

Narratives of ADHD: A qualitative study of women's narrative accounts of living with ADHD.

Summary and initial findings

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Summary

The project was a small-scale interview based qualitative study designed to explore the experiences and sense-making of adult women who have been either formally diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), or self-diagnosed. It contributes to an emerging body of knowledge with a particular focus on the experiences of adult women with ADHD. This is important because research to date has been dominated by a focus on children and on male children in particular, and yet recent years have seen a large increase in the number of adult women formally diagnosed with ADHD, including a growth in the number of women who have identified sufficiently with ADHD to diagnose themselves ('self-diagnosis'). The research aimed to examine women's experiences of ADHD (including their experiences of formal diagnosis and self-diagnosis), and to explore how they perceive ADHD to have impacted on their childhood, on their transition to adulthood, and on their sense of identity. The project was interested in finding out about how women make sense of these kinds of issues in their own words and from their own perspective. The project, therefore, does not claim to generate objective facts about ADHD as a medical condition. Instead, it seeks to describe and present participants' accounts in rich and concrete detail.

16 women participated and provided data in the form of in-depth interviews. Seven women had received formal diagnoses, two of whom had been diagnosed as a child or teenager (the rest were diagnosed as adults). Nine women were self-diagnosed at time of interview, of whom at least one participant has since been formally diagnosed. The very small numbers of participants who received a diagnosis in childhood is consistent with previous findings that suggest a lack of recognition and diagnosis of girls with ADHD.

The project explored narratives at key moments such as in childhood, at school, family life, relationships and work. The women who took part in the project gave rich and varied accounts of their lives. Most of the women interviewed described difficulties in their childhood, transition to adulthood and in the present. ADHD was seen as fundamental to their identity and provided a way of reinterpreting the past and understanding current problems and difficulties. It is significant that

women with a formal diagnosis and those who self-diagnosed with ADHD offered similar accounts of feeling relief when they began to identify with ADHD. Nine women in the sample had children with a formal ADHD diagnosis, which prompted them to identify with ADHD as a way of understanding and explaining their own experiences. Some women discussed being able to take pride in themselves and value skills and abilities, such as forms of creativity and being an advocate for others, that they saw as being part of an ADHD identity.

Initial analysis and findings

Research into adult ADHD is still at an early stage (Vingelis et al. 2015). Few studies have examined the personal accounts of adults with ADHD and most of these focus on experiences of parents of children with ADHD, typically mothers of boys with ADHD (Singh, 2004). Despite the growth in diagnostic rates for adult women, women remain underrepresented in the literature, which tends to focus on 'homogenous samples of clinically referred, young Caucasian males' (Vingelis et al., 2015). Hence this project contributes to a developing body of research by documenting narratives of women with ADHD reflecting back on key periods in life such as experiences at school, transition to adulthood, experiences as a mother and at work.

The project was a small and exploratory study that aimed to:

- Investigate the identity work of women in relation to their experiences of living with ADHD
- Explore (possible) differences in the way women assumed an ADHD identity in either childhood or adulthood; in order to examine how ADHD impacted upon their childhood and the role of diagnosis in childhood, later in adulthood or self-identification
- Explore how women account retrospectively for ADHD in their childhood and how they construe their transitions to adulthood

It is important to acknowledge that the women who took part in our research had significant issues that they felt were as a result of ADHD. The women described difficulties through their childhood including at school, home and with friendships; in the transition to adulthood; and in adulthood with relationships, as mothers and in the world of work. Many described difficulties with strong emotions that were at times overwhelming for them. For example, "I did, I have tried to kill myself, seriously on two attempts because, not because I wanted to be a drama queen. [...] Just because it's almost like I don't want to be dead, it was, I actually do not want to be alive anymore, and I feel personally there is a difference" (participant 5, who received a formal diagnosis in adulthood).

Women in the study who sought a formal diagnosis in adulthood reported that they did so because of a need for treatment for severe personal difficulties, for example:

“I didn't know what it was. So my main reason for it was that I'd been suffering from depression for a long time on and off, and it just wasn't going away, and I kind of had this thought that there was something else, that it was something within me that was stopping me from doing the things that I, that that was what was causing the depression, which isn't, it's a difficult thing to try and describe to somebody because if you are depressed you might be delusional and be thinking like that anyway [...] So that was the route that I took because I've - my main issues are that I find it quite difficult making and maintaining friendships and relationships, and I always have done. And I have not got a clue why” (participant 4, who received a formal diagnosis in adulthood).”

Identifying with ADHD was fundamental to the identity of all of the women who were diagnosed, or self-diagnosed in adulthood. For example, “it's who you are it's who I am to every fibre of who I am. It's not a condition I have it's who I am” (participant 2, self-diagnosed with ADHD). A key theme in the narratives offered by women in their interviews was an awareness of normative childhood against which they differed in negative and uncomfortable ways, “when you have ADHD nothing is normal.” (participant 2). Women discussed feeling different to other children, for example, “I felt like an alien [...] I felt different. I knew I was different, but I could never put my finger on it” (participant 7, who received a formal diagnosis in adulthood). Looking back on their childhood women described themselves as difficult children; “I didn't even like being a child. I didn't get it. [...] I felt that I was not an adequate human being” (participant 5). A diagnosis, or identification with, ADHD in adulthood enabled women to re-interpret their feelings of difference.

It was clear that Identification with ADHD provided a way of making sense of past and present difficulties. Our initial data analysis provides examples of ways in which disruptive and problematic behaviour could be framed as either of a product of a differently working brain or as a result of illness, thus women are not to 'blame' for their behaviour:

“Um, it's hard in the sense of the guilt that I feel around my, my children and the behaviours, my behaviours towards, towards my parenting skills and the things, but, you know, I have to tell myself that I was sick and that I didn't know any different and it wasn't premeditated, I didn't do it on purpose, it was all that I knew, but, er, there are a lot of times when I do suffer a lot of guilt because of. Um, now I feel relief that I don't behave like that anymore.” (participant 3, who received a formal diagnosis in adulthood).

The process of identifying with ADHD can be thought of as a 'transformative resource', which guides and frames experiences. A narrative of 'before and after' was drawn on by women to articulate the transformative nature of a diagnosis:

"Um, however, since the, the diagnosis, oh, oh it's, I, I can only see my life now post-diagnosis and pre-diagnosis, I am a different person. [...] I, I'm still not succeeding at any of those things and I don't know if I ever will. [...] But I'm OK. [...] And I like my - I'm going to get upset now - I like myself, um, and it is the reason for all of those things and that it's not an excuse. [...] It's absolutely 100% the reason why I struggled at all of those things and probably will forevermore and unfortunately you've got this condition which affects memory, organisation, distractibility and then you've got age and it's probably going to get worse! You know, so..." (participant 7, who received a formal diagnosis in adulthood).

A key finding in our study was that women who self-diagnose with ADHD provided similar descriptions of the difficulties in their lives as a result of ADHD and relief at finding an explanation for them. The women in the study who did not have a formal diagnosis in adulthood are significant in understanding and theorising identity. From the accounts that women offered in interview, self-diagnosis with ADHD can be either a permanent status, or a part of a process of recognition, self-diagnosis and then formal diagnosis. Participant 11 was self-diagnosed at the time of interview and subsequently received a formal diagnosis. For others self-diagnosis was seen to be sufficient for example, participant 6, having had a difficult childhood considered that being an adult with ADHD was more manageable. There was also a common view amongst the women who self-identified with ADHD, that support was very difficult to access and may not be helpful; "I can't go to the doctor and say oh by the way, I think I've got ADHD, do you want to diagnose me, and also what would they do for me? What could they do for me?"(participant 8).

Whilst accounts vary, the women who self-diagnose with ADHD did not see medication as an important consideration in their decisions. Indeed one participant (16) rejected the use of medication, "whenever I go through bouts of anything now and then, they try to give me anything, I'm always like, no [...] because I'm quite good at self-managing and I always find that, um, it's a plaster - it's putting a plaster over a gunshot wound. I don't think it, it doesn't solve the problem". In contrast to research by Winter et al (2015) that suggested that women seek out medication, the women in this study were more interested in understanding and meaning making in relation to an ADHD identity.

Another key finding is that for women who had a formal diagnosis and those who self-diagnose with ADHD, it was their identities as mothers that prompted awareness of themselves as someone with ADHD. Nine women who participated in our research were mothers who reported having children with a formal diagnosis, and one woman's son had a partial diagnosis (she withdrew her son from the assessment when it became clear that the only support to be provided would be medication). For seven of these women their child's diagnosis was seen as a pivotal point in recognising themselves as living with ADHD, for example:

"I reckon that - the reason why I got diagnosed was because I have a 13 year old son. He's my second child, I've got a 23 year old son as well, um, and my 13 year old was diagnosed with ADHD last June. [...] Um, so I knew from a very young age with [...] my son, that there was more to him being a spirited child, but nobody would have it. Everybody just kept saying no, no, no, no, no, it's just his personality, it's just second child syndrome, you know, it's the breakdown of your marriage, all of those kind of things, but I just knew, there was just something inside of me that just knew and I, um, just wouldn't let it go. I just wouldn't, I just wouldn't let it go and when he done the transition from primary to senior school it was picked up by a teacher who has ADHD" (participant 3).

Women's identities as mothers were also drawn on to articulate an ADHD identity as one of pride in their abilities and additional skills above the 'norm'. This was articulated in a number of ways, including having insight into the world of their child with ADHD, advocating for their child and also skills to advocate and 'fight their corner':

"I believe that [my son] was sent to me as a gift to teach me and I almost feel that as I work through his problems with him and do the things that he needs, I'm healing that little girl inside of me. So, when he comes home from school and says that things happen with a teacher I believe him and I step up and speak to his teacher about it and fight his corner, whereas I grew up in an environment was, well, you shouldn't have done that. So, so I almost feel like, like as I fight his corner I fight mine too." (participant 3).

Women were, in some instances, able to draw on a positive ADHD identity that values ADHD traits in contrast to the 'norm'. However, the articulation of a positive ADHD identity is mediated by an acknowledgement of the difficulties for themselves and others. It was also evident that all women in the study undertake active management of their lives in order to maintain control and 'normality', "I have accepted who I am but I have to manage that the whole time 'cos if I don't then I'd have no-

one talk to because I'd have no friends because I'd be going off on a tangent constantly" (participant 2).

The project team have begun to develop a theoretical approach to accounting for issues of temporality and how identity and meanings of experience shift through time. Identifying with ADHD can be considered as a 'transformative resource' with which to narrate different meanings of troubled and difficult pasts. The accounts provided by participants were given in the 'now' of the time of interview, and we wanted to attend to the ways in which their talk was oriented to the 'here-and-now' of the interview, but at the same time account for ways in which women were talking about how identifying with ADHD served to transform their understandings of their own pasts.

Our approach shows that a 'naïve realism', which assumes participants' talk about the past is simply a true account, is not an appropriate way to understand women's experiences. What is interesting is how ADHD, as a resource in the present, can transform our understanding of past events and experiences. At the same time, it is important not to adopt an equally naïve constructionism which assumes that the past is somehow irrelevant to the constructions of the present, or that assumes that the label of ADHD is a purely linguistic issue. Our approach is at the forefront of advancing a nuanced, relational process approach which steers a middle way between these extremes.

References

- Singh, I 2004, 'Doing their jobs: mothering with Ritalin in a culture of mother blame', *Social Science & Medicine*, 59, 6, 1193-1205
- Vingelis et al (2015) Vingilis, E., Erickson, P. G., Toplak, M., Kolla, N.J. Mann, R.E., Seeley, J., Vander Mass, M. & Daigle, D.S. (2015) ADHD symptoms, comorbidities, substance use and social outcomes among men and women in a Canadian Sample *BioMed Research International Volume 2015*, Article ID 982072, 8 pages <http://dx.doi.org/10.1155/2015/982072>
- Winter, H., Moncrieff, J. & Speed, E. (2015) "Because You're Worth It": A Discourse Analysis of the Gendered Rhetoric of the ADHD Woman, *Qualitative Research in Psychology*, 12, 4, 415-434, DOI: 10.1080/14780887.2015.1050748