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The impact of attention deficit hyperactivity disorder (ADHD) in adulthood: a qualitative study

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Objectives. There is limited evidence of the unmet needs and experiences of adults with attention deficit hyperactivity disorder (ADHD). Previous research in this area is predominantly quantitative by nature, few studies employing qualitative approaches. This study seeks to provide a deeper insight into the lived experiences of adults with ADHD within Western Ireland.

Methods. A qualitative design, consisting of semi-structured face-to-face interviews with a clinical sample in the Sligo/Leitrim area. Participants were eligible for this study if they screened positive for symptoms of ADHD, and diagnosed with ADHD with the Conners' Adult ADHD Diagnostic Interview for DSM-IV. In total, 11 participants completed this research. The interviews were open ended and exploratory, adopting a phenomenological approach.

Results. Thematic analysis was used to explore three main themes; The Burden of symptoms of ADHD, Perceived Positive and Negative Effects of ADHD and Challenge of Accessing Services, each with several subthemes.

Conclusion. This research highlights the experiences of adults with ADHD. It is important for practitioners to be aware of the perceived positive and negative effects of the disorder, and how it can impact on their patient's lives. In addition, becoming aware of the stigma associated with ADHD can help clinicians improve upon individual treatment plans to meet their patient's needs. It is important to note that this sample experienced co-morbid diagnoses and so this may limit the interpretation of the findings. Further research in this area could explore patient's attitudes towards receiving a formal diagnosis of ADHD.

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Key words: ADHD, adult, attention deficit hyperactivity disorder, qualitative research.

Introduction

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder, which many recognise as a childhood disorder (Rosler *et al.* 2010). However, a review of the literature as well as longitudinal studies of individuals with ADHD reveals that symptoms of ADHD can persist into adulthood (Faraone *et al.* 2006; Davidson, 2008). Regardless of this literature, there is limited evidence of the unmet needs and experiences of adults with ADHD (Matheson *et al.* 2013). It is common among adults with ADHD to experience high rates of co-morbidities; three in four patients have at least one or more co-morbid psychiatric disorder (Faraone & Biederman, 1998). In some cases, these other psychiatric disorders can dominate the picture, causing symptoms of ADHD to be overlooked or even undiagnosed. Therefore, individuals with ADHD can be under-treated and may fail to

receive a diagnosis of ADHD and sufficient treatment which can result in life-long challenges and difficulties.

Research has shown that adults with ADHD often complain of psychological and psychosocial difficulties which can impair functioning, well-being, and health-related quality of life in adulthood (Nigg *et al.* 2002; Murphy & Adler, 2004; Adler *et al.* 2006; Weiss *et al.* 2010). Compared with adults without ADHD, adults with ADHD have a higher risk of developing depression, anxiety, substance abuse, anti-social behaviours, lowered socio-economic status due to work-related stress (Faraone *et al.* 2000; Schubiner *et al.* 2000; Barkley *et al.* 2004; Wilens & Dodson, 2004), social skills deficiencies due to difficulties in affect recognition (Rapport *et al.* 2002), increased anger expression (Richards *et al.* 2006), are more likely to commit anti-social acts and be arrested (Barkley *et al.* 2004), and an increased risk for motor vehicle accidents (Swensen *et al.* 2003). ADHD can have a negative impact on finances, career opportunities, income, retirement funds (due to impulsive spending), friendships groups, families and co-workers (Brod *et al.* 2012). As a result, there is often a substantial psychological and psychosocial burden

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associated with undiagnosed and untreated ADHD (Able *et al.* 2007). Without treatment, these impairments can have detrimental effects on quality of life.

Stigma is an underlining difficulty faced by many people suffering from mental illness, ADHD in particular. Previous research has noted some individuals demonstrate hesitance and reluctance to engage and interact socially with their fellow peers experiencing the disorder. One such study was carried out in an American University. This study consisted of undergraduate students rating the likelihood that they would rather interact with a peer described as having ADHD, a peer with general medical problem, or a peer with an ambiguous flaw such as perfectionism (Canu *et al.* 2008). Peers described as having ADHD were rated less socially desirable than peers with the other two descriptions. It is unclear as to whether stigma stems from a lack of awareness of ADHD or popular myths about the illness in that it is only restricted to childhood. As reasons remain unclear, researchers have requested for further research to examine the stigma associated with adults with ADHD (Lebowitz, 2013).

A significant amount of the available literature on adults with ADHD has used samples from the United States and the United Kingdom, and researchers have requested further research with various methodologies to shed light on the experience of ADHD in adulthood (Lebowitz, 2013). Therefore, this research seeks to explore the experiences of adults with ADHD from a clinical sample in Western Ireland. The rationale of this study is simple; understanding the impairments associated with ADHD in adulthood and the stigma attached to this illness can help practitioners be more aware of the difficulties faced by individuals accessing support services and possible barriers that may affect treatment adherence, particularly within a Western Irish context. Previous research among individuals with ADHD have mostly employed quantitative approaches (Young, 2005; McCarthy *et al.* 2013). However, qualitative approaches are more appropriate at providing an in-depth insight into patients' experiences (Pope & Mays, 1995). Like any illness or disability, early intervention can improve quality of life, self-esteem, overall functioning, outcome and long-term prognosis (Agarwal *et al.* 2012; Shaw *et al.* 2012; Harpin *et al.* 2013; Matheson *et al.* 2013). Therefore, this research is essential to ensuring timely and early support is available to those who require it. There is very little understanding of the perspectives of adults with ADHD reported in the scientific literature (Young *et al.* 2008; Henry & Hill Jones, 2011), particularly regarding those with untreated ADHD. Therefore, it is hoped that this research study will contribute to the literature by informing clinicians of the lived experiences of adults with ADHD.

Aims of the study

The aims of the study were twofold: to examine the functional impairments of ADHD and to investigate perceived attitudes and stigma.

Method

Methodological approach

A qualitative approach using semi-structured interviews was used as it aims to elicit a detailed and in-depth description of the participants' experiences and views. A literature review was carried out to establish topics to guide the interview in order to elicit commentary in several areas, including daily life, social, psychological, and physical functioning, negative effects of ADHD, positive effects of ADHD, experiences accessing support services/treatment centres and attitudes towards ADHD. Demographic information of each participant was recorded in order to generate descriptive statistics.

Recruitment

The recruited sample was a sub-sample of a larger epidemiological study (Adamis *et al.* 2016). Consecutive patients attending any Adult Mental Health Services out-patient clinics of Sligo/Leitrim were invited to participate. Participants completed the Adult ADHD Self-Report Scale and the Wender Utah Rating Scale. Exclusion criteria applied were as follows: age less than 18 or above 65, illiterate, non-English speaking patients. Those who scored positive in both scales were further assessed (second stage of the initial study) with the Conners' Adult ADHD Diagnostic Interview for DSM-IV (CAADID) and the Mini International Neuropsychiatric Interview (M.I.N.I.) (Sheehan *et al.* 1998) for diagnosis of co-morbid disorders. Consequently participants who completed the CAADID and who were considered to have an ADHD diagnosis were invited to complete this research; a qualitative interview in 2016. The first 17 who have been diagnosed with ADHD according to CAADID were contacted by telephone or post to take part in this research.

Study setting

The interviews took place in an out-patient clinic or mental health service participants were familiar with. The interviews were conversational and semi-structured based on previous literature and following a guide that was reviewed by an expert in qualitative research. With the participant's consent, interviews were audio recorded and transcribed in order to be analysed. On average, the interviews lasted ~40 minutes each.

A reflective journal was kept to increase the validity and reliability of the research.

Analysis

Demographic information provided quantitative data that was entered and analysed using SPSS. As data were only collected for descriptive purposes, only descriptive statistics were performed. Qualitative analysis consisted of using a thematic approach in order to determine similarities across transcripts as well as highlighting the differences between them. Analysis consisted of six phases: (1) familiarisation with data, (2) generating initial codes, (3) searching for themes among codes, (4) reviewing themes, (5) defining and naming themes, (6) producing the final report. The end result was a full coding system that was descriptive of the collective experience of ADHD in adulthood. A phenomenological approach was adopted which emphasises the participant's perceptions, feelings and experiences as the paramount object of the study. This approach encourages participants to discuss the topic in their own words, focusing on the human experience subjectively.

Results

In total, 17 out-patients were approached to participate. Two individuals declined to participate and four individuals were unable to be contacted, resulting in 11 participants completing the semi-structured individual interviews; nine male and two female with an age range of 20–54 years (mean age 37.64 years, SD = 11.83). Eight of the participants were currently employed, and three were unemployed. Four participants were single, four were married and one was cohabiting. One participant had obtained an I.T. degree, one had a University degree, seven had completed education as far as the Leaving Certificate, one only had Junior Certificate education and one had a Post-Graduate degree. Co-morbidity was diagnosed based on use of the M.I.N.I. Each participant had more than one diagnoses with the majority being mood disorders ($n = 8$; 72%) following by generalised anxiety disorder ($n = 5$; 45.5%) and panic disorders and/or phobias ($n = 5$; 45.5%).

Three main themes were found: The Burden of symptoms of ADHD, Perceived Positive and Negative Effects of ADHD and Challenge of Accessing Services. Each main theme contained a few subthemes which are described in greater detail below. Quotes from interviews are provided, followed by the number in parenthesis (x) attributed to the interviewee. Ellipses (...) mark parts omitted from the quote and words within brackets are clarifications made by the authors.

The burden of symptoms of ADHD

Inattention and poor concentration

The impairment associated with poor concentration, distractibility and inattention were described the extent and the burden of experiencing symptoms of ADHD in adulthood. Inattention and lack of concentration resulted in significantly difficulties with basic tasks such as reading, watching television, writing a letter, forgetting things (in terms of relationships), multi-tasking and getting 'side tracked by something else' (2). Often in adulthood, demands become more complex and individuals are expected to function more responsibly and independently, yet poor abilities to maintain concentration exacerbate the burden of living with ADHD. The majority of participants often compare their concentration levels with others and are aware of the impact this has on their lives. 'I try watching and learning new things, but I just don't have the concentration for it like others would' (10), 'My concentration levels delay me from completing a task ... so yeah it would probably take me longer to complete a task than the average person' (5), 'I just would not have been able to have focused for nearly as long as everyone else ... It definitely puts me behind in college' (6).

Hyperactivity and impulsivity

Participants reported difficulties related to hyperactivity and impulsivity noting a tendency to blurt things out without sufficient thought in terms of saying things uncontrollably, not completing tasks, negative future consequences and more subtly through relationships. 'It affects my work in that I just can't get things done ... there are a lot of little jobs where I do 80% of it and then I leave the other 20%, and kind of avoid it and go and do something else' (3), 'I would say that I don't have a filter on what I say ... never aggressively, but there's just no filter ... I just sit on my hands and try not to say anything' (8), 'Say I have €20 in my pocket for shopping and I bumped into someone on the street and they asked if I wanted to go do this, then I might spend the €20, all my shopping money and have no food then for the week ... like I lost a lot of weight the last two months ... just from being impulsive with money I have set aside for food and stuff' (4), 'I just think it's a great idea at the time but then I realise maybe it's not a great idea ... let's say I'm painting the garden fence and I've a lot of that to do and that's fine ... and instead of finishing the fence, I go over and start painting the shed' (5). One participant described having a hyperactive mind rather than displaying hyperactive behaviour: 'I wouldn't outwardly be hyperactive, but I might find it very hard to be concentrating on a single clear thought. My mind would be racing and tumbling after itself' (9).

Limited possibilities

Limited possibilities was identified as an emerging theme, in that participants explained how their symptoms and difficulties elicited a sense of lost potential. 'It would stop me doing courses or jobs where I would have to retain the information because I get nervous about it then because I know it won't stay in. So it's that kind of thing that stopped me. You know I would have loved to have gone on and maybe go back to college or do something but that kept me away' (2), 'I could never hold a job down. I would always lose focus of the job or I just wouldn't be bothered just doing the same stuff over and over again and I always found it very mundane. I've had so many jobs since I was 16 its ridiculous' (4). Participants described how they felt like they failed to fulfil their potential, yet knowing they are capable of doing more: 'I'm not doing the work as well as I should be because I know that I can work very well. If I don't, I'm automatically seen by other people as poor performance so then I would be putting myself under more pressure to get the work done ... definitely procrastination is a big thing for me' (9). Again, participants reflected upon their childhood and how undiagnosed symptoms may have limited their educational opportunities from an early age: 'I spent half of my time in the corridor, outside of the classroom. One half in the corridor and the other half in the principal's office' (4), 'I would have to really really learn things and then they were gone. And that used to upset me and I couldn't understand. Things would go in when I learned it and then that night it was gone ... I suppose things just got harder, to retain all of the information' (2).

*Perceived positive and negative effects of ADHD**Every cloud has a silver lining*

Some participants noted the benefits of some of the symptoms experienced. 'I kind of like being like that at the same time as well. Doing things on impulse is always better rather than stuff that you plan out, it never works' (4). ADHD could perhaps contribute to a fulfilled and exciting life 'kind of defines me as a person I suppose ... just the impulsiveness to go and do something that somebody else wouldn't have done' (4). One participant noted the advantages of having an overactive mind, looking to the bright side of being easily distracted. 'I suppose sometimes it is useful (being easily distracted), if I'm stuck in my own head a bit too much and I'm just over thinking things and stuff like that, it's definitely a good thing to be able to let your mind wander a bit, not to think about anything too heavy' (6). It was suggested that being impulsive and unpredictable can make a person more likeable. 'Maybe the spontaneous aspect, people seem to enjoy that' (8).

Low self-confidence and self-esteem

A lot of participants reported psychosocial effects of symptoms of ADHD. For example, some participants reported lack of self-confidence and self-esteem prevented them from taking part in new experiences: 'I get frustrated a lot of how I lack in college work, I would just be very easily distracted and then just lower self-esteem. Like it can happen before I go to do something and then getting frustrated during. Before I start something I think what's the point, I can't do that anyways' (6). Negative comparisons to others affected making new friends: 'I suppose I would have been a little less inclined to get to know people ... I felt like everybody was way ahead of me anyways' (6). Confidence appeared to limit possibilities in terms of employment prospects: 'I never stuck at anything ... then I guess I have no confidence either. I never thought I would be able to do it ... I wouldn't go for a job or I would never try for things' (3), and functioning at work 'I know I should be doing it quicker and I can do it quicker' (5). Low self-confidence and self-esteem had several consequences during childhood, causing frustration and embarrassment compared with peers: 'I get frustrated because everyone else can do it and I can't and I get frustrated out of that' (11), 'It made me a bit nervous, I realised that they were remembering and I wasn't' (2).

Coping

A sense of disorganisation was evident throughout the interviews which was considered debilitating and draining. 'I get distracted with work or that and just getting frustrated and feeling like I can't do it and I get down on myself that I'm not good enough so it's just like being distracted and also just feeling like I can't do it anymore, getting frustrated and giving up. So I definitely struggle with that kind of thing' (6), 'I do procrastinate, again that would be quite typical because jobs often seem very big and overwhelming' (7). The impression from interviews was that daily tasks, such as household chores, clothes washing, packing a bag, making breakfast can appear impossible and overwhelming. 'When I wake up in the morning, just the thought of having to do all of that, I mightn't bother doing that ... because that time in the morning when I'm just after waking up, any series of tasks like that complicated would be insurmountable, I would want another half an hour just staring there beforehand' (9). Strategies were employed to overcome these challenges. 'One trick that I try to teach myself in general was what I've learned from mental health tools is to try and do the next little thing and not think of all the things that I have to do. That's a little bit more manageable in terms of thinking ... I'm trying to

train myself to just think about the next little step' (7). Participants described how they learned to cope with forgetfulness by immediately writing things done or asking different people instead of the same person all the time to avoid being labelled as forgetful. Coping with symptoms of ADHD in adulthood was described as something you just had to accept. 'You just manage, it's like someone with a limp, you just manage to walk. I suppose you just kind of brush it to the side and learn to get on with things' (5).

Challenge of accessing services

Stigma

Perceived stigma towards mental health in general was discussed as an issue for both the person experiencing mental health difficulties and their families. Going to hospital and attending the psychiatric services were considered the most severe and unwanted forms of treatment. 'Well I would say I had a huge resistance to Psychiatry ... because to me that was another downhill step ... as long as I didn't go to a Psychiatrist that meant I was ok. And then at that point, it was as long as I haven't been institutionalised' (7), 'They (my family) can't really handle mental health issues. Like if I had cancer, it would be ok' (7). The majority of participants discussed what they thought ADHD was and confessed that they believed it to be restricted to childhood. 'When I heard of ADHD I used to always think it was hyperness ... I thought it was just a childhood thing' (2), 'I often heard about it (ADHD) in kids really more so than adults. The impression I got is that it would be kids just throwing tantrums ... I always thought it was unruly kids' (5), 'People question is ADHD made up, is it an excuse for boldness' (9). ADHD is viewed in a negative light, and stigma attached to the disorder may arise from character portrayals in the media. 'the bad character in that had ADHD so it's not seen in a positive light. It might not be a positive thing' (8).

Discussion

ADHD is typically regarded as a childhood disorder with little attention given to adults with ADHD, who often go unnoticed and undiagnosed. The scarce literature that is available employs quantitative methods; therefore this qualitative methodology provides further insight into ADHD in adulthood. The main aim of this research was to the experience of associated with ADHD in adulthood, as well as the perceived stigma attached to the disorder. This research highlights the difficulties and challenges faced by an Irish clinical population who have remained undiagnosed until adulthood.

The perceived burden and sense of impairment associated with ADHD symptoms was highlighted persistently through the interviews is in-keeping with previous research in this area, suggesting that symptoms of ADHD persist into adulthood. The negative effects of the symptoms were quite dominant throughout the interviews, however there were some positive effects associated with symptoms of ADHD. Some of the participants viewed their impulsivity in a positive light and felt it made them more likeable to others, whereas others noted how impulsivity affected their work, social life and completing daily tasks such as household chores.

Participants in this research often felt and identified themselves as different to other people. This difference was noticed retrospectively in childhood, while in education, and highlighted when in relationships. The findings suggest that symptoms of ADHD such as inattention, poor concentration, hyperactivity and impulsivity may have affected the participants' ability to remain focused in school making the earlier years an unpleasant period which increased the likelihood of falling behind their peers resulting in reduced self-esteem and self-confidence. This in turn may have resulted in the feeling of missed opportunities and failing to fulfil potential.

Stigmatisation was explicitly recognised as an issue that the general public and clinicians need to be aware of. There was a huge under awareness of the disorder, particularly the fact that it can persist into adulthood. ADHD is viewed in a negative light with one participant making reference to a popular TV show portraying a 'bad' character with ADHD implying it makes children uncontrollable. This stigma may have implications during the diagnostic process. Clinicians need to be aware of the stigma associated with the disorder and thus can maintain the appropriate sensitivity. The perceived stigma can also affect treatment adherence and cooperation with the services. It is clear from the findings that participants benefited the most when accessing both Psychiatry and Psychology services. This is in-keeping with the literature in that treatment outcomes are highest when services work together. 'Gaps' between the services should be addressed with appropriate communication and cooperation.

The findings of this research should be interrupted in light of the following limitations. The sample were predominantly male and contained only Caucasian participants. It is important to note that individuals who are less inclined to access and cooperate with the mental health services in the Sligo/Leitrim area may have different experiences and views of ADHD compared with those who voluntarily participated in this research. Only participants who were considered as having a clinical diagnosis of ADHD, following

completion of CAADID and screening positive for symptoms of ADHD, were invited to participate in this research. However, it is important to note that participants had not yet received a formal diagnosis. Therefore, this may affect the findings in that individuals may not have recognised their symptoms of ADHD and thus the impact they may have had on their life. As outlined, all of the participants had at least one co-morbid psychiatric diagnosis and therefore the experiences described above could be due to other diagnoses. In addition, due to preliminary research with this cohort, researchers were aware of history and information about other co-morbid psychiatric disorders and this may have affected the results in that it may have been difficult to determine the effects of ADHD *versus* those of other disorders.

Conclusion

This research highlights the experiences of adults with ADHD. It is important for clinicians and practitioners to be aware of the perceived positive and negative effects of the disorder, and how it can impact on their patient's lives. In addition, becoming aware of the stigma associated with ADHD can help clinicians improve upon individual treatment plans to meet their patient's needs. Further research in this area should explore patient's attitudes towards receiving a formal diagnosis including perspectives linked with a delayed diagnosis or delayed treatment. Following their formal diagnosis, a follow-up interview would be interesting to decipher the experience of receiving a diagnosis in adulthood.

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Conflicts of Interest

The authors declare that there are no conflicts of interest to disclose.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. Research ethics was granted from Sligo General Hospital to conduct this research.

Verbal and written informed consent have been obtained from all study participants.

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