

Psychological impact of an adult ADHD diagnosis: “A blessing and a curse?”

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Abstract

Background: Attention Deficit Hyperactivity Disorder (ADHD) is commonly thought of as a ‘childhood’ disorder but is increasingly recognized as affecting adults. The aim of this study was to explore the psychological impact of receiving a diagnosis of ADHD in adulthood. Method: A qualitative study was conducted. Twelve adults (seven male, five female; aged 18-54) participated in semi-structured interviews, which were analyzed using thematic analysis. Results: Three master themes were identified with subthemes: (1) Looking back: different, faulty; relief and regret; reframing; (2) Looking inwards (with acceptance); and (3) Looking outwards: labeling: disability, stigma and social comparisons. Conclusion: The results highlighted a dilemma: diagnosis was necessary to access appropriate support and helpful to acknowledge (and potentially reframe) experiences, understand oneself better (including recognizing strengths) and foster a sense of belonging.

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However, after diagnosis there remains a struggle with the sense of self, feeling stigmatized, and the permanence of being or having ADHD forever.

Keywords: ADHD diagnosis; Adults; Thematic analysis; Qualitative study.

1. Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental condition diagnosed in 3-5% of children (NICE, 2008). The diagnostic criteria state that ADHD is characterized by poor attention, hyperactivity and impulsivity (American Psychiatric Association, 2013). Debate exists around the existence and origins of ADHD, with some arguing it is a social construct (Timimi & Taylor, 2004) and others asserting that it stems from a combination of genetics, biological and psychosocial influences (Faraone & Biederman, 1998). There also remains much to be learned about the societal and cultural context of ADHD (Waite & Ivey, 2009; Asherson, Akehurst, Kooij, Huss, Beusterien, Sasané *et al.*, 2012). Most research centers on diagnosis, etiology and medication treatment, despite NICE guidelines advocating a holistic approach to care, incorporating psychological and behavioral approaches in both children and adults (NICE, 2008).

More recent recognition that people experience symptoms of ADHD in adulthood, with 2-5% of adults meeting the diagnostic criteria (Barkley, Fischer, Smallish, & Fletcher, 2002; Wilens, Faraone, & Biederman, 2004; Kessler, Adler, Barkley, Biederman, Conners, Demler *et al.*, 2006) has led to a shift towards studying adults and the lifetime course of ADHD. Clinical observations suggest that adults have more diverse deficits than children in higher-level executive functioning and emotional control (Adler, Faraone, Spencer, Berglund, Alperin, & Kessler, 2017). The continuation of ADHD symptoms into adulthood is associated with a range of social and emotional difficulties: adults with ADHD have more road traffic accidents, higher divorce rates, more substance misuse, change jobs more frequently (Faraone, Biederman, Spencer, Wilens, Seidman, Mick *et al.*, 2000; Wilens *et al.*, 2004; Advokat, Martino, Hill & Gouvier, 2007) and have more psychiatric comorbidities (Wilens, Biederman, Faraone, Martelon, Westerberg, & Spencer, 2009) than adults without ADHD, although causality cannot be established. These associated difficulties are thought to have more of an impact on those who are diagnosed in adulthood. There is international evidence that the impact of ADHD across the life course is similar for individuals across countries, with impacts on addictive and risk-taking behavior, work and productivity, finances, relationships and psychological impacts (Brod, Pohlman, Lasser, & Hodgkins, 2012). The majority of a sample of older adults with ADHD experienced an accumulated lifetime burden of illness that they viewed as impacting their

professional, economic, social and emotional well-being (Brod, Schmitt, Goodwin, Hodgkins, & Niebler, 2012).

The possibility of cumulative illness burden supports the suggestion by some that outcomes may be improved for those diagnosed earlier in life (Klein, Mannuzza, Olazagasti, Roizen, Hutchinson, Lashua *et al.*, 2012) and that early intervention is needed to avoid long-term associations of childhood ADHD with adverse physical health and socioeconomic outcomes (Erskine, Norman, Ferrari, Chan, Copeland, Whiteford *et al.*, 2016; Agnew-Blais, Polanczyk, Danese, Wertz, Moffitt, & Arseneault, 2018). However, it is unclear whether those diagnosed in adulthood also experienced symptoms in childhood and what aspect of the diagnosis may have mediated this relationship, for example, access to services or the types of intervention received. Even where data has undermined the assumption that adult ADHD is a childhood-onset neurodevelopmental disorder, the need for treatment in adulthood has still been established, due to evidenced impact of symptoms on functioning (Moffitt, Houts, Asherson, Belsky, Corcoran, Hammerle *et al.*, 2015).

Despite such a range of social, emotional and mental health issues (Biederman, Newcorn, & Sprich, 1991; Kessler *et al.*, 2006; Klein *et al.*, 2012) being linked with ADHD, there exists little qualitative research into these experiences, with most research taking a medical perspective with the aim of ascertaining cause and improving diagnosis and medication treatment. Such studies contribute little to understanding the impact the diagnosis may have on an individual, especially when ADHD in adulthood is only recently becoming recognized and remains highly stigmatized (Mueller, Fuermaier, Koerts, & Tucha, 2012).

ADHD is only recently widely recognized by health, education and social care professionals; thus many adults may have experienced difficulties throughout their lives without understanding why or seeking support. Stigma continues to surround ADHD, particularly in adults, due to public uncertainty and misunderstanding about the diagnosis, or the nature of the disorder (Kooij, Bejerot, Blackwell, Caci, Casa-Brugué, Carpentier *et al.*, 2010; Mueller *et al.*, 2012). This may limit people seeking help or accessing services and may also contribute to the impact a diagnosis has on an individual.

Few studies have considered the psychological impact of receiving a diagnosis of ADHD in adulthood. Two related qualitative studies have suggested participants and their partners went through six stages of acceptance after diagnosis: (1) relief and elation, (2) confusion and

emotional turmoil, (3) anger, (4) sadness and grief, (5) anxiety, and (6) accommodation and acceptance (Young, Bramham, Gray, & Rose, 2008; Young, Gray, & Bramham, 2009). A study of online narratives (Fleischmann & Fleischmann, 2012) explored the impact of the diagnosis on stress, and themes emerged around the advantages of having an ADHD diagnosis and positive experiences in terms of creativity and spontaneity. The experiences of adults who were diagnosed in childhood and in adulthood was explored by Matheson, Asherson, Wong, Hodgkins, Setyawan, Sasané and Clifford (2013) who identified themes around accessing services, the burden and impact of ADHD, and three themes related to pharmacological treatment. Differences between early and late diagnosis was evident within the themes, for example the burden of ADHD theme included a chaotic life for early diagnosis and accumulated burden for late diagnosis. Consistent with previous research (Klein *et al.*, 2012), positive adjustment was facilitated by younger diagnosis.

Few specific models of adjustment to an ADHD diagnosis exist (Young *et al.*, 2008), therefore it is useful to look to other psychological models of adjustment. The notion that people receiving life-long diagnoses will pass through stages much like a bereavement (Kubler-Ross, 1970) has been criticized for not allowing for individual progression or reaction to a diagnosis. More recent models suggest adjustment is individual and cognitively mediated. A theory of cognitive adaptation (Taylor, 1983) was developed around adjustment response to threatening life events (such as women's experiences of breast cancer) and suggests three themes: search for meaning in the event, an attempt to gain control or mastery over the event and one's life, and efforts to enhance self-esteem, often through social comparisons with others. The focal point of the model is that successful adaptation results from the ability to look at an event in a more positive light. Taylor argues that the first stage – search for meaning – primarily occurs through causal attributions.

Attribution theory, originally proposed by Heider (1958) and subsequently further developed by Kelley (1971, 1973), suggests that we attribute cause to our experiences in order to understand and control the environment around us. There are four suggested attribution dimensions: internal versus external, stable versus unstable, global versus specific, and controllable versus uncontrollable. Cognitive theories around appraisal and adaptation are useful to refer to as preliminary evidence on adult ADHD and adult Asperger syndrome diagnoses points towards re-appraisal post diagnosis (Young *et al.*, 2008; Punshon, Skirrow, & Murphy, 2009).

Labeling theories are useful to draw upon when thinking about adult diagnosis (e.g. Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Being given a 'label' can lead to stigma, reluctance to disclose the diagnosis, reduced self-esteem, and reduced social contact through a process termed 'self-stigma' (Corrigan, Larson, & Ruesch, 2009). However, depending on the person, the label can also incite people to reject the associated stigma (Corrigan & Watson, 2002) or promote group cohesion between those with the same label (Watson, Corrigan, Larson, & Sells, 2007). Group membership can encourage members to jointly challenge the negative consequences of their group identity, consistent with Schmitt and Branscombe's (2002) rejection-identification model. Groups provide emotional support and coping, enabling a rejection of the negative stereotypes associated with the group, leading to a more positive view of the self and a potential impact on well-being.

While there has been increased focus on the impact of ADHD on adults, the experiences of receiving a diagnosis of ADHD and psychological processes have not been sufficiently empirically explored. Given the associations between adult ADHD and reduced quality of life across a number of domains, as well as potential stigma associated with the label, receiving a diagnosis may itself have a psychological impact on adults and require adjustment and reappraisal. As such adjustment is likely to be cognitively mediated, it is important not to make assumptions and to instead be informed by first person accounts of individuals based on experience. The purpose of the present study was to explore from a psychological perspective the processes adults go through when diagnosed with ADHD. With a focus on psychological process, this study contributes to a greater understanding of how receiving an ADHD diagnosis in adulthood impacts individuals, to inform clinicians and service users through this process.

2. Methodology

Thematic analysis (Braun & Clarke, 2006) was used because it enables searching for themes across an entire data set in a systematic and transparent fashion. The research was conducted from a critical realist epistemological position (McEvoy & Richards, 2006), which holds that diagnosis is given but that there are a range of views about its 'truth' and responses to diagnosis will be individual. The data were analyzed at a semantic level to enable exploration of the experiences of those diagnosed.

The first author's prior experience working within services for adults diagnosed with ADHD may have influenced research aims and analysis. This influence was monitored through a reflexive diary, supervision, and second coding of one transcript by the second author with no experience of practice in ADHD services.

2.1. Ethical Approval.

Ethical approval was granted by an NHS Research Ethics Committee in April 2016 with a subsequent amendment approved in July 2016.

2.2. Participants and recruitment.

A purposive sample of 12 adults (seven male, five female) with an ADHD diagnosis was recruited to the study from an adult ADHD clinic. See Table 1 for demographic details.

Table 1 - Demographic Characteristics

Respondents (<i>N</i> = 12)	
Sex	
Male	7
Female	5
Age (at interview)	
18-24	1
25-34	2
35-44	6
45-54	3
Time since diagnosis	
0 - 11 months	4
1 year - 1 year 11 months	4
2 years - 2 years 11 months	2
3 years - 3 years 11 months	1
4 years - 4years 11 months	1

2.3. Data collection.

Participants were provided with study information prior to giving informed consent, which was gathered in writing prior to interview. All interviews were conducted in a private setting by ZY, were digitally recorded and transcribed.

2.4. Instruments.

A semi-structured interview was used to guide data collection. Questions were as follows: What were you like as a child / in your school years? Tell me about when you first heard about ADHD? What did you think about ADHD before diagnosis? What prompted you to seek advice? Tell me about your experiences leading up to getting diagnosed with ADHD. In what way was the diagnosis shared with you? What effect did the diagnosis have on you? Was anything helpful about receiving the diagnosis? (if so, what?). Was anything unhelpful about receiving the diagnosis? (if so, what?). Has the diagnosis changed how you think or feel about yourself? (if so, how?). Which areas of your life have been affected by the diagnosis? Did the support available to you (if any) change the impact of receiving a diagnosis?

2.5. Analysis.

The analysis followed the Braun and Clarke (2006) six-stage methodological process. A mixed inductive and deductive approach was employed. The analysis was data-driven without an *a priori* coding framework but was theory-driven in the sense that prior research on the impact of diagnosis was drawn upon and expectations shaped (Boyatzis, 1998).

Manual analysis began with immersion in the data via transcribing and then reading and re-reading the transcripts. Codes were generated by labeling the data with a short phrase or word that captures the essence of the data. Codes were then clustered together creating broader potential themes and themes were checked as to whether they existed across participants. A map of candidate themes and collated coded data extracts was created and a central organizing concept for each theme was identified. The themes were reviewed in collaboration with the second author (AT) to check that the themes adequately encompass the codes and that there is a thorough and meaningful representation of the data. Final themes were defined and named along with data extracts in order to finalize the narrative and produce the report.

3. Findings

Three overarching themes with sub-themes were developed through the analysis, outlining three different processes participants engaged in following diagnosis. The themes are illustrated in a thematic table (see Tab. 2): ‘looking back’, ‘looking inwards (with acceptance)’ and ‘looking outwards’. Although the themes are presented separately, they are connected and there was no evidence that participants went through each process sequentially. Of note, but not directly relevant to the research question, is that participants talked about the lengthy wait to access diagnostic assessment and the struggle to get a diagnosis.

Table 2 - *Final thematic table*

Overarching theme	Sub-theme
Looking back	Different, faulty
	Relief and regret
	Reframing
Looking inwards (with acceptance)	
Looking outwards	Labeling: disability, stigma
	Social comparison

3.1. Looking back

All participants engaged in a process of looking back over their past experiences prior to receiving the ADHD diagnosis. Subthemes included having seen themselves as ‘*different, faulty*’; a ‘*relief and regret*’ over how things in their lives might have been different had they been diagnosed earlier; and ‘*reframing*’ of past experiences considering the diagnosis.

3.1.1. *Different, faulty*

Within this process, a range of views was explored with some participants who had always seen themselves as “different”, “faulty”, “weird”, “stupid” or an “idiot”, contrasting with others who expressed a sense of not feeling, or knowing they were different, believing others to be like themselves:

“I just thought I was a faulty human being and if only I could pull my socks up and try harder. That the fault must be in me as a person.” (Chloe)

versus

“I think you think that most people are like you, you don’t think that you’re the person that’s different. You look at other people who are quiet and stuff and you think ‘what’s wrong with them?’” (Jen)

These contrasting views of the self can be presumed to have an impact on self-esteem as Chloe expresses an internal attribution of perceived failures and Jen clearly externalizes the problem as being within others. Without an obvious reason for the differences between the two groups, it is useful to consider that such attributions may relate to the different core beliefs about the self and others, based upon individuals’ learning experiences.

3.1.2. Relief and regret

Participants consistently expressed initial relief at being diagnosed. Some also expressed a desire to “roll back” (Russell) due to a sense of regret, anger, frustration and despair over feeling that life had always been a struggle. People wondered how life might have been different if diagnosed earlier:

“I do wonder about what would have happened - how things might have been different if I had been diagnosed as a child [...]”⁴ I could have focused and been more organized and used all the strategies I am using now. Could I have done better? Would it have made any difference? Probably not! But it would make me feel better about myself. I was so cross.” (Phoebe)

Others expressed a sense of pride over the way they had dealt with life prior to diagnosis:

“What the diagnosis confirmed, [was] to actually think of myself as - yes actually, not only am I not stupid but I’m

⁴Some text has been removed to make extracts more manageable as indicated by [...]; this was only done when it did not alter participants’ meanings.

actually quite brilliant to have dealt with this for so long [...] I should actually pat myself on the back. So I started to think like that.” (Russell)

A range of cognitive and emotional reactions to diagnosis were evident, highlighting an individual process of adjustment rather than a sequential or linear process as commonly described in physical health or bereavement literature (Kubler-Ross, 1970).

3.1.3. Reframing

Attributing ADHD to be a “real condition” (Russell) with a “biological” (Imran) basis allowed participants to reframe past experiences and remove self “blame” (Phoebe) given a reason for the ways in which they behave or have struggled:

“Actually, having a list of things that I find difficult - and now there is a reason why I find them difficult, it just makes me feel better. Yes I know I find them difficult and I know I still have to do it but I’m allowed to find it difficult – I’ve got ADHD.” (Phoebe)

Jen also talked about reframing increasing her self-esteem through new understanding.

In looking back, people felt validated about the struggles they faced. Petra demonstrates a shift from an internal attribution, where not finishing university was due to “personal failure and my inability to concentrate basically”, to external attribution: “It is very validating, not just to be told you have a neurodevelopmental condition, that it is the reason for fucking up.” Petra further described a dissonance between cognitively reframing things as not her fault but not necessarily emotionally feeling this to be the case: “I was able to mentally if not emotionally explain a lot of stuff that had happened in the past and know logically, even though it is harder to put in emotionally, that things were not my fault.” (Petra). One exception was Anthony, who described a shift from external to internal attribution after questioning who was to blame for relationship difficulties with friends and colleagues: “I used to think it was much more their fault but actually now I’m thinking, no probably it’s my fault.” (Anthony).

Participants therefore described an experience of letting go of self-blame to differing degrees but more commonly with a sense of a positive

reframing. However, it was often coupled with a realization of the permanence of the diagnosis: “I felt as if I have achieved something at the same time I haven’t, I have something that I have to deal with for the rest of my life” (Majeed). Although attributing ADHD as having a “biological” basis was helpful for some in reframing experiences, others expressed this negatively: “It’s not something you want to hear, that certain parts of your brain haven’t developed to the level that’s deemed normal.” (Russell). Here Russell has captured what many participants echoed by using the word “normal”, suggesting that there is a sense of being ‘abnormal’ or stigma attached to the diagnosis. This relates to the theme of ‘looking outwards’ where contrasting opinions about labeling and stigma will be presented.

Acknowledging and understanding ADHD as something ‘real’ allowed participants to reframe their past experiences, generally leading to self-reported increased self-esteem, although a shift in attribution of blame was seen in both directions. However, some struggled with the notion of a biological basis to ADHD due to the permanence of the diagnosis. In general, the recurrence of reflections in this theme was higher for those diagnosed recently (within 18 months) than those diagnosed longer ago (more than 18 months); however, no differences were noted in the content of reflections within the theme and no age-related differences were noted.

3.2. *Looking inwards (with acceptance)*

Participants consistently engaged in a process of looking inwards as they began to understand, and to some degree accept, the new diagnosis and a change in identity. Some described understanding themselves better through self-reflection. For many, the process of reframing their past experiences contributed to them being able to see themselves in a more “positive light” (Phoebe) and accept themselves as they are:

“It has effectively allowed me to just be me, so I would actually say it is freeing to a great degree. Because now I can say, this is the way I am and I have to deal with that, but I am not going to be upset by it.” (Marco)

Marco described a quick process of accepting himself in response to reading about the diagnosis.

Self-reflection following diagnosis led some participants to wonder “who is the real me?” (Anthony). Some described an identity problem, like being

two people as they tried to reconcile the different aspects of themselves following insights gained from taking ADHD medication:

“You have an identity problem, almost like someone who has been schizophrenic and is treated for schizophrenia – so who is the real me? The one on medication or the one off medication? – because in some ways they are quite different individuals and I think there are facets of the same person.” (Anthony)

Some described a loss of identity as like a grief process:

“I was quite happy at first. It wasn’t an excuse but it explained a lot - but then I did go through that sort of grief. People say it’s like a grief, don’t they - of not being the person I thought I was.” (Jen)

Contrary to this, some saw themselves as unchanged following diagnosis:

“I am still me, if that makes sense. I am the same person who walked into that room, the same person who walked out, same cells, same body, same soul, same mind, same person with the same experiences, just one more experience on top as I walked out.” (Louis)

Some began defining themselves by the diagnosis as they now identify as ‘ADHD’ after finding that the more they learned about ADHD the more they felt it “described” them:

“So when I read that, I was like whoa! It fits so well. The more I read the more I, there are obviously some things that don’t apply to you but the more I read it, the more I am understanding myself and more importantly, I am finding ways to address and deal with”, but on the other hand “It is not the only thing that defines me but it is a really big part of my mental construct, my world view.” (Imogen)

Some identified with the concept of neurodiversity rather than ADHD itself:

“...like I am good at these things and you’re bad at these things and that’s alright because that is you and that’s part of your weird and interesting neurodiversity which is kind of cool. It feels a bit like being in a weird little club.” (Petra)

This point also connects with the third theme of ‘looking outwards’ as she talks about a sense of belonging to a group.

The majority of participants described a positive effect on their self-concept through a process of self-acceptance; seeing themselves in a “more positive light” resulting in them being “kinder” (Phoebe) to themselves and no longer “beating themselves up” (Imogen) as well as giving themselves permission for the ways in which they behave or the things they find difficult:

“I kind of like myself a bit more, I think and whilst I still feel bad about things in the past but now I am much more likely to give myself a break for not having done stuff, like I don’t feel really awful about falling behind at work because there is a reason for that, you know, a process. I am not building up any more hilarious mental scars or fuel against myself, you know.” (Petra)

Although having a better understanding of boundaries and limits has been helpful for many in deciding what to tackle in life, some contrasted knowing “your ceiling” (Louis) with being worried about blaming ADHD for things or making excuses:

“What is caused by ADHD and what you are using ADHD as a crutch for? So an awareness of that. You don’t want to just go ‘that’s my ADHD’ - take responsibility for the stuff that you are responsible for.” (David).

Acceptance of the new identity was often related to people looking for the positives about “being ADHD” (Chloe) such as being “creative”, “good in a crisis” (Anthony), “full of ideas” (Majeed), “empathic” (Petra), “enthusiastic”, “playful” (Phoebe), “determined”, “intelligent” (Russell) and “compassionate” (Jen):

“There are lots of things about being ADHD that I look for [...] the fact that I am spontaneous, the fact that I will still be quite young spirited even when I’m old, that I can find the fun in things, that ideas cross pollinate because they come so thick and fast.” (Chloe)

Accepting the new identity led some to feel a sense of belonging to an ADHD “club” (Petra) contrasting with rejection of the ‘neuro-typical’ club: “I feel stronger to just think ‘oh nuts’ to people, I have decided I can’t be in that club.” (Chloe). Others further suggested a sense of neurodiversity being “cool” and “to be neuro-typical [...] it must be a bit boring.” (Jen)

Self-reflection and looking inwards allowed some participants to accept themselves as they are. For others, there was confusion over their identity, although some were able to incorporate ADHD into their new identity. Acceptance of identity was also linked with finding the positives about ADHD and identifying with an in-group of others with ADHD. In general, the recurrence of reflections in this theme was higher for those diagnosed longer ago compared to those diagnosed more recently; however, it was not evident that contrasting views were explained by the recency of the diagnosis. No trends related to participants’ age were noted in the reflections.

3.3. Looking outwards

Participants looked outwards as they made decisions about sharing their diagnosis and the experience of being labeled (e.g. possible stigma) influenced these decisions. Within this theme participants engaged in social comparisons (comparing themselves to others).

3.3.1. Labeling: disability, stigma

Some participants described a careful decision-making process about sharing the diagnosis as they worried about others’ reactions. Despite this worry, many described the associated positives, such as gaining support at work or university, or with family and friends: “Yeah, it sort of helps communication with my parents” (Chloe) and: “My close friends have all been really positive” (Phoebe).

For many, there were also negative aspects of sharing their diagnosis. Some felt friends had not understood or they felt dismissed by them and some felt work had not been supportive. People were also faced with others

not believing ADHD existed as well as not being believed in terms of their personal diagnosis, which for some echoed their experiences of seeking diagnosis (e.g. being told by GPs: “It doesn’t exist in adults” (Imran)). The experiences resulted in participants feeling stigmatized to varying levels:

“It was knowing that it was right but wishing that it wasn’t. It fit completely, but at that stage I felt a kind of a stigma towards it and I don’t know where that came from other than the fact it was classed as a disorder, an illness, or whatever, a condition and that in itself puts a stigma on it.” (Marco)

Furthermore, some felt understanding about adults was lacking, with some believing “it’s just naughty kids” (Russell) and consequently feeling misunderstood:

“I don’t care about the general public and what people think, but even family members, even my step-daughter, who is an adult, doesn’t understand some things and it can be frustrating when people give you certain odd looks.” (Russell)

Some people found it hard to be labeled, whereas others found it hard to be labeled but also welcomed the label as a tool to work out what to do next:

“I also know that people have a very negative view of ADHD. They’ll either apply those negative views to me - that’s how labeling works - or just think I’m just making an excuse. I don’t know. I was mixed. It felt like a blessing and a curse at the same time.” (Russell)

Some described a sense of a change in culture or attitudes over the last few years resulting in experiencing a reduction in, and potentially a rejection of, stigma:

“... I don’t really give a shit, to be quite honest with you. I don’t care about other people’s opinions, within reason and the fact that, that’s been aided by the fact that opinions have softened.” (Marco)

3.3.2. Social comparison

Participants explored a sense of not understanding others when compared to themselves, of wondering how other people “just sit down and just do the work”, why others “take so long to understand this... simple thing” (Louis), whether “everyone just tries harder than me” (Imran), and how others can be “regimented” (Jen). Such comparisons left participants with a feeling of things being unfair:

“Yes, it is unfair, but at least now I know and I don’t feel like a fool when I’m putting in the same amount [of effort] and not getting the same results.” (Louis)

Some suggested that the diagnosis made them less concerned about making social comparisons and trying to fit in with other people’s ideals:

“If there is something I have spent my whole life trying to force myself to be like everyone else and fit in with other people’s patterns and now realizing certain things, I just need to work around and work to my strengths.” (Imogen)

Some described a sense of belonging or “community” (Majeed) with the realization that there are others with similar experiences to themselves leading to people joining physical or online ADHD support groups, suggesting a sense of an in-group/out-group distinction:

“To feel this alone as well because you can see there are a whole group of people out there who have similar experiences to you and I am now involved in a few online groups [...] you can share that support and understanding, you just don’t really get from anyone else.” (Imogen)

An exception to not being understood was when ADHD was a shared experience within families. Three participants had children diagnosed with ADHD, two participants suspected ADHD in their child and were seeking diagnosis and several participants also described their parents as having “undiagnosed ADHD” (Anthony) or “ADHD traits” (Imogen). The sense of being similar to such family members was comforting, as was things being “normal” within their family: “It was probably when people started to talk about [son’s] differences, that’s when I started to pay more attention to the

fact that it [ADHD] even existed, to me he was normal because he was like me” (Jen); which may have impacted on people recognizing ADHD in themselves.

The theme of looking outwards describes sharing the diagnosis as a carefully made decision which resulted in both positives and negatives. Social comparisons were helpful but also a hindrance as they led people to recognize their strengths, foster a sense of belonging and to make links with associated support networks but also to realize how life was unfair compared to those without ADHD. Participants also reflected on the positives of ADHD being a shared family experience. No differences were noted between those diagnosed recently or longer ago in the recurrence of the current theme or in the reflections or viewpoints expressed. Furthermore, no age-related differences were noted.

4. Discussion

The aim of this study was to explore the psychological processes people go through following a diagnosis of ADHD in adulthood. The impact of the diagnosis was captured by two self-reflective themes: looking back (and focusing on their past) and looking inwards (with acceptance and a focus on identity and understanding oneself); and one interpersonal theme: looking outwards (being labeled and comparing with others).

4.1. Looking back

Participants described feeling different to others or faulty, which may reflect an in-group/out-group distinction (Tajfel, 1982). Participants may have experienced the negative effects of out-group membership prior to diagnosis by way of prejudice or stigma where perceived difference may have been either the cause or result of out-group membership. This experience of ‘difference’ echoes previous qualitative work on the experiences of being diagnosed with ADHD in adulthood (Young *et al.*, 2008). Similarities have also been found in individuals diagnosed with Asperger syndrome in adulthood, which is of interest as a related lifelong neurodevelopmental condition (Punshon *et al.*, 2009).

This study found individuals experienced similar processes to those reported by Young *et al.*, (2008). However, a clear, staged process was less evident in the current sample, despite a tentative trend noted where those diagnosed more recently reflected more on ‘looking back’ and those

diagnosed longer ago reflected more on ‘looking inwards’. In addition, participants in this study placed further emphasis on internal reflections and social comparisons, with a clear sense of not having fully accepted the past. The processes participants described can usefully be framed within Taylor’s (1983) cognitive adaptation model, which includes three stages of adjustment following a significant event: search for meaning, attempts to gain control, and attempts to increase self-esteem.

Consistent with Young (2005), participants in the current study used cognitive coping strategies such as cognitive reappraisal or reframing, which allowed some participants to let go of perceived failures. This is consistent with the first stage in Taylor’s (1983) cognitive adaptation model (search for meaning), which, Taylor argues, primarily occurs through causal attributions (Heider, 1958; Kelley, 1971, 1973). Our propensity to place greater emphasis on internal agency over external reasons for behavior is known as a fundamental attribution error and can be seen by participants prior to their diagnosis. In general, attributions about past failures were shown to shift from internal to external attributions, although this was not always the case and sometimes limited. Participants also suggested a sense of attributions being stable (over unstable) due to the sense of permanence of the diagnosis. It is unclear to what extent this sense of stability or permanence might contribute to people’s perceptions of control (over uncontrollable attribution); what is within their power or abilities. Those diagnosed with Asperger syndrome in adulthood have also highlighted this dissonance between positive reframing and there being no ‘cure’ and a sense of hopelessness (Punshon *et al.*, 2009). Furthermore, biological attributions have been shown to reduce hope for change and increase passivity in schizophrenia diagnosis (Howe, Tickle, & Brown, 2014).

Consistent with the second stage of Taylor’s (1983) theory of cognitive adaptation, participants increased their knowledge of ADHD and searched for strategies and support to gain control or mastery over the event and their lives. Participants expressed positive effects through the use of strategies.

4.2. Looking inwards (with acceptance)

Compared to Young and colleagues’ (2008) description of participants’ acceptance of the diagnosis and themselves, the current study presented a diverse picture of participants’ experiences. Acceptance of the diagnosis appeared to come relatively easily for many (especially after lengthy waits for diagnosis); however, self-acceptance was something not as easily

achieved as people struggled with their sense of identity. Consistent with modified labeling theory (Link *et al.*, 1989), being given a label and subsequently internalizing the label and its stereotypes has led to reduced self-esteem and self-efficacy in mental health diagnoses (Corrigan *et al.*, 2009).

Participants attempted to integrate their diagnosis as well as their new-found insights (e.g. through reframing or self-reflection) with their existing view of self to varying levels of ease or success, which is a process also described in the schizophrenia literature (Estroff, 1989). Models about changes to identity (Cass, 1979; Brady & Busse, 1994) have been developed in the literature on sexuality and have been adapted for application to mental health. One model (Corrigan & Matthews, 2003) suggests a five-stage process of adopting a new identity: identity confusion; comparison; identity acceptance; immersion into the new culture; and identity synthesis. It is possible that in the current study, participants are at the stage of *identity acceptance* where they are learning to tolerate the new identity and beginning to disclose to trusted others. Some may well be in the stage of identity synthesis where the diagnosis has become an aspect of their identity.

Broad views were expressed as to the extent people identified as *being ADHD* or *having ADHD*. This refers to the *I am* nature of the diagnosis which is commonly seen in the literature on schizophrenia diagnoses and also in adults with Asperger syndrome who tend to relate to an *I am* rather than an *I have* view of their diagnosis (Punshon *et al.*, 2009). The extent to which people identified as *being ADHD* opposed to *having ADHD* could also reflect a change in identity and impact on acceptance of the new identity.

A categorical separation of these two belief systems did not seem to encompass the complexity in which the participants described their identity. A continuum approach, which has more commonly been applied to diagnoses of personality disorders, proposes a continuum of the view of self from *self*, to *self-object*, to *object* (Kohut, 2013). For some, ADHD was seen as an external *object* (for those who viewed ADHD as biological), for some as a *self-object* (for those who struggled to reconcile the different aspects of themselves), and for other participants wholly as the internal *self* (who felt that ADHD *described* them). The person's view of self can be applied clinically through *illness-identity statements*, to determine where people fall on this continuum, which have previously been used in schizophrenia research (Estroff, 1989). Understanding this further could usefully inform

intervention as the interaction between the person and ‘disorder’ is important in terms of progress (Strauss, 1989).

Consistent with Taylor’s (1983) first stage of cognitive adaptation (search for meaning), acceptance of identity led some participants to recognize relative positives of ADHD, which has been coined ‘benefit finding’ and is also seen in the literature on Asperger syndrome diagnosis (Pakenham, Sofronoff, & Samios, 2004; Punshon *et al.*, 2009). Identifying with ADHD also prompted a sense of belonging within a neuro-diverse ‘club’. Acceptance of the new identity enables rejection of its negative associations and is suggested to lead to a more positive view of the self (Schmitt & Branscombe, 2002). Affiliation with a similar group with a shared experience led to a more positive view of the self (e.g. as intelligent or capable) in line with theory on social comparisons within similar *others* (Festinger, 1954) and the third stage in Taylor’s (1983) theory of cognitive adaptation (self-enhancement).

4.3. Looking outwards

The potential for stigma impacted on participants’ decision to disclose the diagnosis. This decision has also been argued to depend upon the extent to which the label is part of a person’s identity and the views of the people around them (e.g. trustworthy versus discriminatory) (Corrigan & Matthews, 2003). Many people choose not to disclose, potentially having weighed up the costs (e.g. social disapproval) and potential benefits (e.g. increased wellbeing and decreased distress) of sharing their diagnosis (Corrigan & Matthews, 2003). Non-disclosure may be costly for the individual as secrecy may lead to preoccupation with the label (Lane & Wegner, 1995). However, out of five suggested levels of disclosure (*social avoidance, secrecy, selective disclosure, indiscriminate disclosure* and *broadcasting*) (Corrigan & Matthews, 2003) those in the current study most commonly engaged in selective disclosure where they shared their diagnoses with only those closest to them, although with some degree of shame remaining for some. Although disclosure had a range of positive and negative effects on people, sharing the diagnosis was experienced positively when it led to a sense of belonging to a group, which can help people resist stigma through a sense of group identity and empowerment (Watson *et al.*, 2007).

Along with disclosure, people made other attempts to reduce stigma; the use of less pejorative labels as a way of dealing with stigma or discrimination has been described (Corrigan & Matthews, 2003) and in this

study some described themselves as “neurodiverse”. This is more commonly used within the autism literature where the neurodiversity movement calls for autism and ADHD to be seen as a natural human variation rather than a disability (Armstrong, 2010; Jaarsma & Welin, 2012), although people did think that societal attitudes about ADHD were changing, which mirrored views of those diagnosed with Asperger syndrome in adulthood (Punshon *et al.*, 2009).

4.4. Clinical implications

Calls have been made for earlier recognition of ADHD (e.g. Kean, 2004). Earlier identification may avoid the development of negative core beliefs (Safren, Sprich, Chulvick, & Otto, 2004; Newark & Stieglitz, 2010). This study also has several clinical implications where ADHD is diagnosed in adulthood.

De-stigmatization by way of public awareness campaigns is emerging (e.g. Craven, Simons, Gillott, North, Schnädelbach & Young, 2015); however, the current findings highlight the need for further campaigns to reduce stigma, specifically on understanding ADHD in adulthood and could focus on success stories of adults living with ADHD, highlighting potential positives and benefits in line with the literature on benefit finding (Affleck & Tennen, 1996; Sears, Stanton, & Danoff-Burg, 2003). Awareness should also be increased in the UK healthcare system, as the study highlighted a lack of understanding of ADHD in adulthood among medical practitioners, which may reflect a gulf in knowledge between child and adult services (Asherson, Chen, Craddock, & Taylor, 2007).

Assessing somebody’s appraisal of the diagnosis (pre- and post-diagnosis) seems fundamental as a range of cognitive and emotional reactions was found. This could identify the need for interventions for those who find it difficult to reappraise negative attributions, which could be facilitated through exploration of the event, provision of information and support to develop coping strategies possibly through Cognitive Behavioral Therapy (CBT) (Safren *et al.*, 2004).

The findings suggest the need for specific testing of models of attribution in relation to diagnosis and interventions to support adjustment to diagnosis. This should be carried out through the development and testing of screening tools relating to appraisal of the diagnosis and information giving (which could include contact with others who have previously been diagnosed and adjusted). Furthermore, research into cognitive interventions about self-

concept and the interpretation of the diagnosis would be beneficial.

4.5. *Limitations and Conclusion*

Participants were interviewed at different time points following diagnosis, so could be at different stages in the adjustment to the diagnosis. However, the time taken to adjust is likely to be individual and there are additional benefits of variation in experience. Additionally, each participant was interviewed only once and retrospective accounts were relied upon. A trend related to the time since receiving a diagnosis was noted (a higher recurrence of reflections on ‘looking back’ for those diagnosed recently and on ‘looking inwards’ for those diagnosed longer ago), which should be interpreted with caution given the small sample and nature of qualitative research, but is important to consider when interpreting the results and their transferability. A longitudinal design where participants were interviewed at various stages could therefore further develop understanding of adjustment. The relatively small sample limits the transferability or applicability of findings more broadly but offers an initial insight into themes common to individuals diagnosed with ADHD in adulthood.

The current research has highlighted a dilemma: that receiving the diagnosis was necessary to access appropriate support, was helpful to acknowledge people’s experiences (and potentially reframe them), understand oneself better (as well as recognize strengths) and foster a sense of belonging, but there remains a struggle with the sense of self, the way people are viewed by others (e.g. feeling stigmatized) and the permanence of being or having ADHD forever.

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