustrated in tables. Quotes from the interviews were presented to validate that the themes represented the lived experience of the day-to-day life of people aged 50+ diagnosed with ADHD. The findings from the interviews were analyzed by the first author after repeatedly reading the texts at every stage of the analysis process. The

second author (ACJ) also read the texts produced by the first author, providing guidance and support. The results were processed through discussions with the third author (KP) to reach consensus. The steps of the research process were described and ought to give the reader the ability to judge the credibility of the findings. To strengthen *transferability*, background data and setting were described to enable readers to judge how the findings can be transferred to other settings or groups.

It should be noted that while the aim of this study was the older adults' experience of ADHD, other psychiatric and physical comorbidity may have influenced their accounts, and therefore the findings.

## Conclusion

This Swedish study was an opportunity for people with ADHD to express, in their own words, the pros and cons of the disorder. Professionals in health care and social services who encounter people with ADHD in international contexts can also apply knowledge from the results of this study in their everyday work. Assessments and medical treatments are now available, but addressing personal finance problems, lack of social interaction, effects of being single, having parents and children with the same disorder, not being able to work full time and support oneself are some of the remaining problem areas to handle. A multidisciplinary focus seems needed including physicians, nurses, occupational therapists, and social workers for a more holistic support approach. A problem yet to be solved is how to interact with middle-aged individuals with ADHD in different settings in healthcare and social services in a way that allows them to avoid feeling different and not fitting in. Strategies have been developed for meeting with children and younger adults, but are also needed for older people, in work life and in elder care as they run especially high risk of having their special needs ignored.

## Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

## Ethical approval

Ethical approval and permission to conduct the study was given according to national standards and procedures by Kristianstad University.

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