

“Going through life on hard mode” - The experience of late diagnosis of autism and/or ADHD: a qualitative study

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Abstract

Background – In the UK, over 2.5 million adults with undiagnosed neurodevelopmental conditions, such as autism and ADHD, can face difficulties accessing diagnosis and support. Our qualitative study explores people’s experiences of receiving a diagnosis in adulthood and its impact on their lives.

Methods – We conducted semi-structured interviews with seven healthcare professionals and 13 late-diagnosed adults (five autistic, five with ADHD and three with dual diagnoses) using reflexive thematic analysis.

Results – We developed five themes from the analysis representing the journey and factors influencing participants’ experiences of receiving a late diagnosis: 1) The key role of relationships and mental well-being; 2) the wider impact on well-being and life-long mental health; 3) understanding: the answer to post-diagnosis changes; 4) the flip side of diagnosis- the burden of a label; 5) are you ready- the importance of timing.

Conclusion – Our study demonstrates the multiple impacts lack of diagnosis has and the many benefits experienced from receiving one. While a lack of diagnosis can at times have some negative effects, the importance of understanding and the wider impacts on relationships and mental well-being are discussed. Primarily, the emerging concept of being ready and the importance of the right timing highlight an important nuance in the diagnosis journey.

Background

Currently, in the UK, it is estimated that over 2.5 million adults with neurodevelopmental conditions have not received a diagnosis^{1,2} and therefore struggle to access support.³ The most common

neurodevelopmental conditions, attention deficit hyperactivity disorder (ADHD) and autism affect 5% and 1% of children and adults in the UK - on average one child per classroom.⁴⁻⁶

Autism is a lifelong condition resulting in differences in social and communication style, difficulties adapting to unexpected change, restricted interests, and sensory processing differences.⁷ ADHD is categorised by symptoms of impulsivity, hyperactivity and inattention leading to considerable daily impairment.^{8,9} Individuals with autism/ADHD and their families have reported many impacts of these conditions such as significant academic underachievement and educational problems,¹⁰⁻¹² increased prevalence of depression and anxiety^{13,14}, higher rates of offending behaviour and imprisonment,¹⁵⁻¹⁷ divorce,¹⁸ driving accidents,¹⁹⁻²¹ unemployment,^{13,22,23} suicidal thoughts and behaviours^{24,25} and other mental health issues.^{26,27} Studies have shown that adults with undiagnosed autism/ADHD, are more likely to have educational problems, depression and anxiety, commit crimes and abuse substances.²⁸ In most healthcare systems, formal clinical diagnosis is necessary to access support services, therefore these poor outcomes could be reduced with earlier identification.²⁹⁻³¹

While autism and ADHD are developmental conditions, many autistic people and/or people with ADHD (henceforth autism/ADHD) have been missed in childhood and only receive a diagnosis in adulthood.³² Additionally, it is estimated that millions of adults with autism/ADHD are currently undiagnosed in the UK³³⁻³⁵ and this issue prevails around the world. In Denmark for instance, over half of the children surveyed in a national birth cohort who reported ADHD behaviour at age 7 were not diagnosed at follow-up many years later.³⁶ Autism and ADHD often overlap with 38.5-59% of individuals having both conditions,^{37,38} sharing high genetic heritability and impaired social and executive functioning.³⁹ Both conditions are widely under-diagnosed^{2,40,41} and carry significant stigma.⁴²⁻⁴⁴ Additionally, the diagnostic process and care pathways for autism/ADHD are often very similar.⁴⁵ These shared experiences highlight the importance of exploring overlapping experiences across these two conditions.

Few qualitative studies have explored the experience of receiving a late diagnosis of autism/ADHD in adulthood. Studies **have highlighted** the negative impacts of lack of diagnosis, the process of acceptance, and the feeling of being different.⁴⁶⁻⁴⁸ A qualitative study exploring the experiences of late diagnosed autistic men highlighted the negative impact that late diagnosis had on their psychological well-being and the benefits of receiving an explanation for long-standing difficulties.⁴⁶ Another qualitative study of late diagnosed autistic women showed the impact of limited understanding of others, the stigmas and assumptions around autism and the process of acceptance.⁴⁷ Similarly, women report high levels of masking autistic characteristics, vulnerability and specific difficulties with gender-centred demands.⁴⁹ Gellini and Marczak⁴⁸ describe the experience of late

diagnosis of autism as “feeling like an alien”, not understanding why you don’t fit in but also a sense of liberation from being able to be yourself post-diagnosis.

With regards to ADHD, Matheson and colleagues⁵⁰ describe a persistent sense of failure and missed potential from living with the impact of ADHD impairment. It led to an accumulated psychosocial burden, especially among those diagnosed from late adolescence onwards, and positive adjustment was facilitated by a younger age at diagnosis. Additionally, delayed diagnosis has been shown to cause suffering and dysfunction, by adding unnecessary struggles and highlighting the potential of a better life, what could have been if ADHD had been recognised earlier.⁵¹ The positives of receiving a diagnosis was the most widely shared experience, by providing self-knowledge, a sense of belonging and increased value. Finally, Aoki and colleagues⁵⁴ described the relief and acceptance that the diagnosis brings.

The experience of adult diagnostic processes of autism/ADHD are very similar across the two conditions³⁹ and reflects a commonality in the impact that undiagnosed neurodevelopmental conditions have. While previous studies have explored these impacts in specific contexts such as gender experiences, this study wanted to investigate these impacts through a broader lens, regardless of condition, gender, country and other factors. To gain further understanding of the factors intertwined with late diagnosis of autism/ADHD, our qualitative study explores people’s experiences of receiving a diagnosis in adulthood and the impacts this had on their lives.

Methods

Study design

Our study investigates the question: What are the experiences of adults receiving a late diagnosis of autism/ADHD? The lead investigator (BF) conducted the interviews over the course of a month in August 2023.

Participants

We recruited twenty participants from two different groups: 1) healthcare professionals who specialised in autism/ADHD diagnosis (n=7); and 2) and people who had been diagnosed with autism and/or ADHD in adulthood (n=13). Participants originated from across the UK (n=15) and other countries (two from the US, one from France, one from Germany and one from Australia). We selected participants through our research database and contacts to give a representative sample in each group. Participants with autism/ADHD were selected from our database to represent a range of genders, conditions, ages and time since diagnosis⁵⁵ while healthcare professionals were selected from our personal contacts to represent adult and children services for both conditions. Our

database comprises over 300 adults diagnosed with autism/ADHD, recruited throughout different research projects and who wanted to take part in future research. Due to ongoing issues with fake participants taking part in online studies⁵⁶, multiple checks had been made to ensure that the participants were genuine. We interviewed participants in no specific order to limit biases from specific groups, and offered all participants a £20 voucher for their time.

Healthcare professionals:

We interviewed three male and four female healthcare professionals (mean age: 49y, range: 41y-55y). Four participants worked within public healthcare adult services and dealt with adult diagnoses of autism/ADHD (one in Germany and three within the UK National Healthcare System (NHS)). Two participants worked with children in NHS diagnosis settings of ADHD while one participant worked privately and diagnosed children and adults with autism/ADHD.

Late-diagnosed adults with autism/ADHD:

We interviewed four male, eight female and one non-binary adult diagnosed with autism/ADHD in adulthood (mean age: 45y, range: 30-62). Five participants had received an autism diagnosis, five an ADHD diagnosis and three both. Participants had to be over 25 and have over 4 years since diagnosis to be eligible, allowing for greater insight into the impact of the diagnosis.

Advisory Group

We recruited an advisory group of nine adults diagnosed with autism/ADHD in adulthood from UK-based charities and support groups. Our advisory group informed the development of the interviews, helped the research team interpret findings from our previous systematic review²⁸, identify risks not explored in previous research and those risks which require further investigation in our current qualitative study. The group also assisted in drafting the interview schedule, reflecting on topics covered and the language used for all the questions.

Data collection

We conducted individual semi-structured interviews to explore the risks associated with late diagnosis of autism/ADHD in adulthood. After we discussed the interview process with participants, we obtained informed consent through a secure Microsoft form filled in by the participants at the beginning of the interview. We offered participants a choice of telephone (for UK-based participants) or online interviews on Teams. We developed two interview schedules (one for healthcare professionals and one for adults) based on a recent systematic literature review²⁸ and discussion with our advisory group, which included specific topics as well as more open-ended questions (Supplementary Material 1). We applied the interview schedule flexibly and reviewed this regularly

with data analysed in an iterative process. We changed or added questions as different topics emerged throughout the interviews. We also omitted certain questions depending on the participant's experience. We took detailed notes after each interview and following each analysis step which were included in an analysis diary. We recorded all interviews, transcribed these verbatim, and subsequently anonymised these. Our institution's ethics committee granted ethical approval for our study (refF1440R).

Data analysis

We used reflexive thematic analysis to analyse the data.⁵⁷ We chose this analysis method as it facilitates capturing opinions, views and experiences and how these are interconnected. The lead researcher (BF) also has extensive personal experience on the topic which would have impacted data analysis, lending itself well to the reflexive component of thematic analysis.

The lead researcher (BF) undertook the thematic analysis from an essentialist theoretical position with experiences understood as the participant's reality. Analysis was data driven and carried out inductively, themes were derived from the data, as opposed to from a pre-existing theoretical framework or previous research. BF identified themes and subthemes using an adapted approach of Braun and Clarke's⁵⁷ reflexive six-stage process as follows. The analytic process began by transcribing each interview verbatim, shortly after being conducted. Following this process, the lead investigator first familiarized herself with the interviews by listening to the audio tapes and reading through the transcripts several times. Following verbatim transcription, the lead investigator took notes in a diary of her preliminary thoughts on the content of the interviews. From this close familiarisation with the transcripts, preliminary codes were identified in a coding manual. After familiarisation with these codes and long reflections on their meaning, they were then collated and combined to be classified into broader themes using ongoing comparative analysis both within and between transcripts. Finally, as the analysis evolved, these broader themes were reviewed and refined and generated the final themes proposed. To get a meaningful analysis, we ensured that data within each theme was coherent about each theme and subtheme as well as within the context of the overall dataset. While previous literature reviews²⁸ highlighted topics that needed to be explored, we developed the interview schedule in a way that allowed new topics to emerge inductively within the interview schedule, aiming to freely explore the participants' experiences. Our ongoing analysis allowed for a clear definition of the final themes. A second researcher (SC) reviewed the resulting themes to ensure that they mapped to the original transcripts. The second researcher also confirmed that data saturation was reached and that no new themes emerged in the last few interviews. The second researcher checked the coding manual and theme extraction along with the individual coding of transcripts. Inter-rater reliability was tested on a small proportion (10%) of the transcripts' themes

and sub-themes and showed a unanimous agreement in the classification of the themes. Our results were validated collectively as a team, and any discrepancies were discussed and reconciled.

Positionality statement

It is important to note that the main researcher BF approached the interviews from multiple standpoints, a service-user, a clinical and a researcher standpoint. Firstly, having received a diagnosis of ADHD as an adult, BF had extensive experiences with primary care from a service user's point of view. Secondly, BF has been facilitating service-user' workshops for parents and adults with ADHD for the last thirteen years. Finally, BF has been working as a neurodevelopmental researcher for the last decade. As such, she brings her own biases to this important topic and her personal experience will have impacted the analysis as well as the questions and methods for this study. While keeping as much integrity as possible, it would be impossible to be completely objective while dealing with such a sensitive topic. BF had a very positive experience of receiving a diagnosis in adulthood and it is important to acknowledge the potential biases this might create. Careful consideration was given to not letting personal experiences affect data collection and minimise the impact on data analysis and BF did not disclose her personal experiences to the participants during the interviews. Despite her best efforts, this sensitive topic brought a lot of high emotional responses throughout the process by hearing similar experiences or other's struggles. Therefore, please bear in mind the context and positionality of the lead researcher in the study within which the data was collected and analysed.

Results

We generated five themes from our analysis: 1) The key role of relationships 2) the wider impact on well-being and life-long mental health; 3) understanding: the answer to post-diagnosis change; 4) the flip side of diagnosis- the burden of a label; 5) are you ready- the importance of timing. The themes represent the journey and factors that influence the experiences of receiving a late diagnosis.

Theme 1- The key roles of relationships

This theme centred on the importance of relationships. In this context, the term relationship includes different aspects of social life including friendships, partners, families, work colleagues, teachers, and acquaintances. Relationships seem to be at the core of many struggles and positive supports that impact work, education and many more aspects. These nuances of the impact of relationships are discussed further below.

Pre-diagnosis, relationships seemed to impact everything, from school performance to employment or self-esteem. **Some** adults with autism/ADHD felt that because of the nature of autism/ADHD, they were an easy target for others and were sometimes taken advantage of. Their self-beliefs about what

they could achieve, and how they could react were constantly affected by others' beliefs. *"I thought I was, I thought it was a moron. I didn't finish high school. Yeah, I was just always kind of treated like I was lazy and stupid, so I assumed that was correct."* P8

However, the support of specific relationships could also have a positive impact, supporting individuals through their struggles. The support of partners or parents can make all the difference in whether individuals retain a job, stay and perform well at school or manage social situations. *"They set up a special program [...] So I actually was able to succeed in school because of that program that my mom and my teacher developed."* P5

Post-diagnosis, adults with autism/ADHD felt that receiving a diagnosis impacted how partners, friends or parents interacted with them. While a couple of relatives experienced the diagnosis negatively, primarily having an explanation for their difficulties was received very positively. Families could then understand better and can put strategies and support in place such as learning not to fight, not getting offended by certain behaviours, and being more accepting of who they are. *"There was a lot of conflict. There was my girls living with their father at times, really hating me. I mean, so much conflict that we had to get services involved, family services [...] but I have great relationships with my daughters now, and we're all more aware of talking about our triggers."* P14

Many participants reported positive and negative impacts of the diagnosis on relationships. It helped some set boundaries with others and realise who was truly supportive of them. While this could create further distance from others, it was mostly felt as a benefit as they struggled less. For many, being able to understand their differences, led to better communication in work, school, marriages and peer situations. *"My relationships were unhealthy, very, very unhealthy. And I would think, well, that's the best you can get because you're flawed, at the back of my head, that's what I was thinking. But now I'm in a very healthy relationship."* P13

Receiving a diagnosis allowed many adults with autism/ADHD to feel like they belonged and to find a different community. The sense of community of sharing experiences with others experiencing the same gave a new meaning to relationships. *"How important community is and finding other ADHD people. Because I felt so lonely all my life, I felt so different and I just felt like I was just a failure and a weirdo [...] And just finding other people that just get you [...] we get each other."* P14

Finally, advocacy was also very important, both in terms of feeling confident to advocate for themselves but also for others. Some adults with autism/ADHD became advocates for others, supporting families, creating peer communities and championing this new-found identity and its

community. *“The only thing is, I'm much more advocating for the people, especially people I know that are neurodivergent and struggle to express themselves or get the treatment.” P3*

Theme 2 – The wider impact on well-being and life-long mental health

Every participant's testimony described how their mental well-being was impacted throughout their lives, pre-diagnostic principally but also during and post-diagnosis. The concept of not fitting in, and being different was strongly highlighted and this could change by gaining understanding.

All participants reported mental-health difficulties post-diagnosis including anxiety, depression, suicide ideation, self-harm and addiction. Their sense of self was strongly impacted by existing in a world where they felt they didn't fit in, including a lot of self-blame and self-esteem. Burnouts were often experienced, sometimes impacting their sense of safety. Adults with autism/ADHD felt that a lot of their difficulties were their fault, that they were “broken”. All participants reported difficulties in growing up feeling different and not understanding why, feeling like something was wrong and that they were not good enough, continuously impacting their self-esteem. *“Just knowing that I'm not a broken version of something else that I'm exactly how I meant to be as an autistic and ADHD person. I just used to think that I'm just bad at this, I'm just bad at being a human.” P07*

“I had this idea in my head that I would never get better and that I would just, end up taking my life because I couldn't keep going because it was just too much all the time.” P11

Receiving a diagnosis mostly impacted mental well-being positively, often bringing hope. Most adults with autism/ADHD felt better afterwards, being able to understand and work around their mental health difficulties. It allowed them to validate and accept their past experiences and struggles. They felt more able to regulate and communicate their emotions, having fewer meltdowns and burnouts. While some mental health struggles were explained and lessened, some struggles were still present, but they were able to find strategies to stop them “spiralling”. The diagnosis helped them feel able to deal with day-to-day struggles and at times, feel safer and more confident. *“(a diagnosis) it gives it a licence, it gives it fairness, it gives it recognition. I can own it and treat it, I can understand it. Just knowing why you do those things impacts on your schema and your self-esteem.” P101- healthcare professional*

Theme 3- Understanding: the answer to post-diagnostic change

The key benefit of receiving a diagnosis was being able to understand why relationships are difficult, why you feel like you don't fit in, and why things like school and education are harder for you. The concept of validation and giving a framework was widely discussed and how it allowed adults with autism/ADHD to understand their strengths and weaknesses and seek support/strategies accordingly.

The main feeling post-diagnosis was one of validation and acceptance. The diagnosis gives meaning, ownership and a framework to work around. It highlights a framework within which adults with autism/ADHD can own their differences. It is not an excuse but an explanation of why it isn't their fault. It increases confidence and adults reported being kinder to themselves, giving themselves more time, more breaks or caring less about being different. *"I really think that every single day my life is impacted positively by having a diagnosis and better self-understanding."* P06

"I was actually in the same gear as everyone else that's the best way to describe it because (before) I seem to have always been stuck in first gear." P01

The understanding that comes with the diagnosis also allows most adults with autism/ADHD to understand both strengths and difficulties. They can assess the positives that come with their differences as well as the areas of life that they struggle more with. By understanding this, they feel better able to be who they are and navigate the complexities of living with autism/ADHD in a typical world. *"It's giving me permission to be myself more and unapologetically myself."* P07

"But just having that understanding that you do this because you have ADHD, not because you're a failed human." P14

The diagnosis allows individuals to put strategies in place, as well as access support that facilitates many aspects of life. It helps them to make the right choices, make changes and address some of the difficulties they experienced. The changes are often a learning process of what works for them, but this sense of understanding brings many benefits and changes. *"All right, what's a good solution instead of what I previously would have done would have been probably self-blame or self-shame, not coming up with a solution and just thinking I need to do better. Seeking support for sure, but seeking the right support."* P06

Theme 4- The flip side of diagnosis, the burden of a label

This theme describes the negative aspects of receiving a diagnosis, principally around the stigmas of the labels of autism and ADHD. Other people's reactions were mainly to blame **with them expressing** strong misconceptions, misrepresentations and stigmas. Few participants also reported negative feelings such as anger and regrets, while others felt some self-doubts.

The stigmas around autism/ADHD labels were by far the most negative aspect experienced by adults with autism/ADHD. Some aspects of the labels and diagnosis were felt as deficit-focused, primarily highlighting difficulties rather than conditions with pros and cons. While some were at first uncomfortable with the diagnostic label, it was primarily other's reaction to that label that was experienced negatively. They felt that the labels autism and ADHD carried a lot of stigmas that others

judge them on. *“because when people talk about autistic people, they often talk about us in stereotypes like we're not actual people.” P04*

“So the child gets handed over year to year as Johnny with ADHD and people will have their stereotype of what that means. And potentially, it not so much self-fulfilling prophecy, but they might be looking out for those behaviours and giving them less opportunities or less chances from that point of view.” P102- healthcare professional

Others' perceptions also strongly impacted adults with autism/ADHD negatively. Misunderstandings, misconceptions and misrepresentations around the diagnosis were often very difficult to deal with. Such as having to explain yourself, or not react to others' misplaced comments or actions.

Participants also reported that others would compare their conditions to others they knew or would force a conversation about autism/ADHD just because they knew you had a diagnosis. One participant was asked randomly to explain what autism was like and she responded *“I don't know how to explain it because it's different and it's, you know it's just who I am. It's like asking me to explain to somebody how do you experience being a man? (P07)”*. Others just didn't “believe” or judged the accuracy of the diagnosis. *“I told her, I've got Asperger's Syndrome and she said no, no, no, you've got far too much of a sense of humour to be autistic.” P15*

Additionally, many times, these misunderstandings led to misdiagnosis as others were not able to understand these conditions fully, especially in females. For example, one participant's ADHD was diagnosed as post-partum depression while another picking of skin for regulating autism was diagnosed as self-harm. This lack of understanding and stigmas from others led a lot of adults to doubt their conditions. It created a lot of self-doubt and feeling like an imposter. They felt that it looked like it was an excuse for not trying as hard. *“Sometimes I find it hard to accept because I get a lot of people coming up to me and going, you can't be autistic. Am I autistic enough?” P12*

Theme 5- Are you ready? The importance of timing

The final theme highlights the importance of timing and being ready for the diagnosis. While many adults experience the diagnosis positively, a minority do not, often due to not being ready. Age, support and time in life as well as therapists' preparation may affect responses to diagnosis. Adults with autism/ADHD often wonder “What could have been” with a lack of support post-diagnosis strongly reinforcing negative feelings that might arise.

A key concept highlighted primarily by healthcare professionals is the importance of being ready. Timing, where an adult is at, is very important to take into consideration when seeking and giving a diagnosis. If individuals are not ready, the process can lead to a lot of upset, anger and depression. For example, understanding whether somebody is seeking the diagnosis or not is very important.

Preparing the individuals for the potential outcomes is key in managing these risks. *“This is one of the things that I think that ensuring that someone's ready for an assessment is really important. NICE guidelines talk about it. I don't think many private or NHS processes give much focus on preparing or if a child or an adult is ready to see value difference and value difference in themselves.” P105- healthcare professional*

Emotional readiness is also an important concept. This can be understood in where they are in their lives, in terms of environment, big life changes, but also experience and age. Younger adults seemed to accept the diagnosis very differently than older adults, the latter expressing how they felt it had come too late. Even when individuals are seeking the diagnosis, understanding the emotional place individuals are at and whether it is right for them at that point in their lives is key. *“The person even wanting to go down that route, that sort of assessment route, too, because of how they might think about themselves and how other people might think about them. I think the age does make a difference.” P103 – healthcare professional*

With this readiness comes the ability and will to change. Being able to seek support, accept the past and alter some potential unhelpful behaviour can lead to much better outcomes post-diagnosis but is directly linked to this sense of being ready to take on this label. In that sense, the diagnosis could also bring a lot of regret and anger. Only a minority of adults with autism/ADHD reported feelings of anger of what “could have been” and often felt *“a sense of grief or loss in terms of it's taken this long to get to this point and life could be different.”* Especially in older age groups, adults felt like it was too late to change and that they had wasted a lot of opportunities. *“One of the hardest and most awful things is realizing the wasted potential” P08*

“I just see my life as being wasted. Really. I don't particularly enjoy it. I don't particularly enjoy life at all.” P15

Finally, adults with autism/ADHD had mixed feelings about whether they would like to have had the diagnosis sooner. Surprisingly, most felt that it might not have been useful. Many factors impacted this, for instance, cultural changes over the last decades mean that nowadays acceptance and understanding are much more common. But 20-30 years ago, growing up with a label such as autism or ADHD would have not been necessarily as easy. The level of stigmas around these labels might have led to less disclosure, less self-acceptance and potentially more struggles. *“I don't think I'd have been so open and accepting of it if it had come earlier in my life. Because female autism visibility wasn't there. It was still very, you know, not neurodiversity affirming type things in the sense that people were like, if you're autistic, you won't achieve anything, you can't do this [...] I would have*

perhaps rejected the diagnosis rather than, you know, accept it and embody it. Whereas like now I'm very open." P10

Others felt that an earlier diagnosis might not have been useful in terms of the life experiences they had. By struggling through undiagnosed autism/ADHD, some felt that it allowed them to work harder, try harder and experience things that they wouldn't have otherwise. A diagnosis might have led to less effort, not trying as hard as they would, **expecting they** just couldn't do certain things. For example, the risk-taking behaviour of one participant who worked with dangerous reptiles for years would have been more controlled and might have stopped them from succeeding. *"But if I could have ever changed anything, I probably wouldn't have because of having to work that hard to get where I am now. I wouldn't be the person I am now. If it came easy, I probably wouldn't be trying as hard as I do now in my athletic aspects, my school aspects. So, you know, no regrets." P5*

Discussion

Our results reflect the many ways receiving a late diagnosis impacts adults with autism/ADHD from the view of late diagnosed adults and healthcare professionals. The five themes highlighted impacts on mental health and relationships, the importance of understanding through a diagnosis and label, with at times a negative side of this label and finally the importance of being ready for the diagnosis. The last (theme 5) demonstrates a unique facet of diagnosis that has not yet been explored in previous studies. Differences between conditions (autism/ADHD) and stakeholders (late diagnosed adults/healthcare professionals) were expected. However, although each group's data was coded separately, the similarities of their experiences meant data were combined across the groups. This suggests uniformity of the findings between the different stakeholder groups **and the overlap of these two conditions.**^{45,58}

The impact of undiagnosed autism/ADHD on mental health and relationships has been reported in previous studies.^{47,50,59} Legg and colleagues⁵⁹ for instance, reported how new knowledge following a diagnosis of autism **facilitated change in often poor relationships and interactions. Matheson and colleagues⁵⁰ showed that the persistent** sense of failure and missed potential from living with the impact of unsupported ADHD impairment led to an accumulated psychosocial burden and mental health difficulties.⁵⁰ The importance of understanding, psychoeducation and the power held by having a diagnosis and being able to identify your struggles has also been often reported as a key component of the healing process^{22,54} primarily centred around a sense of acceptance and identity. A few of our participants described that their diagnosis allowed a deeper understanding of their mental health difficulties and why they felt like they didn't fit in, access new communities, and help others.⁴⁷ The concept of providing a framework was often mentioned in our interviews which echoes

findings from Lupindo and colleagues⁴⁶ facilitating self-acceptance and positively impacting well-being.

The concept of not fitting in, “pretending to be normal”⁴⁹ or feeling “like an alien”⁴⁸ was often discussed with all participants reporting difficulties in social interactions. While gender was not a theme of this study, the difference between genders was often mentioned by the group of healthcare professionals and how the different gender presentations had different impacts. This echoes Bargiela and colleagues⁴⁹ findings that, especially in females, gender led various professionals to miss their underlying autism and demonstrating an obvious conflict between autism and a traditional feminine identity.

The negative aspects of receiving a diagnosis were primarily centred around stigma associated with the labels of autism/ADHD. Many studies have reported the negative stigmas associated with these labels and the impact this has on access to care,⁶⁰ education⁴⁴ or relationships.⁴³ In our study, these negative experiences were mainly due to other people’s beliefs about these labels. While some participants reported an initial discomfort at times with these labels, this always changed as their understanding grew. However, the response of disclosing your diagnosis to others and their reaction can be negative and upsetting. Similar results were found where many benefits of a diagnosis were experienced as it was necessary to access appropriate support and helpful to acknowledge (and potentially reframe) experiences but could at times be experienced as a curse.⁵³

While many of these themes and negative impacts have been highlighted through different studies,⁴⁶⁻⁴⁸ the positive impact of diagnosis on behaviour and relationships is important.^{53,61,62} The post-diagnosis strategies and small changes that can be made through understanding in terms of communication or decision-making for instance are very impactful. Whether it is communicating differently with peers or families or realising that some relationships might not be healthy, these changes lead to better well-being, fewer mental health difficulties and positive social impacts. A few studies have highlighted similar findings with diagnosis positively impacting quality of life,⁶¹ allowing the creation of supportive environments⁶² and fostering a sense of understanding and belonging.⁵³ This has important implications in terms of support and how this could be used by therapists or peers in implementing change post-diagnosis.

Additionally, the concept of timing and being ready for a diagnosis is also novel. This theme was primarily raised by the group of healthcare professionals who articulated the important notion of timing and preparing families/individuals for the diagnosis. They explained that this was essential in experiencing benefits from the process. While only a minority of individuals experience receiving a diagnosis negatively, they explained that this was mainly due to not being ready, not being prepared

for it. As one the many benefits of a diagnosis is being able to implement change through understanding, this is not possible if the diagnosis is rejected. Only a couple of participants reported these negative impacts, and they were both close to retirement, with the negative impact mainly being the loss of time. They wondered what could have been and felt that it was too late to change which created a lot of resentment. Participants also discussed timing in terms of how they felt that awareness of autism/ADHD had improved over time, with less stigma attached to these labels now than in previous decades. This meant that for some participants, they felt that their diagnosis had come at the best time for them and might have led to increased problems and loss of opportunities if they had perhaps been diagnosed earlier on in their life.

Strengths and limitations

This study has many strengths in its methodology and results. Firstly, to our knowledge, it is the first study which looks at the experience of late diagnosis of autism/ADHD together. Most studies focus on one condition but the commonalities between the experiences are so significant that it makes sense to not limit the sample to a specific diagnosis. This allows for the broader impact of neurodevelopmental conditions to be discussed. Secondly, by capturing both testimonies of service users and healthcare professionals, this study allows different viewpoints to be triangulated, reflecting a more comprehensive view of the diagnostic process and experiences compared to previous studies. The healthcare professionals' accounts allowed us to capture a broader range of experiences through their years of supporting adults through an autism/ADHD diagnosis. Finally, this study reveals intricate difficulties with having undiagnosed autism/ADHD and the experience of a diagnosis that can be very useful for future research but also clinical care. For instance, the significant impact that living with undiagnosed autism/ADHD has on relationships and mental well-being is extremely important for supporting these groups in clinical settings. Every participant stated the significant impact of late diagnosis on their mental well-being, ranging from depression, lower self-esteem or suicide attempts. In terms of research, future studies could further investigate the emerging concept of timing and being ready and its impact on the individuals' reaction to diagnosis.

One of the limitations of this study is the lack of representation from other groups such as families or partners. While we would have liked to include another group reflecting the views of partners and/or family members, we were unable to recruit other groups within the scope of this study due to time and resource constraints. However, this would have allowed for a more external view of the experiences of the diagnosis that might reflect insight not noticed by service users or healthcare professionals.

Conclusion

This study highlights the many benefits and importance of receiving a diagnosis of autism/ADHD and the impact it has on multiple aspects of life such as mental well-being and relationships. The concept of being able to understand why you are different and why you might struggle at times was key in helping participants make positive changes in their lives. While a few negative impacts were noted, the positive impact of diagnosis on healthier behaviour and relationships is an important novel aspect that has many implications. **Being ready and the timing of the diagnosis are also essential in experiencing any benefits post-diagnosis.** We recommend that clinicians and service users familiarise themselves with the many impacts of receiving a diagnosis. Clinicians should consider the readiness of the adults seeking a diagnosis and prepare them for the potential negative reactions this might have. Service users can also often see a diagnosis as an end goal, an answer to years of struggle. However, the journey post-diagnosis is very tumultuous and can bring conflicting emotions and insight which are important to understand. This study is the first of its kind looking at autism/ADHD together and the similarity in experiences regardless of the label.

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Conflict of interest

Dr French reports personal fees and nonfinancial support from Takeda and Medice. Dr Cassidy reports no conflicts of interest.

Author contribution

BF wrote the manuscript and SC revised it. BF and SC have developed the study together. BF conducted the analysis which was reviewed, checked and confirmed by SC.

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