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“Pixies, monkeys and living in-the-moment”:

Toward a new conception of ADHD

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Declarations

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I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included as part of the thesis a written statement, endorsed by my supervisor, clearly outlining the extent of collaboration, with whom and under what auspices.

I, Rosalind Redshaw, attest that I was responsible for the review of literature and writing of the manuscript contained within this thesis. I trained in IPA under my supervisor, I conducted the recruitment of participants, the semi-structured interviews and the transcribing of data. Associate Professor Lynne McCormack designed the study and independently analysed the data. In accordance with the protocols of IPA, both authors contributed to the interpretation and write-up of the data and implications of the findings. Drafts of the manuscript were forwarded to A/Professor Lynne McCormack for review, and amendments were made based on her feedback.

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Abstract

Attention Deficit Hyperactivity Disorder (ADHD) has been described as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. This qualitative study was interested in two questions: 1) What is it like to be ADHD in a neurotypical world, including potential advantages? and 2) Can participants' subjective interpretations of the way they operate in the world offer new insights into the mechanisms underlying ADHD? Five females and four males aged 29 to 54 years (mean age 39) participated in the study. Data was collected using semi-structured interviews and was transcribed and analysed using Interpretative Phenomenological Analysis. One superordinate theme: *Unique ways of operating in ADHD*; overarched three subordinate themes: (i) *Otherness, medication and social expectations*; (ii) *Pixies, monkeys and living in the moment*; and (iii) *Blest not broken*. The themes highlight the personal, changing impact of ADHD across childhood and into adulthood, and specific characteristics and behaviours that participants attribute to an ADHD mental architecture. A unanimous tendency to live 'in-the-moment' was found across participants. The potential relationship between operating on a single-dimension timescale and classic symptoms of ADHD is discussed. Our findings offer a new perspective from which to understand both the difficulties and strengths of ADHD and have implications for quantitative research and theory-building related to the cross-temporal organisation of behaviour in individuals with ADHD. The benefits of developing a more balanced view of ADHD traits in terms of clinical practice is also discussed.

Keywords: ADHD, qualitative study, living in-the-moment, advantages of ADHD, timing deficits

Introduction

ADHD is a common neurodevelopmental condition affecting over 68 million people worldwide (Lawrence et al., 2015). The DSM-5 (2013) characterises ADHD as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. Three subtypes have been identified: Combined inattention and hyperactivity-impulsivity; predominantly inattentive; and predominantly hyperactive/impulsive presentation. Difficulties at school and negative effects on day-to-day functioning are well-known. With few exceptions, the picture presented in existing research is one of deficit and disorder, a focus clearly reinforced by the label Attention Deficit Hyperactivity Disorder. The current qualitative study seeks to gain a deeper understanding of the adult experience of ‘being’ ADHD. It explores participants’ interpretations of the specific ways in which their brain operates differently to others, the meaning they derive from these differences, and perceived advantages and disadvantages of their unique mental architecture. This approach differs from much of the existing research in that it does not assume a starting point of deficit and pathology. Typical assumptions about ADHD based on objective research are laid aside in order to explore an inside-perspective of ADHD that could offer new directions for both qualitative and quantitative research.

Extensive quantitative and qualitative research on ADHD exists. Common areas of study include symptoms in multiple contexts, implementation and outcomes of pharmacological and behavioural interventions, and issues and benefits surrounding diagnosis (e.g., Cortese et al., 2018; Molitor & Langberg, 2017; Schatz et. al., 2015; Tarver, Daley & Sayal, 2014). Imaging and cognitive studies have investigated potential brain areas and the neural mechanisms underlying ADHD, while social and biological studies have sought to

identify risk factors and genetic links (e.g., Kasperek, Theiner, & Filova, 2015; Caye et al., 2016).

A recent systematic review of qualitative studies investigating adult experiences of ADHD published between 1990 to 2015 (Bjerrum, Pedersen & Larsen, 2017) reflects an emphasis on dysfunction. Importantly, the authors acknowledge that individuals with ADHD ‘do not necessarily regard themselves as being impaired’ (p.1082) and ‘adults with ADHD are creative and inventive’ (p.1087), however data from the studies are viewed through the lens of coping strategies and managing symptoms.

In his essay, ‘What is it like to be a bat?’, Nagel (1974) points out that our capacity for understanding the phenomenological experience of something or someone different to ourselves is limited by our own experiences and the resources of our mind. Collectively, we judge deficits by the yardstick of what is most common and tend to devalue ways of operating that we do not possess or understand. An example is the perception that self-stimulating, repetitive behaviours in autism are abnormal, leading naturally to attempts to discourage them. Evidence suggests, however, that these behaviours may actually be functionally beneficial to people with autism (Amundson, 2000). Current treatment of ADHD likewise aims to eliminate certain behaviours (e.g., inattention and impulsivity). A more reflective process of inquiry that seeks to understand the nuances of the behaviours – and the internal states that drive them – can potentially enable us to work 'with' rather than against these behaviours.

Krueger and Kendall (2001) investigated descriptions of ‘self’ in adolescents with ADHD and found their participants defined themselves as 'being ADHD' rather than 'having ADHD', suggesting they saw ADHD as an important dimension of their personality and way of being in the world. Krueger and Kendall argued that this perception reflected a disrupted, distorted sense of self, however an alternative interpretation is that individuals identify as

being ADHD because they *value* certain aspects of their personality that they specifically associate with ADHD. Indeed, the males in this cohort saw themselves as "smarter, braver, more daring than others", yet also "unappreciated and/or misunderstood" (p.65). Canela et al (2017) used a qualitative approach to investigate coping and compensation strategies in 32 adult outpatients with ADHD. The authors noted that, "interestingly, many patients also perceived some typical ADHD symptoms as their personal skills or strengths..." (p.5)

A study by Mahdi et al. (2017) investigating ability and disability in ADHD was among the first to explore potential strengths of an ADHD brain architecture. Participants were 41 individuals with ADHD and 35 parents and professionals working in the ADHD field. Using focus group discussions and semi-structured interviews, Mahdi et al. identified energy and drive, creativity, hyper-focus (providing the activity was of interest), and agreeableness as perceived strengths. An earlier study by the same authors about various health constructs related to ADHD surveyed 174 experts in ADHD who identified characteristics such as high energy levels, flexibility and resiliency as perceived abilities (de Schipper et al., 2015). Recently, Sedgwick, Merwood, & Asherson (2018) used a phenomenological approach to explore whether successful adults with ADHD compensate for ADHD-related impairments or whether some ADHD traits are intrinsically adaptive rather than impairing. The authors proposed that constructs including adventurousness, divergent thinking and hyper-focus are attributes specific to ADHD, and called for more research to clarify their observations.

It should come as no surprise that some ADHD traits might function as a doubled-edged sword. Many traits can be advantageous in some situations and disadvantageous in others, although the contrast is perhaps more obvious in non-typical abilities. Borrowing again from the example of (high-functioning) autism; a bias toward attention to detail may be beneficial in high-tech professions (Baron-Cohen, 2012), but in comparison to the more

common heuristic approach, it does not fare as well in extracting global meaning or navigating social situations (Happé & Frith, 2006). Likewise, callous and unemotional psychopathic traits are well-known for their negative effects on relationships, but Dutton (2012) argues they can be invaluable in professions that require 'nerves of steel', such as first responders or paediatric brain surgeons.

So where might we look in ADHD to find a similar story? One possibility is response inhibition, identified as a core deficit in adult ADHD that leads to impulsivity and becoming easily distracted (Barkley, 1997a). Participant statements such as, "My mind is all over the place" and "My mind is constantly trying to do 10 things at once" (Meaux, Hester, Smith & Shoptaw, 2006) are reasonably common in qualitative studies of ADHD and often reflect a sense of disorganisation or chaos. Mahdi et al.'s (2017) findings of high-energy, flexibility and creativity may well be the other side of the coin.

New models of ADHD are beginning to challenge rigid views about ADHD, including the notion that hyperactivity impedes learning. At least one study has found that higher rates of activity predicted better working memory performance in children with ADHD, whereas this was not the case for non-ADHD children (Sarver, Rapport, Kofler, Raiker & Friedman, 2015). Only a few studies have investigated anecdotal claims of superior dual-tasking ability in ADHD individuals (see Gawrilow et al., 2011). However, the use of tools such as fidget-spinners, stress balls or peg tasks in classrooms and therapy sessions suggests that controlled dual-tasking may improve executive attention capability. Research has consistently found activity in the default-mode network (DMN) is greatest at rest and is typically reduced during cognitive tasks. Non-suppression of DMN activity during tasks is associated with lapses in attention and on-task performance, hallmarks of ADHD (Castellanos & Proal, 2012). The DMN encompasses the anterior medial prefrontal cortex and posterior cingulate cortex as well

as the dorsomedial prefrontal cortex and medial temporal lobe subsystems. DMN fluctuations also typically operate counter to fluctuations in other networks activated by externally-oriented tasks (Kelly et. Al, 2008). It could be that networks related to hyperactivity or certain types of dual-tasking (e.g., use of tactile tools) assist other internal neural systems to suppress default network activity, resulting in an increased ability to focus.

One of the challenges for understanding the neurophysiology of ADHD arises from the heterogeneous nature of ADHD. As such, multiple pathway models have been proposed (Sonuga-Barke, 2005). Despite the intra-individual variability in ADHD, heritability has been established and there is evidence for differences in brain structure and function related to key cognitive processes (Castellanos, Sonuga-Barke, Milham & Tannock, 2006). These include deficits in executive function, defined as functions necessary for mature goal-directed behaviour such as attention control, motor response inhibition, working memory, planning and decision-making (Willcutt et al., 2005). Influential theories of ADHD have implicated deficient inhibitory control that disrupts other executive processes (Barkley 1997a); or else an overall inefficiency of information processing that arises from disruption of cognitive mechanisms of attention, energy and effort mechanisms (cognitive-energetic model: Sergeant, 2005). Motivation- and developmental-based models propose alterations in dopamine activity that affect attention and behavioural organisation, reward/reinforcement, and motor and learning systems (e.g., Sagvolden, Aase, Johansen, & Russell, 2005).

Findings of impairment in motor, perceptual and temporal foresight domains in ADHD are supported by functional neuroimaging studies that show abnormalities in key networks that mediate timing functions (Noreika, Falter & Rubia, 2012). Behaviours that many take for granted, such as working towards a goal, or suppressing an urge to act inappropriately, rely on the ability to automatically initiate, maintain and synthesise

information cross-temporally. Thus they are able to sense the passage of time and monitor progress as well as consider present behaviour in the context of past experiences and potential consequences. Timing deficits are associated with impulsiveness and inattention and as such are key to the symptomatic profile of ADHD. (Barkley, 1997b). Furthermore, methylphenidate has been shown to improve timing function (Noreika, Falter & Rubia, 2012). Barkley (1997b) argues that processes related to the cross-temporal organisation of behaviour underpin behavioural inhibition deficits in ADHD: “ADHD is associated with a form of temporal myopia or time blindness... The behavior of those with ADHD is more controlled by the temporal ‘now’ than by internally represented information pertaining to past and future” (p.275).

The high prevalence of ADHD (5-10% worldwide; Gau & Chang, 2012), its lifelong nature, and the wide-ranging effects it has on the lives of the individuals means that the importance of improving our understanding of ADHD cannot be understated. The literature informs us that individuals with ADHD face significant stigma associated with ‘being different’, ranging from perceptions that ADHD does not exist or results from bad parenting or poor diet, to debate around over-diagnosis, over-medication and questions about what is ‘normal’ behaviour for children (Kellison, Bussing, Bell & Garvan, 2009). Clinicians must also be concerned about the impact a purely dysfunction-oriented approach can have on individuals’ sense of competency, self-actualisation and relationships with others (Ryan & Deci, 2000; Maslow, 2013). On the other hand, for individuals struggling to function, receiving an accurate diagnosis can have a positive impact (McCormack & Thomson, 2017). Individuals can also grow from the adverse consequences of being different to the general population (Joseph, 2009).

Although other qualitative studies have sought to understand the breadth of experiences of those diagnosed with ADHD (Mahdi et al. (2017; de Schipper et al. 2015), the present study seeks to explore subjective interpretations of what it is like to be ADHD in a neurotypical world, including potential advantages. It is also interested in new insights into the mechanisms and processes underlying ADHD that may arise from participants' subjective interpretations of the way they operate in the world.

Firstly, a more balanced view of ADHD would acknowledge neurodiversity and focus on building strengths and accommodating differences rather than rushing to 'fix' them. This is not to suggest that difficulties experienced by individuals with ADHD in everyday life should be downplayed. It remains important to identify the unique difficulties faced by individuals with ADHD and to develop effective strategies (including medication) that mitigate challenges and enable individuals to thrive.

Secondly, exploring the subjective experiences and interpretations of how participants feel their brain 'works' presents an opportunity to gain new insights into the ways an ADHD mental architecture might differ from a neurotypical one. This approach presupposes that as experts in their own experiences of ADHD, these individuals represent a rich source of information that is inaccessible to objective methods of inquiry, potentially opening up new avenues for research.

Method

Participants

Following University Human Ethics approval (see Appendix 1), participants over 18 years of age with a formal diagnosis of ADHD were recruited via advertising within The University of Newcastle, The University of New England, and support groups (see Appendix 2). To reduce possible confounding variables and in recognition of research that suggests inattentive type

may be a qualitatively different condition (e.g., Barkley (1997(b))), only individuals with combined subtype and no comorbidities were eligible. Nine participants aged between 29 and 54 with a mean age of 39 participated in the study (five females and four males). For demographic information, see Appendix 7. A sample size of three to six participants is considered adequate for an IPA investigation (Smith et al., 2009), hence the sample size of nine provides an ample, rich data set. All but one participant was taking medication for ADHD at the time of interview.

Procedure

Qualitative data were obtained through individual interviews lasting approximately 60-90 minutes each. Consent for the interview and audio recording was sought pre and post interview in accordance with ethics requirements. Participants were informed of the study's aims and instructed that they could withdraw at any time. They were also given details of support agencies should the interviews raise concerns (see Appendix 3 for participant forms). Interviews were conducted via Skype and took the form of a semi structured interview according to the protocols of IPA (Smith et al., 2009). Open-ended questions and reflection were used to elicit the person's own understanding, thoughts and feelings of their experiences of having ADHD. Participants were provided with the interview schedule, which formed the basis for the open-ended questions, one day prior to interview (see Appendix 4).

Data Analysis

The qualitative data were transcribed for analysis by the first researcher (RR) and analysed independently by both researchers (RR and LM) using IPA (Smith et al., 2009). IPA is an ideographic approach to qualitative research useful for investigating particular phenomena that have been poorly researched (Smith & Osborn, 2008). In contrast to experiments that test specific predictions and hypotheses, studies utilising IPA take an open-ended approach,

allowing unique concepts and understandings to emerge from the data that can inform clinical practice and provide directions for future research. The IPA approach involves an interpretive cycle that begins with acquiring knowledge about the topic. This knowledge along with researcher assumptions and any suspected biases are then bracketed in order for the researcher to enter the world of the participant through a semi-structured interview.

The process of analysis in this study involved: 1) Reading and re-reading each transcript and making initial notations; 2) Independently developing emerging themes prior to consultation between researchers; 3) Searching for connections across emerging themes and highlighting verbatim quotes to illustrate each theme; 4) Identifying patterns across cases; and 5) Creating a coherent narrative of the subjective lived experience of participants based on the interpreted themes of the data. A more detailed breakdown of the process is included at Appendix 5.

IPA values subjective experience and directly targets the source. The cyclical, reiterative style of IPA is underpinned by double hermeneutics whereby the researcher seeks to make meaning of participants' striving to make meaning of their own experience (Smith, Flowers & Larkin, 2009). The two important commitments of IPA are therefore to 'give voice' to the participant and to then 'make sense' of the participant's interpretations.

To ensure credibility and validity of the analysis and interpretation of participants' accounts, the data was first scrutinised and audited independently by both researchers. Rigorous discussion between researchers followed to eliminate or highlight biases and presuppositions until a consensus was reached. It was ensured that status differences between researchers were not a bias when it came to the consensus.

Results

One superordinate theme, *Unique ways of operating in ADHD*, overarched three subordinate themes: (i) *Otherness, medication and social expectations*; (ii) *Pixies, monkeys and living in the moment*; and (iii) *Blest not broken*. The superordinate theme highlights the need for greater understanding and acceptance of the unique ways of operating in ADHD in addition to addressing the difficulties participants face. The subordinate themes reflect both the personal, changing impact of an ADHD mental architecture across childhood and into adulthood, and specific characteristics and behaviours that the participants attribute to an ADHD mental architecture. Participants' quotes support the interpretative process within the three themes.

Otherness, medication and social expectations

This theme describes participants' experiences issues related to their sense of self, beginning in childhood and extending well into adulthood. Impacts tend to fall into three categories; those related to being different; the effects of negative attributions of others; and changes to 'self' brought about by medication. There is a struggle to reconcile the medicated and unmedicated selves. While the medicated self brings acceptance and approval by others, there is a strong sense that something real, and in many ways more desirable, has been sacrificed:

Which was the real me? That sense of, 'OK, who am I really?' Is the 'on medication' person just a visage of other people's expectations of who I 'should' be whereas the real me... me in my natural state without medication just being able to be creative... yes, perhaps somewhat chaotic, but...you know, perhaps a little bit more carefree and... and enjoying life in that regards. (Harry)

For some, the feeling they are being disloyal to their real self is too much to accommodate, especially as they enter adolescence, and sometimes leads to discontinuing medication:

It was like, everybody approves when I'm on this and nobody approves when I'm not ... It was too much like my own rejection of myself, to me. (Evelyn)

Over time many come to appreciate the value of medication for managing daily challenges and move into a second stage where they are able to integrate their medicated and unmedicated selves. Integration resolves the dilemma of choosing between conforming and preserving the 'real' self, and leads to a new acceptance of their ADHD:

You realise that they're just constructs that we impose on ourselves ... I am still the same person; it's just a matter of okay how well can I function on a day-to-day basis? The reality is unmedicated me struggles to function at even the most basic level whereas medicated me can get on not only with the tasks that I immediately have to do but also more profound things like planning ahead in time. (Harry)

Samir's late diagnosis evokes mixed emotions, including grief over 'what might have been' had he received a diagnosis and intervention in childhood:

I couldn't take the diagnosis to be honest, because it was like, well I haven't had a fair go, you know.

For the others, adulthood brings a new perspective as they come to understand more about ADHD, find their niche and begin to value their differences to others. Memories of their struggles in childhood, however, remain:

I wish I could go back and tell teenage me that I was okay ... I used to feel like I was broken ... and now I know that I'm just built different and ... yeah ... it's actually a beautiful thing and I think knowing that you have some strengths because you're different is a huge key to that. (Evelyn)

For two participants, the realisation that they like who they are crystallises during the interview as they reflect on the question of whether or not, given a choice, they would exchange their ADHD brain for a neurotypical one:

That's a hard question because I don't know what I'd be like without it. Really ... um to be honest, I'm happy with it you know. I mean it makes me who I am doesn't it? My worst nightmare would be being a normal, law abiding, quiet citizen. (Samir)

Self-love and acceptance are hard won. The accumulation of negative attributions of other people throughout the early years has a powerful and long-lasting impact on participants' self-beliefs and aspirations, despite the internalised limitations being rejected during adulthood:

It leaves you with very deep, deep beliefs that you are stupid, lazy, can't study, you can't focus, can't do any of these things because that's what you hear. (Wiyona)

The challenges of operating successfully in a world adapted to a different mental architecture are exacerbated by other people's lack of understanding about the wide-ranging impact ADHD has on functioning:

I don't think they really understand what it is and how much it impairs daily life. (Lalage)

Particularly during the younger years, there were times when the sense of difference between self and others was seen as too great to overcome. At these times authenticity was sacrificed in order to fit in:

I was at a point where I would not tell people the truth...I would leave certain details about myself out of conversations because I was just tired of having to explain myself. (Lenny)

Whilst medication is universally seen as positive when it comes to managing the most challenging characteristics of ADHD, it is no panacea. There is an increased sense of control but many of the issues remain:

Medication doesn't 'fix' things; it just makes it a little bit easier to drive your own bus.

(Wiyona)

It also comes at the cost of some of the more valued aspects of ADHD, often evoking an uneasy feeling that the vibrant ADHD has been dampened:

The medication really helps you focus on things but I also feel like it makes me a little bit one minded and boring. (Lalage)

Pixies, monkeys and living in the moment

This theme explores the central realisation of participants that they operate differently to others. These differences go beyond simple inattention and hyperactivity in certain contexts to include distinct characteristics and traits that are consistent across participants. Among them is a constant drive to be 'doing' and to act on thoughts and impulses as they arise. They talk of having exceptional reserves of energy, of the irresistible power of interesting stimuli and the unbearable situation of boredom. Participants convey a striking sense of living almost entirely *in the moment*, and they link this to their lack of awareness that time has passed or that they have deviated from a task. In addition, some identify a duality where the conscious self often has to compete against automatic processes for control.

Participants describe high levels of energy and stamina that have carried through from childhood into adulthood, and a drive to fill every moment with as much intensity as possible:

I'll mow my lawns, then I'll go to my neighbour and I'll mow his lawns... and I can't walk while I'm doing the mowing; I've got to run, cause everything's done at a hundred miles a minute. (Kevin)

Reserves of energy and stamina are understood to be greater than those of others. This energy is interpreted positively and others are viewed as somehow missing out:

I think a lot of people are a bit boring to be honest. I'll never understand people's desire to sleep for long periods of time. I'd much rather be up and about doing something. (Lenny)

Boredom, on the other hand, is experienced as painfully unbearable and stimulates attempts to escape the boring situation:

It's like the only thing you can think about but you've got to try and do things to distract yourself... you start holding your seat... rocking on your seat because your body's filled up with this urge, you know. (Belinda)

Sometimes, the need to escape results in creative solutions:

I managed to get the hiccups every single maths class and I used to get kicked out of every class to go get a drink of water. (Harry)

Boredom is not alleviated through meaningless activities which are interpreted as superficial and miss the point of engagement:

If it's just, well, go and sit on the beanbag, or go and play with these tactile toys, it doesn't do anything; it doesn't have any meaning in itself. (Belinda)

Some participants managed classroom boredom by escaping into the rich, unrestricted landscape of their minds. Quiet in their seats and conforming to expectations, they flew under the radar of teachers and daydreamed their way through school. But although subdued in class, energy was given free reign outside the classroom through high intensity sport or exercise:

I was extremely active and I'd do gymnastics all the time whether I was at the gym or it was lunchtime at school but in class I could sit in my seat and not be running around like a lunatic. I would be more daydreaming in class. (Lalage)

The pressure to do and be all things when unmedicated was sometimes experienced as overwhelming, exceeding the limitations of what was physically possible:

I used to think I wish I had four arms and then I could do all the things in my head you know, at once. I felt this constant barrage of things that I wanted to do but I just physically couldn't do them. (Belinda)

Sometimes energy and the drive to act 'now' translates into a fun-loving, approach-oriented attitude:

You just like a spontaneous adventure. I always put my hand up for that. (Evelyn)

In other situations, such as social interactions, '*being happy and excitable*' can quickly turn into a realisation they are being '*too full-on*', leading to embarrassment and withdrawal:

I'll say things that I don't think about you know... it's almost Tourette's... it's just... blah.... whether it's positive or negative. (Samir)

Drive reduction theory (Ursin & Eriksen, 2003) posits that a negative state of tension is created when certain psychological needs are not satisfied, with tension increasing over time in the absence of feedback. For Kevin, release from the ever-present tension and drive to 'do' comes from physical exhaustion:

I think it exhausts me and I need to push myself to exhaust me because that gives me a sense of relief.

The abundance of energy is not limited to physical activity. Participants experience constantly busy minds and a free-flow of information that cannot be shut down or switched off,

It's like a computer with about fifty internet tabs open. There's a lot going on, like, I could be talking to you and then I could be thinking about a service station I passed and then why

the dinosaurs become extinct and what happened to the Nazis, like all in one second you know...it's like a brain with a thousand tentacles going at once. (Samir)

Many describe a sense of conflict between an essential self and another self that cannot be controlled. Wiyona refers to the energetic, driven (and sometimes troublesome) part of her mind as 'her monkey', She is able to occupy this 'monkey' by undertaking certain types of multitasking – leaving 'her' free to think in peace:

I call it 'giving my monkey something to juggle'. I'll be drawing something while the TV's on, so kind of watching TV, kind of drawing... the cat will be on the bed... but the main thing I'll be doing is processing, and all the stimulation happening is actually helping me to feel very calm and allows my mind to go wandering. The monkey is very busy when that's happening so there's no interference, if you like. It actually allows me to access a deeper part of my brain, I think. (Wiyona)

Across participants, energy frequently translates to enthusiasm, and 'interest' is identified as a powerful motivator of behaviour and emotion. Emotions are deeply felt, particularly in relation to sensory experience:

I get very excited about little things, like a smell, or a texture, or a taste or a...moment.
(Wiyona)

Once interest is kindled, be it by external stimuli or internal thoughts, the desire to engage is irresistible and any commitment to a previous task or thought falls away. This diversion of attention might result in hyperfocus on the stimuli of interest or take the participant on a journey where they bounce from one thought to a seemingly disconnected other in a busy, vibrant world where there are no restrictions. In any case, sense of time is lost:

I call it following a pixie down the path... (Wiyona)

The appearance of a pixie; that is, something more interesting than the current task, the switch is instant and complete. There is no looking back.

I'd just drop what I was doing and... I'm in a new zone and completely new mind frame.

I've totally forgotten what I was doing before. (Lalage)

Participants give the impression of being seekers of joy, a state of being that goes hand-in-hand with childlike curiosity, openness to new experiences and following pixies. Many see curiosity as the underlying cause of their tendency toward distraction:

I think I have a greater sense of wonder about the world around me... and that's what causes me to easily get distracted. It's because my brain is constantly asking, "oh wait, what about this? And something over there's shining...Why is that shining? (Harry)

As much as interest can be easily engaged by a wide range of stimuli, however, it cannot be manufactured:

Definitely there's things that I can put a lot of time in to focus on but I don't know where those things come from... I don't know why stamp collecting was something that I really, really enjoyed whereas coin collecting I couldn't give a shit about. (Belinda)

Underlying participants' interpretations of their energy and drive to pursue interesting stimuli is a strong sense of operating *in the moment*. Evocative of Barkley's (1997b) 'temporal myopia', they are frequently locked in the present, without consciousness of time:

Time'll go and I don't even realise time's gone. I always get stuck in the moment. (Evelyn)

This *in the moment* timelessness is one-dimensional, corresponding with an absence of objective monitoring of self in time and space. It is interpreted as being different to the way 'regular' people operate:

I guess I would go longer than a regular person where I don't stop and realise what I'm doing or sort of check in with myself or be self-aware if you know what I mean. (Lenny)

Without this monitoring system, past and future have no traction. There is no awareness of task progress or deviation; hence they have no way of realising they have deviated from a 'goal':

If it's not in my hand right now, it's gone, it doesn't exist. (Belinda)

Likewise, no thought is given to consequences, which sometimes results in unintentional risk-taking. Realisation comes after the event:

I am a risk-taker, like I wouldn't say I get a kick out of it. I just don't consider consequences.

I would regularly take risks, but I'd always say to myself, "I've got to stop doing that".

Participants work hard at self-regulation, despite facing perceptions of laziness or lack of effort from others to whom monitoring comes naturally and automatically. Staying on track requires continuous, conscious effort that is emotionally and physically exhausting and can only be maintained for short periods of time.

No offense, but this interview is definitely cognitively taxing because I have to try and remember what is a) the question and b) then how do I give a well-structured and directed response. (Harry)

There is a sense that the divide between ADHD and neurotypical mental architectures is widest at this point, with neither side able to fully appreciate what the other experiences:

My reply was always, "I can't help it, I try". And she says "Just pay attention". And I'd say, "I can't - it's not something that I can do. I don't understand how you do that. (Lenny)

Even when the task being carried out is a practical one, there is no guarantee that the conscious mind will stay on the job:

I'm never thinking about what I'm doing, I'm thinking of something else. (Lenny)

Medication 'clears the clutter', eliminating *monkeys* and *pixies* and enabling focus. The temporal space becomes multidimensional, leading to increased self-awareness and an ability to stand back and observe the self-in-action:

Medication brings an awareness to what you're doing rather than being very automatic. I have the ability to decide what I'm gonna do. (Wiyona)

As the *in the moment* timescale is expanded, past and future considerations are incorporated into decision-making, bringing a sense of control over thought and action:

I've now got that little bit of extra time before I do something or say something to think about it, to stop myself from acting straight away...sort of consider, "Is that the best thing to say right now? Is that a smart idea to buy that thing? No, it's probably not. (Lenny)

Blest not broken:

An important aim of the study was to explore any perceived advantages to having an ADHD brain. Within this theme, participants describe five main strengths that they link to ADHD: energy, optimism, unique problem-solving ability, adventurousness, and curiosity:

When I wake up in the morning, when the alarm goes off at twenty past five ...I bounce out of bed, I sing in the shower. (Kevin)

Positive engagement and joy of life coupled with boundless energy allows them to imagine, create, and dream possibilities that are beyond their non-ADHD peers:

I'm able to create linkages between quite often very abstract concepts or ideas and bring them together in a way that perhaps other people would never have thought of. (Harry)

As they speak, there is a youthfulness that has survived their negative experiences of 'being' ADHD:

It can be described as a childlike access to joy, I guess. (Wiyona)

Along with an inclination to live life to the full:

If there's something I'm passionate about and I want to go after it, there's just no stopping me. (Lalage)

Lenny applies his inbuilt optimism to his ADHD traits and interprets them as an advantage:

I've had a positive experience with my symptoms because I've been able to make them work for me and I do that in every aspect of life... I just always find a way to enjoy it. (Lenny)

Participants use a variety of strategies to manage the difficulties associated with their ADHD.

Like Wiyona, some participants become masters of their own thoughts when they simultaneously undertake familiar, repetitive activities – examples were knitting, sewing, drawing, drumming and listening to familiar music.

I play drums specifically for my ADHD... because my head will just go...'bbckooo' so I need to settle that down with noise. (Samir)

Routines and diaries are commonly used to manage difficulties with organisation and planning:

I have set routines in place. I have everything in one book and I always have it with me. (Lalage)

Participants have gravitated towards occupations where their ADHD qualities can be accommodated:

I need a job that's got its boring day-to-day components but I also need to be able to jump from this to that very quickly. I've got my structured parts [and] I get to have my creative time. (Wiyona)

Rather than keep the lid on their energy, they harness it creatively and for the benefit and enjoyment of others:

As a classroom teacher I wouldn't teach from a desk. I would be bouncing around the classroom.. and look I'd put a theatre on for the five full periods... the kids loved coming in because I guess I was engaging, I was interesting; I'd like to think I was funny. (Kevin)

Discussion

Findings from this interpretive phenomenological study show that from an early age, participants felt they were different to the norm, and they sensed that others universally disapproved of this difference. Beliefs that they were broken or defective were pervasive and influential, although the participants in this study were largely able to challenge and reject those belief as they entered adulthood. Connecting with their authentic selves and accepting the pros and cons of 'being' ADHD facilitated this transition. The majority of participants are in relationships and have gravitated toward and attained success in careers that utilise their strengths. Even so, few of them choose to openly disclose their ADHD diagnosis to others for fear of a negative reaction.

The aims and outcomes of this study are relevant to ADHD research in two ways. First, our findings regarding the perceived advantages of an ADHD mental architecture extend the research of Mahdi et al. (2017), de Schipper et al. (2015) and Sedgewick, Merwood, & Asherson (2018) and have implications for clinical practice (discussed below). In terms of perceived advantages to having ADHD, characteristics identified by participants

were convergent across the data sets and can be grouped under the headings of energy, optimism, unique problem-solving ability, adventurousness, and curiosity. Table 1 applies the double-edged sword concept to positive ADHD-related attributes identified by participants. These attributes were often interpreted from a negative perspective in other contexts, for instance, in the classroom.

Table 1:
The double-edged sword of ADHD traits?

Positive	Negative
Spontaneous/adventurous	Impulsive
Curious, interest-oriented	Distractible, inattentive
In-the-moment and carefree	Off-task
Imaginative	Daydreaming
Energetic	Hyperactive
Fun and interesting	Absent social filter
Creative problem-solving	Flight of ideas
Enthusiastic, joyful	Irrational
Entrepreneurial	Non-conforming

Second, the emergence of a tendency to live *in the moment* in our participants is informative and potentially important for ongoing research on timing deficits in ADHD. Participants in this study were consistent in terms of describing how they function, with variations between participants more a matter of degree than difference. Regardless of their level of acceptance of their ADHD, operating differently to the norm was perceived as central to the challenges of navigating everyday life. The effects of ADHD went beyond hyperactivity and attention difficulties in certain contexts, extending to all areas of functioning. Indeed, accounts from these participants match Krueger and Kendall’s (2001) finding that individuals with ADHD perceive ADHD to be a particular *way of being*. Certain characteristics and processes were interpreted by participants to relate specifically to their ADHD mental architecture. Among them were higher than normal levels of energy and a

compulsion to pursue interesting stimuli, whether internal or external, in the moment the urge was experienced. “Following pixies” inevitably resulted in going off-task and was compounded by participants’ feeling that they did not regularly ‘check in’ with themselves, hence had no way of realising they had been distracted. Two of the most important effects of medication were identified as a newfound ability to consider and choose one’s response before acting and increased awareness of what one was doing.

Underlying the compulsion to act and lack of awareness was a sense of operating exclusively *in the moment*. It is interesting to compare this in-the-moment experience to qualia. Qualia is the particular state of consciousness, free of narrative, that is the direct experience of what something is like right now (e.g., seeing the colour red, taste of *this* apple). Qualia contrasts with what Orpwood (2017) refers to as ‘representational redescription’, where a system is able to reflect on its own internal states and generate beliefs and descriptions about an experience (i.e., remembering or anticipating). By definition it does not include either narrative and awareness, which require an ability to step back and oversee or describe an experience. Qualia is thus attention confined to a single dimension of time. According to attention schema theory (Webb & Graziano, 2015), awareness and attention are linked but dissociable. In this model, awareness is an overseer to attention and operates to link thoughts and behaviours over time. So while qualia can be perceived as just one of many layers of consciousness operating at any moment in the neurotypical brain (awareness represented by other layer/s or dimensions), it offers one way of understanding the ‘living in the moment’ experience articulated by the participants in this study.

Participants’ interpretations of their ways of operating and the processes that underlie them hint at a present-dominated system with reduced reflective and predictive capacity. In line with drive reduction theory (Ursin & Eriksen, 2003), a present-dominated system would

need real-time, ongoing feedback, which could result in compulsions to constantly sample the environment. Drive in a present-dominated system could also explain a low threshold for following *pixies*, low tolerance for unbearable situations of boredom, and possibly even the perception of excessive energy. Participants expressed a strong preference for activities that provide ‘hard’ information, such as Kevin’s need to exhaust himself to feel relief and the common theme across participants of indulging in high-intensity exercise. Absence of input or soft feedback may effectively create a vacuum of information, leading to a state of tension or agitation that manifests in impulses to ‘do something’. This could include movement, interaction with the environment/other individuals, or some other form of stimulating information flow (including internal stimuli). Thus the source of feedback may be kinaesthetic or cognitive, and could explain why an individual might struggle to sit still in a boring situation, but not when engaged in a stimulating video game or a task of interest. Other ‘hard’ information that reduces drive and induces a stable state could include situations with an element of risk, such as deadlines or pressure in terms of physical safety (e.g., *I work in the big towers on the edges and stuff - it makes me feel really nice and calm* (Samir).

The hypothesis that individuals with ADHD operate largely on a single-dimension *in the moment* timescale could also explain other behaviours associated with ADHD. Perception, motor and cognitive control, and decision-making rely on predictive processes that synthesise information about the past and present and generate information about future states of the body and the environment (Bubic, von Cramon & Schubotz, 2010). Key functions of cognitive processing on a *past* timescale include reflection, task progress, and behaving according to internalised social rules and norms. Functions of a *future* timescale include planning, prioritising and ordering steps toward a task goal, conceiving long-term reward or negative consequences, and contemplating different options and possible outcomes.

Participants' perception that boredom is more unbearable for them than for neurotypicals can be understood in the context of a reduced ability to rationalise the pros and cons of engaging in a particular task (including listening). For example, 'waiting' or 'enduring' are concepts of a future timescale. Likewise, without an overseer function (such as awareness) that coordinates past and future considerations, not only is task progress and behaviour unmonitored, but information-flow is unfiltered, therefore connections between thoughts and ideas can occur without inhibition (i.e. seemingly randomly). The double-edged sword of disinhibition may well be creativity and an ability to generate unique solutions to problems.

The neurotypical brain oscillates between timescales, sometimes reminiscing, sometimes planning ahead, sometimes fully focused on the task at hand. Recounting an experience in writing demonstrates the coordination of the three timescales. One must simultaneously recall information from memory, track what has been written, write, and anticipate what to write next as progress is made toward a known conclusion (Redish, 2013). It is this ability to monitor or regularly 'check in' on all three timescales, (i.e., where am I relative to where I began and where I am going?), that was absent in the participants of this study.

The single timescale hypothesis also offers an explanation for some of the positive characteristics identified by participants. Living in-the-moment is compatible with '*a carefree existence*' and '*a childlike access to joy*'. Indeed, it is ironic to consider the current trend of encouraging individuals to practice certain aspects of mindfulness in the pursuit of these same goals (e.g. Goldstein, 2013) . '*Following the pixie*' without a second thought is this mindfulness in action. Living in-the-moment has implications for the effects of reward. It may account for findings in the literature that children with ADHD choose smaller, more immediate rewards over larger, later rewards more often than do controls (Marco et al., 2009).

A similar effect of immediacy is suggested in Douglas & Parrys' (1994) findings that ADHD children matched neurotypical ones on tasks involving *continuous* reward but were slower and less consistent than controls in partial or no reward conditions.

Some participants described an awareness of conscious and nonconscious processes working sometimes in parallel and at other times with the conscious mind lagging behind. Examples include carrying out tasks on autopilot while the mind was elsewhere and automatically reacting to stimuli with the brain '*catching up later*'. There was also a sense of two minds operating; one closely connected to the 'self', and another often uncontrollable one. (Captured by Wiyona in her description of '*giving my monkey something to juggle*'.) By simultaneously undertaking familiar, repetitive activities such as knitting, sewing or drawing, Wiyona became free to engage in uninterrupted conscious processing. Samir felt drumming helped regulate his thoughts and Harry used loud, familiar music to be able to '*engage with [his] own thoughts*'. The value participants placed on these tasks in terms of control over thoughts offers some evidence of a role for multitasking in ADHD. It also links to the association between difficulty with attention and non-suppressed default mode activity (Castellanos & Proal, 2012). Perhaps certain types of multitasking can aid focus by activating networks that are able, collectively, to suppress activity in the default mode network.

Diaries were a popular strategy used by participants to manage difficulties encountered in relation to planning and organisation. Diaries provide a tangible link to responsibilities, tasks, and goals that are otherwise unlikely to be held in mind. Several participants carried notebooks allowing them to record and access important information in the moment. The diaries and notebooks thus work as extensions to the present-dominated timescale on which participants operated, expanding their temporal reach to include the dimensions of past and future. Many participants used routines to create habits that could be

executed without conscious involvement, useful for mitigating common problems such as inadvertently leaving the keys somewhere. Breaking tasks into smaller pieces was another strategy employed by some participants to stay on-task. Such a strategy works naturally on a shorter timescale, avoiding the probability that individuals will lose their connection to a goal too far in the future.

Strengths and Limitations

Identification of themes and interpretation of participants' narratives was undertaken with strict adherence to IPA principles in an attempt to remove the potential for researcher biases. However, a limitation of this interpretative qualitative study is that in seeking a homogenous group to explore in detail poorly explored phenomena, the results cannot be generalised nor can inferences of cause and effect be drawn. The small sample size of this study is in keeping with principles of phenomenological qualitative research. It focuses on depth rather than breadth in seeking to understand a phenomenon through the perspective of the individual, including how the individual makes sense of his or her experience. Generalisability relies on future nomothetic studies developing hypothetical aims from the findings of this study.

Despite these limitations the present study bridges some of the gap between quantitative and qualitative research by supporting a move towards viewing the ADHD mental architecture in terms of diversity rather than deficit. It also has implications for future qualitative research and theory-building on the mechanisms and processes underlying ADHD behaviours.

Conclusions and Future Research

The participants' accounts and interpretations in this study offer insights into the experience and processes unique to ADHD, including the effects an exclusively negative interpretation of ADHD has on the individual, and specific traits that can contribute to a more balanced and

constructive view of the ADHD mental architecture. Living in-the-moment was a ubiquitous theme that emerged across participants and offers a new perspective from which to understand both the difficulties and strengths of ADHD. Our findings in this regard 1) add to existing research on timing deficits in ADHD, and; 2) suggest that further investigation into the multiple functions that rely on perception and management of different aspects of ‘time’ (as distinct from memory processes) may be fruitful for increasing understanding of ADHD. Future research could explore the validity of the single timescale hypothesis based on the mechanisms and processes that underlie coordination of different timescales in the neurotypical brain. Innovative experiments could then be devised to investigate functioning related to timescale differences between individuals with ADHD and controls. Energy was a consistent theme and played a significant role in behaviour for the participants in this study, however its expression and the role it plays in non-hyperactive subtypes needs further elucidation.

More qualitative research is needed to deepen our understanding of how individuals with ADHD interpret the specific processes that help and hinder them as they navigate their way through the world. There is scope for devising interventions that acknowledge and harness advantages associated with an ADHD mental architecture as well as testing the outcomes of a strengths-based approach on both sense of self and performance.

The results offer clinicians a window into what it is like ‘being’ ADHD and suggest that a new approach to interventions is needed. Such an approach must begin at the grass-roots level with a change in the perception of ADHD as purely deficit and disorder. It is interesting to ponder, for example, how differently clinicians might approach treatment if ADHD referred to an attention-diversion hyperactivity disposition. Taking the concept of ‘broken’ out of an ADHD diagnosis allows for the development of new interventions that not

only help individuals with ADHD to manage difficulties, but also enable clients to recognise and harness the advantages of their unique mental architecture. Lenny serves as inspiration: *A lot of ADHD symptoms can be looked at in a positive way or a negative way...I will take a lot of time to show my daughter how to make her symptoms work for her instead of against, because I think I'm just lucky that I was able to do that myself.*

A strengths approach does not seek to downplay the wide-ranging effects ADHD can have on functioning in multiple areas of life, nor to minimise the emotional impact. The difficulties and challenges are real and significant. In reality, the world is unlikely to drastically change and will remain geared toward the mental architecture of the largest portion of the population. As such, medication is likely to retain an important place in managing difficulties associated with the ADHD brain. Perhaps the greatest benefit to a more balanced approach to ADHD lies in protecting the vulnerable sense of self, particularly as children and adolescents, that participants in this study so clearly portrayed.

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Appendix 1: Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE



Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Associate Professor Lynne McCormack
Cc Co-investigators / Research Students:	Ms Rosalind Redshaw
Re Protocol:	The lived experience of ADD/ADHD
Date:	30-Apr-2018
Reference No:	H-2017-0297

Thank you for your **Response to Conditional Approval (minor amendments)** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to a variation to the above protocol.

Variation to:

1. Change the selection criteria from requiring 'a diagnosis of ADHD in childhood' to 'a formal diagnosis of ADHD'.
2. Offer participants the option of a Skype interview.
3. Reword the PWB-PTCQ for ADD/ADHD.
 - Recruitment Poster (v3, Jan-July 2018)
 - Information Statement (version submitted 04/04/2018)
 - Consent Forms (version submitted 04/04/2018)
 - Semi-structured Interview (version submitted 09/02/2018)

Your submission was considered under **Expedited** review by the Ethics Administrator.

I am pleased to advise that the decision on your submission is **Approved** effective **30-Apr-2018**.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request.

Associate Professor Helen Warren-Forward
Chair, Human Research Ethics Committee

For communications and enquiries:

Human Research Ethics Administration

Research & Innovation Services
 Research Integrity Unit
 The University of Newcastle
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 T +61 2 492 17894
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Appendix 2: Advertising Flyer

Dr Lynne McCormack
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Faculty of Science
University of Newcastle
Callaghan NSW 2308
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lynne.mccormack@newcastle.edu.au

Jan-July 2018



**Would you like to be involved in research
investigating the lived experience of ADHD?**

Must be 18+ and have received a formal diagnosis of ADHD. Researchers from the University of Newcastle are planning to conduct research exploring the positive and negative experiences of adults with ADHD. If you would like to find out more about this study please contact Rosalind Redshaw at rosalind.redshaw@uon.edu.au or Dr Lynne McCormack on 4985 4543.

**RESEARCH
STUDY**
www.newcastle.edu

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2017-0297

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Appendix 3: Participant Information Sheet

Dr Lynne McCormack
 School of Psychology, Faculty of Science
 University of Newcastle
 Callaghan NSW 2308
 Ph: 4985 4543



**Information Statement for the Research Project:
 Making meaning as adults of the 'lived' experience of ADHD**

You are invited to participate in the research project identified above which is being conducted by Dr Lynne McCormack (Senior Lecturer/Clinical Psychologist) and Rosalind Redshaw (Masters Student Researcher/Psychologist) from the School of Psychology at the University of Newcastle. The research is part of Rosalind's studies at the University of Newcastle, supervised by Dr Lynne McCormack from the School of Psychology.

Why is the research being done?

Most of the current research into this area does not include the 'voice' of those who have ADHD nor does it explore any perceived positive aspects. The aim of this study is to gain a deeper understanding of ADHD by exploring the positive and negative experience of having ADHD from an adult perspective.

Who can participate in the research?

We are seeking 10 people aged 18 and over who have been formally diagnosed with ADHD. Eligible participants will **not** have been diagnosed with another mental health condition as well as ADHD.

What choice do you have?

Participation in this research is entirely your choice and only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way. If you decide to participate, you may withdraw from the project at any time without giving any reason and have the option of withdrawing any of your data. The Consent Form offers you the opportunity to be contacted in the future for further research projects, however agreeing to be contacted in no way obligates you to participate in future research.

What would you be asked to do?

If you agree to participate in the study, you will be asked to:

- Complete a demographic questionnaire prior to interview.
- Partake in an audio recorded interview with the student researcher where you will be asked about the positive and negative aspects of your experience of being diagnosed with ADHD. Please note that the focus of the interview is your interpretation of your experience rather than specific events. Interviews will take place in the Psychology Clinic at the University of Newcastle or via Skype.

Because the interviews will reflect your interpretations at the time of the interview, we will not ask you to review or edit the transcript of the interview. However, if you wish to withdraw your interview at any time, you are free to do so.

How much time will it take?

The interview is usually around an hour; it may take more or less depending on how much you would like to share with the researcher. Completion of the questionnaire will take approximately 5 minutes. If you need a break at any time, this can be negotiated with the student researcher.

What are the risks and benefits of participating?

It is possible that participants in the interview may feel some increase in stress and anxiety as difficult times are recalled, especially if your experience was particularly negative. If participants experience any discomfort or distress they may contact counselling services in the local area (University Psychology Clinic:

49215075; and Lifeline: 131114 telephone counselling service), if additional support is required. By being part of this research, you will have the opportunity to talk about your experiences and tell *your* story. You will also contribute to a more accurate understanding of what it is like to live with a diagnosis of ADHD.

How will your privacy be protected?

Your data collected from this research will be de-identified immediately after collection. The interview will be transcribed by the student researcher. All hard data and audio files will be stored in locked filing cabinets or on password protected hard drives within locked rooms, accessible to the research supervisor and student researcher, for the duration of the research and publication of any findings. Furthermore, only those researchers directly involved in this study will have access to these files. The data and consent forms will be disposed of 5 years after all investigations are complete.

How will the information collected be used?

The information collected from this research will form a substantial component of the thesis to be submitted by the student researcher. In addition, research outcomes from this project may be published in scientific literature by the researchers and/or used for educational, future research and conference purposes. Individual participants will not be identified in any reports arising from the project.

You will be asked to indicate on the Consent Form if you would like to receive a summary of the results of the research. This brief summary will be mailed or emailed to you at the conclusion of the study. Participants will also be advised of the details of any journal publications arising from this research project.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the student researcher.

If you would like to participate, please advise the student researcher by email and include a telephone number by which you can be contacted. The first 10 participants to respond will be contacted by the student researcher via phone to arrange a convenient time for the interview. You will be asked to bring your signed Consent Form and completed questionnaires to the interview.

Further information

If you would like further information about this project please contact Rosalind Redshaw or Dr Lynne McCormack using the contact details below. Thank you for considering our invitation to be part of this research.

Dr Lynne McCormack
Senior Lecturer/Clinical Psychologist
School of Psychology
Faculty of Science
University of Newcastle
Ph: 4985 4543

Rosalind Redshaw
Student Researcher/Psychologist
School of Psychology
Faculty of Science
University of Newcastle
rosalind.redshaw@uon.edu.au

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2017-0297. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.

Appendix 3: Participant Pre-Consent Form



THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA

Consent Form for the Research Project:

Making meaning as adults of the 'lived' experience of ADHD

Project Supervisor: Dr Lynne McCormack

Student Researcher: Rosalind Redshaw

- I agree to participate in the above research project and give my consent freely
- I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained
- I understand that I can withdraw from the project at any time and do not have to give any reason for withdrawing
- I consent to attending an interview session as part of this study at the University of Newcastle or via Skype, as outlined in the Information Statement
- I consent to the audio from the interview being recorded
- I consent to the data collected being used within a post-graduate research project and possibly also a paper to be published in the scientific literature, presented at conference or for teaching purposes
- I understand that my personal information will be de-identified, pseudo-names will be used and I will not be identified in any way
- I have had the opportunity to have all questions answered to my satisfaction
- I will not be asked to or able to review the transcript as this is a phenomenological study and relies on collection of data to be a one off event in time and place. I am able to request a copy of the audio recording of my interview.
- I ☐ do / ☐ don't consent to being contacted in the future for further research projects (please tick one).

Print Name: _____

Signature: _____ Date: _____

NEWCASTLE | CENTRAL COAST | PORT MACQUARIE | SINGAPORE

The University of Newcastle enquirycentre@newcastle.edu.au T +61 2 4921 5000
Callaghan NSW 2308 Australia CRICOS Provider Number: 00109J www.newcastle.edu.au

Appendix 3: Participant Post-Consent Form

Dr Lynne McCormack
School of Psychology
Faculty of Science
University of Newcastle
Callaghan NSW 2308
AUSTRALIA
Ph: 4985 4543



Post-Interview Consent Form for the Research Project:
Making meaning as adults of the 'lived' experience of ADHD

Ethics Approval: H-3027-0297

Chief Investigator: Dr Lynne McCormack

Student Researcher: Rosalind Redshaw

- Prior to participating in this study, I was made aware that I would not be asked to review or edit the content of my interview.
- Having now completed the interview, I re-confirm my consent to the de-identified data collected being used for research, scientific literature, and/or for educational purposes.
- Please indicate if you would like to receive a summary of the results of the research by circling your response:

Yes No

Name: _____

Signature: _____

Date: _____

Appendix 3: Demographic Information Form

Demographic Information

1. What is your gender?
☐ Female
☐ Male
☐ Other (Please specify)
2. Age range: ☐ Under 25 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55 and Over
3. Are you in a permanent partnered relationship?
☐ No ☐ Yes

 If so, how many years?
4. Do you have children
☐ No ☐ Yes (Please specify how many and gender)

5. Are you affiliated with a particular religious or philosophical belief? (You can choose not to answer this question)
☐ No ☐ Yes (Please specify)

6. At what age were you formally diagnosed with ADHD?

7. From where/whom did you receive your diagnosis?

8. Have any other members of your family been diagnosed with ADHD? Who?

9. Are you currently taking medication for ADHD?
☐ No ☐ Yes
 If yes, name of medication and dosage:

10. Have you taken medication in the past?
☐ No ☐ Yes (Please specify)

Thank you

Appendix 4: Interview Questions

Semi-Structured Interview Schedule (guide to questions)

- How do you think other people perceive ADHD
 - What does 'being ADHD' mean to you?
 - How did receiving a diagnosis of ADHD impact on you?
 - How do you perceive yourself in relation to your ADHD?
 - How do you think having ADHD has influenced the way you think/feel about others, your relationships, your view of the world?
 - Could you describe both positive and negative aspects of ADHD for you?
 - What factors of ADHD influence your strategies for living/succeeding in life?
 - As an individual with ADHD, how do you see your life going forward?
-

Appendix 5: Stages of Analysis in IPA

Stage 1: The audio recording of the first interview is listened to, and the transcript read a number of times in order to become as familiar as possible with the account.
Stage 2: The left margin of the transcript is used to annotate interesting or significant material in terms of language, content or sense of the participant. There are no rules regarding what is considered salient and no requirement to assign meaning - the researcher simply attempts to make sense of what is important to the participant in his or her experience.
Stage 3: The researcher returns to the beginning of the transcript and uses the right margin to document emerging themes. The aim is to capture the essential quality of what was found in the text and to extract theoretical connections within the data that is still firmly grounded in the participant's specific account. The emergent themes are then listed in the order they appear on a separate sheet of paper.
Stage 4: The above steps are repeated for each of the other interviews in the order they were conducted, with each transcript fully completed before commencing on the next.
Stage 5: To ensure credibility and validity, both researchers (student and student's supervisor) independently audit the data, abiding by each of the steps above. This serves as a quality control measure of the student researcher's interpretations (Smith, 1996).
Stage 6: The student and supervisor meet in order to come to an agreement on themes within each transcript and across the data, looking for both convergent and divergent themes. Agreement is reached through rigorous discussion that explores, interprets and continually reflects on what is known and what is assumed. Biases and suppositions are challenged and continually brought to consciousness.
Stage 7: The themes are ordered more analytically or theoretically, with some themes clustering together and others emerging as superordinate concepts across the transcribed interviews. A thorough understanding of the data is developed and a concise statement of the important aspects is then constructed.
Stage 8: A coherent narrative of the subjective lived experience of participants is created based on the interpreted themes of the data. Credibility is maintained through continued interpretation between the researchers until the final results are complete.

Appendix 6: British Journal of Clinical Psychology
– Guidelines for Contributors

Author Guidelines

The Editorial Board of the British Journal of Psychology is prepared to consider for publication:

- (a) reports of empirical studies likely to further our understanding of psychology
- (b) critical reviews of the literature
- (c) theoretical contributions Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

All papers published in The British Journal of Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 8000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

4. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use [this template](#). When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention, results or conclusions of the article.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

Appendix 7: Participant Demographic Information

Sex	Female	5
	Male	4
Age		
	25-34 years old	2
	35-44 years old	4
	45-54 years old	3
Employment		
	Unemployed	0
	Employed	7
	Self-employed	2
Medication	Currently taking	8
	Ritalin:	4
	Moclobemide:	1
	Dexamphetamine:	2
	Unknown:	1
Age at Diagnosis		
	5-13 years	3
	25-31 years	4
	45 years	2
