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## Looking back on compulsory school: narratives of young adults with ADHD in Sweden

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### ABSTRACT

Relegated to the margins of the large body of research on ADHD and school is individuals' own retrospective accounts of schooling. Drawing on multiple narrative interviews with nine young adults with ADHD in Sweden, the present study explores their experiences and reflections concerning their years in compulsory school. Despite variations in the gradient of decline, time in school was described as a slippery slope, with rapid deterioration in secondary school. Participation in sports and cultural activities outside school emerged as strong supportive factors. The expectations placed on the individual in the school context and relationships with teachers were described as key hurdles. In hindsight, school was perceived as a meaningless phase of their lives. The present findings nuance the skewed diagnosis focus in contemporary research, raising questions about timing of support in school and offering important insights concerning girls with ADHD.

### KEYWORDS

ADHD; school; narratives; young adults; support

### Introduction

Students with an ADHD diagnosis have been identified as a vulnerable group in school, with poor academic performance, high school dropout rates, lower numbers proceeding to upper secondary, and among those who do, a continued lag in academic performance (Loe and Feldman 2007; Ek et al. 2011). Given these bleak outcomes, which seem to continue into adulthood (Kuriyan et al. 2013), there has been rapid growth in research aimed at understanding what is going wrong in schools.

From a deficit perspective, the focus has been on school-related challenges and limitations arising from ADHD symptomology and possible interventions and strategies meant to address these problems (Humphrey 2009; Moore et al. 2018). Opposing this heavily medicalised discourse, many have contended that the neurological difference attributed to ADHD is solely socially constructed (Hinshaw and Scheffler 2014), questioning the relevance of the diagnosis in school, where there is a move towards pathologizing educational problems (Harwood and Allan 2014) and using the diagnosis as an organisational solution in schools. The negative impact of the diagnosis on the individual's identity and life opportunities has also been raised (Hjörne and Evaldsson 2015).

Although in opposition, one could argue that central to both the deficit and the critical approach in the research is the diagnosis, with limited attention being paid to the personal experiences of school and education of individuals with ADHD. This is gradually changing, however, and recent research has focused on accessing students' voices in relation to specific aspects of school (Wiener and Daniels 2016). These studies have provided important insights, but only include a highly selective sample of voices of those who have an ADHD diagnosis while in school. It is increasingly

common to receive a diagnosis in adulthood, particularly for women (Nussbaum 2012), thus obscuring the breadth and diversity of ADHD experiences in school.

There continues to be a large gap in our knowledge concerning how young adults with ADHD, with or without a diagnosis while in school, have experienced their school years and, even more importantly, how they view these years in hindsight. This gap is striking, considering the volume of research on the topic of ADHD and school. The aim of the present article is to try to fill this gap by exploring the personal accounts, experiences and reflections regarding the compulsory school years among young adults with ADHD. This exploration of personal experiences and understandings of school life provides a largely untapped perspective that can inform educational practice and policy. More specifically, the following questions are addressed here:

- (1) How do young adults with ADHD describe their years in compulsory school?
- (2) What do they identify as the enabling factors and barriers during their years in compulsory school?
- (3) What significance do they ascribe to compulsory school in their lives?

The chosen context in which to explore these questions is the Swedish compulsory school, which prior to the recent addition of the obligatory pre-school year extended from Year 1 to Year 9 (7–16 years of age). In Sweden, there has been a documented increase in the number of learners with ADHD since the 2000s (Rydell et al. 2018). There is also considerable evidence showing that students with ADHD face high levels of exclusion from and within schools, have high levels of absenteeism and are overrepresented among out-of-school children (Swedish Schools Inspectorate 2016). They are often excluded from the mainstream, receiving education in separate special settings (Malmqvist and Nilholm 2016; Giota and Emanuelsson 2011), and there is increasing evidence to suggest that schools are not able to meet the educational needs of students with ADHD (Bolic Baric et al. 2016; Swedish Schools Inspectorate 2014).

These developments are in stark contrast to the stated goals of Swedish education policy (SFS 2010, 800), which from the end of the 1990s has centred on an inclusive education system aimed at meeting the needs of all students through general education. Special needs provision are to be provided within students' regular classes, and only in exceptional cases should instruction take place in a special teaching group. Individual needs are to be the driving force behind accommodations and interventions in school and are to be met regardless of whether a child has a medical diagnosis. However, studies conducted in Swedish schools have shown just the opposite, where medical diagnoses like ADHD are major determiners of the type of support received (Hjörne 2005; Malmqvist 2018).

## Research on the school experiences of persons with ADHD

A thorough literature search revealed a paucity of research on the compulsory school years from the perspective of adults. Only a few studies from USA and Sweden had directly or indirectly addressed adults' retrospective accounts of school, with a focus on experiences of support, barriers faced and strategies perceived to be useful.

Shattell, Bartlett, and Rowe (2008) identified feelings of difference, misunderstanding and struggle in young people's narratives of school and friendship during their childhood. Difficulties in social relationships with peers are also predominant in Bolic Baric et al.'s (2016) study, as are increasing problems with schoolwork, culminating in secondary school and resulting in truancy or dropping out. Family support during the school years was considered important, as were teachers' caring behaviours and belief in the student (Bartlett, Rowe, and Shattell 2010; Hellberg and Kjellberg 2012; Bolic Baric et al. 2016). The use of active teaching strategies and individualised teaching methods was noted as helpful. In the learning environment, cognitive support, adaptation of the physical environment, concrete information and taking frequent pauses were identified

as supportive, and lack of structure in presentation of assignments and little clarity in expectations were described as barriers (Hellberg and Kjellberg 2012). A general finding across these studies was limited knowledge about ADHD among school staff and a lack of understanding of how it impacted the individual.

While these studies provide important insights into a largely unexplored area, the sample included only relatively successful individuals with ADHD. Of the 20 participants in Hellberg and Kjellberg (2012) study, all but one left school with complete grades, and in Bartlett, Rowe, and Shattell (2010) study, all of the young people with ADHD were attending college. While the intention behind this sampling was to maximise understanding of what had led to positive outcomes for these individuals, one can question whether the findings are reflective of the school experience of individuals with ADHD, among whom high rates of school dropout and low rates of proceeding to upper secondary school are well established (Ek et al. 2011).

One commonality across the above studies is also their reliance on semi-structured interviews for data collection. This provided qualitatively rich data, but the depth of information possible to acquire in one meeting is likely to be limited, as regards both recalling the past and building rapport and trust with the interviewer and thus enabling deeper accounts of sensitive experiences. However, narratives have been captured in other ways. Fleischmann and Miller (2013) examined the online life stories of adults with ADHD. Thirty-eight of the 40 narratives mentioned having experienced problems during school. Most described their teachers' view that their academic failure had been caused by laziness or a defective personality. There were, however, also accounts of support from teachers who had positively affected their lives.

While there is a dearth of research on adults' accounts of compulsory school, the voices of school-aged children with ADHD are more visible (Eccleston et al. 2019; Ringer 2020). The bulk of these studies have focused on the ADHD diagnosis, investigating areas such as children's perceptions, meanings and understandings of their diagnosis and their school experience in relation to medication and treatment. By viewing ADHD as the object of the research, these studies have subdued the students' voices and experiences. In contrast, research that has foregrounded students' perspectives on their school experience has provided a much more nuanced understanding that goes beyond the diagnosis ADHD to appreciate students' experiences while at school (Honkasilta, Vehkakoski, and Vehmas 2016).

In an Australian (Gibbs, Mercer, and Carrington 2016) and a Canadian (Wiener and Daniels 2016) study, 14- to 16-year-olds described secondary school as a much more positive experience compared to earlier school years concerning their peers and education. Students in these studies also described the characteristics and practices of good teachers who had supported their learning and helped them stay focussed. Alongside this, there were also frequent accounts of teachers who perceived students' difficult behaviours as deliberate, resulting in negative responses. Not surprisingly, teachers' knowledge of ADHD and supportive classroom strategies were considered important, which also finds support in Kendall's (2016) study in the UK. Reliance on parents to support learning, resolve conflicts and advocate for accommodations was also noted (Wiener and Daniels 2016).

## Method

The present article is part of an ongoing research project titled 'Participation for all? School and post-school pathways of young people with functional disabilities' and financed by the Swedish Research Council. It is limited here to the data on young adults with ADHD, with a specific focus on their narratives on their compulsory school years.

To gain access to a diverse group of young adults with ADHD, contact was established through different channels, such as online forums, adult education centres, posters set up at universities and in public spaces, and by word of mouth. In line with the larger study, the main criterion for including informants in the study was that they had an ADHD diagnosis. The final sample includes nine young woman and men, between the ages of 18 and 31.

There was great variation among informants on a range of dimensions. The descriptions here concern the status of informants when they agreed to participate in the study. Six women and three men participated. Seven informants had been diagnosed after the age of 18 and two during their compulsory school years. There was variation in place of residence, both current and while in school: big city, small city and smaller town. At the start of the study, the informants lived in different situations: with parents, single, single with a child, with a partner, partner and child, and in a collective. There was also variation in occupation: studying at university, adult education programmes, upper secondary education, unemployed, on sick leave and on parental leave.

The present article takes a narrative approach (Esin, Fathi, and Squire 2014) to exploring the meaning young adults with ADHD made of their experiences of their compulsory school years, the goal being to develop an understanding of individuals' lives from their perspective. The focus is on informants' personal reconstruction and interpretation of their experiential memories and reflection and on what they chose to narrate. A particular strength of the method used here is that the narratives are not restricted to one interview, but involve multiple meetings carried out in diverse places over time. On average, the informants have been followed for over two years.

As part of the larger study, documentation from institutional settings was collected, including schools, social services and health services. While the data from these documents are not included in the present analysis, they did in some cases contribute to a conversation that delved more deeply into the informants' time in school. Based on their accounts, a timeline was created to visually map different stages at school, and it was used as a support in follow-up conversations, a method shown to enhance data quality when researching sensitive topics (Berends 2011). For many of the informants, this period of life was distant, with much having happened in their lives since. Having regular meetings over time, as well as the timeline, often helped informants to gradually return to the various stages of schooling and provide deeper accounts of incidents, experiences and reflections. The narrative interviews were audio-recorded, in the case of short informal conversations, detailed notes were made directly after.

While formal ethical approval was obtained prior to data collection, it was important to constantly reflect on and negotiate ethics in practice (Guillemin and Gillam 2004) in this study. For many of these individuals, their school experience was a sensitive topic. School was often associated with negative experiences, anger and accounts of failure. This required a sensitive approach suited to each individual. The method used also required building a trusting relationship with informants, to facilitate following them over time; it also carried with it a risk of dependency. The researcher was aware of this and regularly established boundaries, re-affirming that participation in the study was voluntary and the young person had the right to withdraw at any time. While representing young people's voices in the results, particular care has been taken to balance confidentiality with authenticity.

The analysis followed the three-step coding process suggested by Neuman (2014). Holistic and descriptive initial codes were generated to organise and condense the large amount of data. This was guided by the research questions, and resulted in codes, such as description of school years, supports, hurdles and significance of school. This was followed by identifying clusters of ideas within the initial codes, which were closely linked to how informants had described it in their narratives. For instance, supports in schools was further coded as support in school and support outside school; descriptions of school were coded as primary, middle and secondary. Finally, deeper patterns and connections within such themes were investigated. At this stage, close attention was paid both to how these young adults had experienced school while they were attending, and to how they looked back on it as adults. This resulted in the final themes presented in the results section.

## Results

The findings begin by engaging with how the informants described their time in school as a whole. The subsequent two themes focus on the support and hurdles at different phases in school, as

identified in informant narratives. The final theme delves into how school is positioned in their life journey.

### *School – a slippery slope*

Six of the informants had positive memories from primary school (Year 1–3), but at a varying level of detail. They described general enthusiasm about starting in Year 1. The reasons for this varied from having a sibling or a friend already in school, to not having previously been in any pre/play-school setting. The excitement about starting school coincided with positive initial experiences: 'I became good friends with my teacher. I enjoyed being in school a lot I remember' (Johan).

The primary teacher was often described with fondness and, not surprisingly, informants started recounting their experiences from primary school by mentioning the name of their teacher: 'My teacher Malin Johansson, she was fantastic' (Johanna). This was not found in their narratives about later school stages.

Positive accounts concerning the primary years were in some case accompanied by descriptions of their own particular behaviours, characteristics or difficulties during that time. Nonetheless, these were described as having had little influence on the quality of experience during the early years.

I had a lot of energy and had a hard time concentrating. I went and sharpened my pencil 15 times because I didn't want to sit and work. I went to the toilet very often because I wanted to move around. I remember this so clearly. I thought school was fun, but I didn't think it was fun to sit still and work. (Ella)

In these six informants' narratives, their positive experiences from the primary years was often contrasted with their intense negative experiences in middle school (Year 4–6). Their description of the middle-school years was filled with accounts of severe conflict, getting in trouble, frequently being misunderstood, and negative emotions.

I enjoyed primary school, after that most memories I have is when people have become angry with me, it's something that recurred. I have this horrible feeling that people were constantly screaming at me. I don't have such experiences from primary school. There I enjoyed being in class with my peers. For my teacher there it was always okay that I was careless and too fast. (Pernilla)

In middle school we changed teachers, and since then all my memories from school are negative. There was trouble, a lot of fighting and conflicts in general. (Elin)

In contrast to these six informants, the remaining three described predominantly negative experiences and emotions associated with school from the outset. For Sandra and Maja, this was connected to not being able to understand what they were doing in school.

I found it tough to go to school because I didn't understand why I was there and what to do there. I don't think I was ready for school. (Maja)

Others, like Dan, expressed their strong dislike for school in general:

I hated school so much, it was the worst thing I knew. Going to school was punishment. I didn't like it at all. I was very good at playing sick ... just to avoid going to school. I didn't think school was fun.

Despite informants' varying experiences of primary school, for many the transition to middle school marked the beginning of a steady decline in their school journey. The gradient of this decline differed, but the downward trend was similar. Niklas's description, beginning from when he started school, summarises this phenomenon well:

Imagine a graph or something and so imagine that it goes like this [upwards], and then you get to Year 3 and it starts going like this [flat] and then Year 4 it goes steadily down.

An exception to this were Sandra and Johanna, where the initial transition to middle school was perceived as more positive; this was justified by describing specific aspects of the new school context that were better aligned with their needs. Johanna had moved to a specialised dance school in Year 4

and described Year 4 and 5 as the best period of her life. The school she attended was less focused on academic subjects and more on dancing, something she excelled at and enjoyed. Nonetheless, Johanna and Sandra moved to a new school in Year 6, which for them as well led to a rapidly accelerating downward spiral.

This steady decline culminated in secondary school, which almost all described as the worst period in school. Pernilla's statement resonates with the sentiments of many: 'The first term in Year 6 went quite ok, the second term it started to go downhill and by Year 7, it started to go to hell'.

It was in Elin's case that secondary school marked a change in the positive direction, and here too the reason provided was the good match between the new school's context and her needs. After a critical phase of conflict and spiralling problems up until Year 6, she started at another school that she described as having strict discipline as compared with the average Swedish school.

I could study there, it was so heavenly ... There were the same rules in the whole school ... so then I had to follow it, but it worked because I knew what was expected.

### *Supports in and beyond school*

In informant narratives, afterschool activities were described as providing vital support. All of the six women had been actively involved in sports (e.g., football, judo, handball) and/or cultural activities (e.g., playing an instrument, theatre). They frequently vocalised the value these activities had added to their lives, weaving together aspects such as recognition, feelings of belongingness, friends and something to focus on.

I played football throughout school. It's been very good for me and I was best at it too, because I wanted to be the best and gave it 110%. I practised all the time. I have poor self-esteem and I think I got recognition through football. I also had the football gang of friends and something after school that I had to go to. (Elin)

I played a lot of sports. I was figure skating from when I was 6 years old. I had regular training, camps and competitions and there I actually had friends, something I didn't have in school. (Sandra)

For four of these women, involvement in these external activities reduced drastically or stopped totally during secondary school, which they attributed to events in their lives at that stage.

Handball disappeared for me in secondary school. I just stopped and I haven't played since then. It's a pity ... I felt I was busy enough doing nothing. My life got in the way. (Pernilla)

I just felt there was no point, it didn't really matter what I did. I just couldn't get it into my head [studies]. So I just stopped bothering with it, only partied, drank and smoked, and hung out with friends and I stopped sports completely. I changed my priorities in life and figure skating wasn't so important anymore. (Sandra)

Interestingly, such activities seemed to be entirely absent among the three men in the study. The only afterschool interest that was briefly mentioned by two of them was playing computer games.

Another factor that seemed to have played an important supportive role during the school years was parents, and in some cases siblings. Four of the young people had received considerable direct support from the family at different stages through school, including practical help with homework and assignments.

I've been lucky to have my parents. They've always helped me, sat with me and studied, and said do this and then do this. If I hadn't had them, it would have gone to hell. Maybe I wouldn't have bothered with it. (Elin)

Unlike Elin, Ella and Johan had a much harder time with their studies. Ella explained how she barely managed to finish her assignments. Time and again she described the significance of her parents in supporting her and recognising when things were going downhill.

Even Maja narrated how she never understood what they taught in school, and it was her mother who tried to teach her at home.

I know that if mamma hadn't helped me it would have been worse. She tried different things ... like for math she used apples, cut them and asked how many I have now and taught me percentages like that ... she showed me things, she realized I learnt nothing when I was just listening to teachers. She used all sorts of objects to teach me, I can still remember this so clearly.

Eight of the informants briefly alluded to what can be described as forms of accommodation and support provided by the school. While some mentioned individual or extra time with teachers, sitting with a special educator and/or in spaces other than the classroom to do their work, it was participation in small teaching groups – for certain lessons, short periods and/or in the longer term – that was most prominent in their narratives. Three of the informants, like Johanna below, noted that this intervention had added little value to their school journey.

At the end of Year 8, I ended up in a smaller class with 6 students for some subjects. I don't know if I got any grades from there, but I do remember it was an immature and aggressive group ... similar type of people who had ended up together. They constantly commented during the lectures saying things like 'seriously why do you need to have this subject, you think we are going to listen to you'. I had low self-confidence anyway, so I didn't want to talk at all during the lessons. It affected me.

Others like Niklas greatly appreciated the opportunity to be in a smaller group, where they could focus and receive more individualised support and instruction.

By Year 9 I'd stopped caring completely, I didn't go to school, the school had had enough and they got me a place in a small group in another area, but I was still counted as their student. It worked better for me there. I could focus better there and got a lot done. We were five in the group, everyone was in the same boat, we related to each other more easily, I actually even made friends there.

For Pernilla, being in a small group was not about extra support, but about flexibility. She could take frequent breaks and structure her work in a way that was best for her.

Many informants mentioned frequent meetings between the school, parents and even others, like the social services, as well as initiation or intensification of interventions during the secondary school years. However, they noted that the effect of these measures on their school experiences was very limited owing to their own lack of receptivity at that stage.

I had stopped going to school, it was too late and whatever they did had little effect. (Johanna)

They tried everything from Year 7 but by then I had stopped thinking of the consequences, nothing worked, I was hardly in school. I was too busy drinking and taking drugs. (Sandra)

### **Hurdles in context**

According to all of the informants, the expectations placed on them by the school constituted a hurdle. For some, these expectations were predominantly in relation to studies. Sandra's narrative contained numerous examples of the difficulty she had experienced understanding what was expected of her during lessons and regarding homework. In an account of her primary school years, she explained:

I often had a very hard time understanding what it was we were supposed to do, even simple stuff – take this book out and write the date. I remember sitting and looking at others and trying to do the same. I didn't understand [the instructions], I was so afraid whatever I did would be wrong.

Similarly, regarding Year 6 Sandra recounted:

I didn't understand the homework, even though it was written on the paper to look up information on Spain or something, but what the hell did they want to know, what should I write, I didn't understand what I had to do.

When describing his experiences, Johan mentioned that school was only designed for certain children.

What has been difficult is that I haven't always wanted to do all the tasks in school, when I had no interest. Everyone has to fit into a template at school and it wasn't good for people like me.

Others frequently brought up the behaviours expected in the school context. These were prominent in informants' accounts of their schooling, from middle school onwards.

I've always had a pretty hard time in school with rules that exist just because they do and not really because they have a purpose and as a child I argued against them. I've finished first in the math book, I've read the most difficult books and so studies themselves have always gone well, but they were extra particular with how you did a mathematic calculation, that you draw a straight line under with a ruler and so on. I could use a ruler and do a certain task if I saw a purpose in doing an exercise I didn't want to do. So stuff like that hasn't always been smooth. (Pernilla)

Often closely related to these expectations was a negative relationship with certain teachers. This was particularly evident for Elin and Pernilla, who performed well academically. They provided numerous examples of how they were treated by their teachers.

My middle school teachers didn't like me ... I had listening exercises for English, where you listened and then you had to write down the answers. I realized then that I didn't remember what I was listening to, so I started taking notes so I could remember. Now I write notes all the time, but I discovered the strategy back then. But the teacher told me off in front of the whole class, Elin cheats you think it's ok ... I felt completely misunderstood and couldn't explain myself, they saw me as a badly brought-up child. (Elin)

Many informants acknowledged that, in hindsight, they have realised that they might not always have been the easiest student to have in the class, but also questioned the teachers' maturity, ability and understanding in approaching them. Pernilla explained this:

In middle school, I got a new teacher and he never really understood me at all, we fought from the very beginning. There were continuous conflicts and I questioned a lot, why I had to do things in a certain way. There were so many conflicts between us. We stood and shouted at each other. I was not so easy, but that teacher also had a distinct inability to deal with me.

The informants offered a number of reflections on the impacts of class size and the peer group during their school years. For example, the hurdle of being part of a large class was brought up by Maja concerning the onset of the terrible period of secondary school:

It was a very big secondary school, six sections in each year, big classes with 30 students in each class and I think it was a bit too big for me, something I realize when I look back.

Rowdy peers were often mentioned in connection with having a large class. Sandra described how class size and her peer group had impacted the learning environment:

I changed schools because it got so chaotic at school, there were many new refugee children who arrived ... we changed to a school in the countryside, it was a small calm school. The teacher had time to sit and show me what I had to do. I enjoyed school, the sound level was low, not many children and it was easier for me to learn and pick up what I had to do.

Niklas described how a large class and rowdy peer group, together with individual difficulties, had not benefitted his school situation in any way. 'In Year 6 I had lot of difficulties concentrating, I had a very big class and very disruptive too'.

However, a small class without the right pedagogy seemed to be of little value, as noted by Dan and Pernilla. Dan moved to a smaller school with fewer students in each class in Year 7. He said that the specific philosophy of teaching had been poorly suited to his learning style: 'this wishy-washy teaching didn't work for me, it made no sense, I didn't learn anything'.

### *Purpose of going to school*

Permeating informants' narratives was the notion that school was a place to get grades, which they described as essential to future life opportunities. However, they clearly differed in when they had this realisation or began understanding the link between school, grades and future.

Four of them seemed to have internalised early in their school career the importance of leaving school with complete grades. Evident here was the role of having parents who, from an early stage, emphasised the value of education for their future life. As Pernilla explains:

I've always heard it from my parents, even when things have been messed up and I haven't gone to school. I've always had this with me, you have to have good grades and of course you have to study at university or else you'll end up working at a supermarket. It's been very deeply rooted.

The remaining five seemed to have gone through most of school without really understanding what school was for and why they were there: '... I didn't know what I was doing in school and I didn't know what purpose it had.' (Sandra)

It was only towards the end of secondary school that these five had realised they should also try to obtain grades before leaving school. While three of the five left school with a few grades, they stated clearly they had not deserved them. Grades had been obtained by getting sympathy from teachers and/or cheating:

I had a really kind teacher who passed me in science or something, just because I sat and cried the days before. (Sandra)

I sucked up to my teachers, this was my pass grade. (Johanna)

There is a lot of grades I would not have received in school that I received anyway. Two teachers said they wanted me to move on with my other friends. I thought it was quite cool and so I started at upper-secondary. (Maja)

While Johanna, Sandra and Maja mentioned having been happy at the time and satisfied with having received some grades, they have at different points in life questioned whether it has actually been more of a hurdle than a help. These grades may have facilitated their entry into certain post-school settings, but they have had significant difficulties coping with academic demands, resulting in frequent dropout. This had caused them to realise later on that obtaining grades merely to move on is of little value if the grades are disconnected from learning.

What is particularly interesting is that 'sympathy grades' were only brought up by the young women, and not by the two men who had left school with no grades. Nonetheless, a common question raised by all five was the purpose and value of attending school, which for them had been a meaningless period of continuous suffering.

Why did I have to go to school and suffer, but still leave without what is most important for my future – grades. (Niklas)

I struggled, I went to school a lot, I suffered through the whole school period and still I got nothing for it. (Sandra)

Dan described this as a wasted period in his life:

'I had all fails when I left Year 9. You have to go to school every year, nine years but then you go out, then you have to do the same thing again after you leave'.

School was also identified as a good place to interact with friends. Most of them had negative associations with the formal lessons, but positive attitudes towards the social aspects of being in school. 'I hung around in school for friends, two girls ... they were normally committed to school, we started hanging out and then I went to school a lot only to see them' (Sandra).

## Discussion

The present findings have provided valuable insights into the experiences of compulsory school and reflections on this life phase, as seen in hindsight, among young adults with ADHD. The variation captured in the sample, regarding gender, time of diagnosis and life trajectories, has made visible aspects that, to date, have not been captured in previous research, which has tended to have more

homogeneous samples. Although diverse experiences of and reflections on school were expressed, there were some strong commonalities across the narratives as well as interesting departures from previous conclusions drawn in the research on ADHD and school, both of which are discussed further here.

A clear trend in the informants' accounts was the slippery slope characterising their schooling, usually starting with a steady decline around middle school that accelerated in secondary school. This finding of peaking of difficulties in secondary school are also the results presented by Bolic Baric et al. (2016). Thompson, Morgan, and Urquhart (2003) noted that this phase is an intense period, with increased academic and environmental demands and changed peer relationships, which heighten the difficulties faced by students with ADHD. However, this finding was contradicted in two studies (Wiener and Daniels 2016; Gibbs, Mercer, and Carrington 2016), where adolescents described secondary school as a more positive phase than their earlier school years. One possible explanation for the difference is that the students in the aforementioned studies had adequate support structures in place by the time they reached secondary school.

In the present study, despite variation in the gradient of decline and intensity of difficulties, what is noteworthy is the similarity across individual narratives regarding the period they identified as the negative turning point in their school trajectory, which seemed to have started long before the identifiable crisis Year 7 onwards and largely coincided with middle school. The fact that most of the informants did not have a diagnosis while in school makes this similarity in decline even more interesting. It has been argued that, in Sweden, having an ADHD diagnosis in school puts the student on a different educational pathway (Hjörne and Evaldsson 2015; Malmqvist 2018), but the present findings clearly question this notion, showing that the decline might have already gained momentum long before the step towards an official diagnosis or move to a special class is taken.

While some of the informants described receiving some forms of accommodation and/or support in middle school, almost all were cognisant of the intensification of these efforts during secondary school. The paradox they mentioned, however, is that these efforts had a very limited impact on their school trajectory owing to their own lack of receptivity at that stage. This powerful insight on the part of the individuals themselves may explain why the plethora of intense interventions offered in secondary school (Giota and Emanuelsson 2011) seemed to have had little effect, with high dropout rates and low academic performance continuing to persist in this group (Swedish Schools Inspectorate 2016). These particular findings point to the importance of the phase prior to the visible crisis in school, a critical period in which early recognition of difficulties and appropriate timing and intensity of support could result in better individual and societal outcomes. This topic is clearly worthy of more research attention than it has received to date.

A particularly interesting finding was the way in which informants chose to frame both their positive and negative school experiences. They did not allude to ADHD per se, but provided nuanced accounts of the interaction between their own characteristics or needs at a particular time and the school and/or classroom environment. Honkasilta, Vehkakoski, and Vehmas (2016) also found that ADHD played a limited role in the spontaneous narratives of adolescents with ADHD. This calls attention to the implicit risk that ensues when a strong medical lens is used in studies exploring students' experiences.

Irrespective of whether a diagnosis had been made while in school, the forms of accommodation and/or support described by the informants were very similar to those found in previous studies from Sweden (Giota and Emanuelsson 2011; Bolic Baric et al. 2016; Malmqvist and Nilholm 2016). While some informants' narratives were very much in line with the existing criticism of special teaching groups (Hjörne 2005; Malmqvist 2018), others appreciated the opportunities this approach offered. It is important to be mindful of these nuances, as the debates on the *to be, or not to be* of these groups are strongly polarised in Sweden.

Supporting findings from previous studies on retrospective ADHD accounts, parents were identified as an important source of support and help throughout the school years (Shattell, Bartlett, and Rowe 2008; Wiener and Daniels 2016). This was not the strongest supportive factor identified, however, as activities outside school, such as sports, music and dance, seemed to have played an even more significant role. While in recent years much attention has been given to the effect of

physical activity on the cognition and behaviour of students with ADHD (Suarez-Manzano et al. 2018), the present findings show that participation in these activities outside school met individual needs that were probably unacknowledged and uncompensated for within the school setting. This has probably failed to receive any attention to date because of the overrepresentation of the male voice in studies on schoolchildren with ADHD (see e.g. Ringer 2020). While this is not surprising, considering more school-aged boys receive an ADHD diagnosis than do girls (Ramtekkar et al. 2010), one could argue that findings from existing studies largely represent the voice of adolescent males with ADHD while they are still in school. The importance of these activities outside school in the narratives of all six women could be one of the explanations for why many girls manage to cope with school until the start of secondary school or slip under the radar during the school years.

Previous studies drawing on retrospective accounts have shown that teachers both provide significant support and are the source of many of the problems faced during school. In the present study, there were hardly any positive teacher experiences narrated from Year 3 onwards, and the relationship with teachers was found to be a key hurdle. This finding is in line with the conclusions of Ewe's (2019) systematic review, where students with ADHD were found to be less close to their teachers than were their non-ADHD peers and where this was also reflected in teachers' accounts. In addition, teachers experienced less co-operation and more conflicts in their relationships with their students with ADHD than with other students.

Note that the informants' narratives about school were not greatly marked by social difficulties, such as lack of friends or problems with peer relationships. While almost all mentioned certain peers they tended to get into conflicts with, this was not attributed much importance, as it was in retrospective accounts (Shattell, Bartlett, and Rowe 2008; Bolic Baric et al. 2016) or those of school going children (Gibbs, Mercer, and Carrington 2016).

One finding that raises great concern is the little significance ascribed to school by many of the informants, who weaved together suffering through nine years of school and leaving without anything of value. While the phenomenon of students leaving school without complete grades has frequently been debated in relation to individual life outcomes, productivity and the impact on the economy (OECD 2012), young people's experience of the nine years of compulsory school as completely meaninglessness has rarely been raised.

It is important to reflect here on some of the limitations of this study. The size of the sample might be argued as limiting to the scope of the findings. A variety of mediums was used to contact the informants, but it is likely that the study still excluded voices that would have furthered nuanced the debate. However, the depth of information gathered over time, and the wide variation within the sample, led to rich accounts. Drawing on accounts of experience retrospectively, also introduces the possibility of fallible memories on the part of the informants. This study taps into personal reconstruction and interpretations of their experiential memories, and is not necessarily a reflection of what actually happened in school. The findings from this study cannot be generalised to the Swedish context, but it has raised important insights which need to be followed up in future research. These include: 1) school experiences of girls with ADHD both retrospectively and while in school; 2) the supportive role of sport and cultural activities outside school for children and teenagers with ADHD; 3) longitudinal ethnographic research that follows students with ADHD during the school years; 4) deeper understanding of the critical transition from primary to middle school.

## Conclusion

The lack of research on adult retrospective accounts of school has not only kept an important perspective out of the discussion, but also denied a voice to those who did not have a diagnosis while in school. One important agenda of the present paper has been to give space to these individual voices and bring attention to valuable insights that can nuance current debates on schooling for persons with ADHD. The tentative differences identified between experiences of men and woman are clearly interesting, but need further investigation. The dominant focus on the ADHD diagnosis per se in

much of the contemporary research has resulted in failing to acknowledge what the present findings show, which is that, with or without a diagnosis, school careers have largely been similar in the past. In the present study, most of informants did not have a diagnosis while in school. Nonetheless, they raised concerns regarding schooling that were very similar to those found in previous research on ADHD. While it is important to question the explosion of diagnoses like ADHD in school and the impact this may have on individual identities, we must also consider how we can meet the needs of a vulnerable group of students and how best they can be supported, so that they leave school with positive experiences, rather than memories of suffering and seeing school as a wasted period in their lives.

## Biographical note

Shruti Taneja Johansson is a senior lecturer at the Department of Education and Special Education, University of Gothenburg. Her main research interests are perspectives, practices and experiences related to inclusive education, and more specifically to the education of people with disabilities, in Sweden and South Asia. In a recent study she has looked at educational and life trajectories of persons with ADHD.

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