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“I was exhausted trying to figure it out”: the experiences of females receiving an autism
diagnosis in middle to late adulthood

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Running title: Experiences of late diagnosed autistic females

Abstract

Females often receive Autism Spectrum Condition (ASC) diagnoses later than males, leaving needs misunderstood. This study aimed to explore the lived experiences of female adults diagnosed with an ASC in middle to late adulthood. Eleven autistic females diagnosed over the age of forty years completed semi-structured interviews, analysed using Interpretative Phenomenological Analysis (IPA). Four superordinate themes emerged: *A hidden condition* (pretending to be normal and fitting in; mental health and mislabelling); *The process of acceptance* (initial reactions and search for understanding; re-living life through a new lens); *The impact of others post-diagnosis* (initial reactions; stereotyped assumptions); *A new identity on the autism spectrum* (negotiating relationships, connections and community; changing well-being and views of the self; the meaning of diagnosis). Findings highlight several factors not previously identified that affect late diagnosis in females, including widespread limited understandings of others. Diagnosis was experienced by several participants as facilitating transition from being self-critical to self-compassionate, coupled with an increased sense of agency. Participants experienced a change in identity that enabled greater acceptance and understanding of the self. However, this was painful to adjust to at such a late stage.

Keywords

Autistic female; middle to late adulthood; autism diagnosis; Interpretative Phenomenological Analysis

Introduction

Receiving a diagnosis on the autism spectrum is an important milestone in an individual's life. However, the diagnostic process can be experienced as challenging and arduous (Crane et al., 2018). A recent survey indicated that less than half of adults receiving an autism diagnosis in the UK were either "very" or "quite" satisfied with the process (Jones et al., 2014). Diagnosis typically occurs later for females compared to males, particularly for females who are of average to above average intellectual ability (Begeer et al., 2013; Siklos & Kerns, 2007). Understanding gender differences and lifespan issues have been identified as priority areas for research by autistic adults (Pellicano et al., 2014). Work on understanding the experience of being autistic has been emerging in recent years (see DePape & Lindsay, 2016 for a review) though to date, there has been little research that specifically focuses on older females. Hence, their experiences and needs are not currently well understood.

There is strong evidence that the experience of being autistic differs between males and females (Gould, 2017; Lai & Baron-Cohen, 2015). Approximately three times more males than females are currently diagnosed (Loomes et al., 2017). It has been suggested that there is potential for females to be underdiagnosed based on traditional assessments (Knickmeyer et al., 2008; Rynkiewicz et al., 2016). It is problematic that knowledge and conceptualisations of Autism Spectrum Conditions (ASC) are largely derived from male samples (Gould & Ashton-Smith, 2011; Kreiser & White, 2014; Mandy et al., 2012) and there is emerging evidence that females are more likely to 'internalise' their difficulties, presenting as anxious, passive, depressed or with eating difficulties (Attwood, 2007; Mandy et al., 2012). Furthermore, females often use compensatory strategies to 'mask' or 'camouflage' their difficulties (Hull et al., 2017; Tierney et al., 2016), allowing them to 'blend in' to social situations with hypothesised functions including aiming to reduce shame or bullying and attempting to cope with the

social world (Bargiela et al., 2016). This can take significant cognitive and emotional effort and impact negatively on mental health (Bargiela et al., 2016) particularly if camouflaging is engaged in across multiple contexts or if an individual is engaged in switching between camouflaging in some contexts but not in others (Cage & Troxell-Whitman, in press). Thus, based on historical understandings of ASC, the needs of females are often difficult to recognise and may appear subtle, or not prototypically autistic, to GPs and educators who are responsible for referring individuals for assessment.

Despite recent increased interest in reporting the experience of autistic adults, to date there has been very little research specifically on aging and autism (Happé & Charlton, 2012). Of the research that has focused on middle to late adulthood, studies have included adult participants who received a diagnosis in childhood or early adulthood (e.g. Griffith et al. 2011), have mostly focused on males (Hickey et al., 2018; Elichaooff, 2015; Punshon et al., 2009) or have not discussed gender as a factor (Lewis, 2016). Thus, there remains a scarcity of research that investigates the specific experiences of adult females, especially those in middle and later adulthood. In adult ASC diagnostic services, the gender ratio is lower (approximately two males to one female) than in child services up to 11 years (approximately five males to one female) suggesting that females tend to be missed earlier in life (Rutherford et al. 2016). Therefore, focusing research on older females will likely lead to improved understanding of a more representative sample of autistic females than observed in research solely investigating younger age groups.

Two recent studies have begun to address the gap in understanding of the adult female experience of diagnosis. An online study by Lewis (2017) demonstrated that females receiving a diagnosis of ASC in adulthood reported significantly more severe barriers to diagnosis than males. The nature of barriers experienced were broad ranging

with “concern that I will be evaluated but will not be diagnosed with ASD because of my gender”, “difficulty finding an ASD specialist who also specializes in my gender” and “concern that I will be told I am ‘making up’ symptoms” demonstrating the largest difference in mean severity between males and females. The prevalence of these issues is concerning and indicates that, currently, autistic women feel misunderstood. Bargiela et al. (2016) investigated the experiences of adult females diagnosed between nineteen and thirty, noting that late-diagnosed women tend to express elements of the female autism phenotype that are under-represented in samples of those identified in a timely fashion, thus providing insight into how such characteristics led them to being missed by clinical services earlier in life. The females in Bargiela et al.’s (2016) study described misunderstood needs and ongoing mental health difficulties and findings suggested camouflaging behaviours, internalising and stereotyped understandings influencing later diagnosis. However, to date, no qualitative interview studies have specifically focused on the experiences of females receiving their diagnosis in middle to late adulthood. Given what is known about the likelihood that females’ needs are under recognised (Gould, 2017) and their support needs often misunderstood and misattributed to different diagnoses (Attwood, 2007; Eaton, 2018), a comprehensive understanding of the experience of older autistic females is needed. Thus, the goal of the current study is to better understand the lived experience of autistic females who receive a diagnosis in middle to late adulthood.

Method

Methodological approach

This study employed a qualitative design, using Interpretative Phenomenological Analysis (IPA) with semi-structured interviews. IPA studies enable focus on subjective accounts of specific lived experiences of the individual, and how individuals respond to

and interpret these experiences (e.g. Macleod et al., 2016; Pietkiewicz & Smith, 2014; Smith et al., 2009). Data is analysed via an in depth iterative process where the researcher engages in a ‘double hermeneutic’ process, making sense of how individuals make sense of their world. The analytic process is designed to give a voice to individual participants, by providing an interpretative account of their experiences in their unique context (Larkin & Thompson, 2012; Larkin et al., 2006; Smith et al., 2009). Ethical approval was obtained via the Integrated Research Application System (IRAS, 218102) and from Sheffield Health and Social Care NHS Foundation Trust for governance.

Participants

Participants were 11 female adults who had received an ASC diagnosis at or over the age of 40 years. Recruitment was via a local NHS diagnostic service. Participants were excluded from taking part in the study if they lacked capacity to provide consent; were born male (i.e. individuals were not included if they had transitioned from male to female); did not identify as female; were unable to speak English. See Table 1 for demographic information.

Procedure

Three autistic adults were consulted via the local NHS diagnostic service when developing the interview schedule. The main adaptations based on these discussions related to prompts to support understanding. Participants were interviewed in person by the first author. The interview schedule was developed based on the aims of the project and in line with methodological guidance (Larkin & Thompson, 2012; Smith et al., 2009). Previous research findings and interview questions from Punshon et al. (2009) were used to support this development. The main interview questions are listed in Table 2. Interviews lasted between 35 and 95 minutes. Participants were debriefed at the end of each interview.

Analysis

Following each interview, notes were made by the interviewer to consider non-verbal interactions, emotions, and personal thoughts as part of the researcher reflexivity process. These notes were referred to when undertaking the analysis to ensure the results were drawn from the data and to support transparency. The interviews were transcribed verbatim. Transcripts were read alongside recordings and initial ideas noted down 'line by line' on the transcript in the right hand margin. Notes focused on linguistic processes, conceptual ideas and descriptive comments made by participants. Next, tentative emerging themes were noted in the left hand margin of each transcript. Then, themes were grouped together with the use of notes and conceptual maps, based on their characteristics and given initial codes for all transcripts. Data was analysed as a whole by exploring overlapping themes, concepts, exceptions and clustering themes alongside theory and literature. This continued until a list of overarching 'superordinate' and subthemes were developed. The contribution of participants to each theme was recorded. An independent audit of each stage of the analytic process was conducted on three of the transcripts by a peer to ensure a high standard of rigor.

Results

Analysis of the data produced four superordinate themes, along with sub-themes. These are specified in Table 3. and discussed below. All participant names are pseudonyms used to maintain anonymity. Some quotes have been edited to support clarity for the reader and missing data is represented by the use of '....'. Additional explanations of points are included within '[]'.

Theme 1 - A hidden condition

This superordinate theme considers the hidden nature of ASC in females, including attempts to make sense of themselves in a world comprised of a myriad of 'norms' and expectations.

*Pretending to be 'normal'*¹ and fitting in. Efforts to 'fit in' were influenced by several factors, including confusing social interaction attempts and perceived failures. For some, 'unsuccessful' connections led to internalised beliefs that they were "wrong" "broken" or "bad" (Alice, Olivia, Lily). This appeared to relate to a need for acceptance that at times was so strong, some participants took on a persona that was ego dystonic in order to fit in:

"...it started at school and it went on to college as well....[I wore] different clothes to everything that I wore at home...., I hated this person that I put on."(Hannah)

Women had several motivations for disguising their true selves. These included attempts to develop relationships. For others, the aim was to blend in and not appear 'different':

"I never felt like I fitted in anywhere....other people just seemed so – like their lives have always seemed much easier....they've just seemed to do things without the whole thought process that I have to go through."(Ruby)

Strategies were developed to try to cope in a social world. Some appeared to be unconscious or less deliberate. Others were practised with the aim of learning social rules and appearing 'normal' when making comparative evaluations to people who appeared to be part of the social norm or 'in-group'. These strategies were effortful and sometimes avoidance of social contact was reported as being a preferable strategy. For many, pre-diagnosis, hiding or mimicking served a survival function. However, the consequences of doing so were complex, with some feeling deeply unhappy and exhausted. In part, this was due to many attempts not appearing successful, leaving participants feeling on the periphery despite considerable efforts.

¹ Use of the word 'normal' by some participants refers to 'neurotypical' or non-autistic people

Mental health and mislabelling. Experiences of mental health difficulties were expressed and, for some, this was associated with complex family histories, trauma, struggling in school, and bullying. Participants often reported that their experience was not understood by professionals. Lily described seeking support within mental health services leading to several diagnoses which did not explain her experiences. Failure to find an appropriate understanding or formulation added to the sense of confusion. This appeared to factor in her exhaustion with life, and attempts to end her life:

“[Clinician] would say ‘oh, you’ve got borderline personality disorder’I explained to him exactly why I wasn’t BPD....I wasn’t getting any answers, I just stopped going. I just stopped asking for help, I just stopped, you know, looking for answers.”(Lily)

“I was exhausted trying to figure it out....why things were so different for me, and....by the time I had got to that diagnosis, I was already half dead, I was already in a functioning depressed state.”(Lily)

Participants described not only significant ongoing battles with their mental health, but this being entwined with a battle to understand themselves. Within their descriptions is an implied power imbalance where labels were enforced upon them. When receiving (non-autistic) diagnoses, some described self-doubt, struggling to trust their own judgements even when they knew the suggested diagnoses did not adequately describe or help them:

“....got to a point where I was almost convinced that they wanted to be right and I’d actually buried some deep trauma and I had no memory of it and I started questioning the whole – like everything.”(Mia)

As well as resulting in missed support opportunities and misattributed blame, participants’ experiences likely resulted in ongoing confusion about identity. Many appeared to have internalised unhelpful messages, leading to a devalued sense of self

and strongly held beliefs of being fundamentally “*mental*” (Kate) “*wrong*” (Alice, Olivia, Celia) or “*defective*” (Lily, Alice, Mia).

Theme 2 - The process of acceptance

This superordinate theme describes participants making sense of their diagnosis, grieving and adjusting, alongside re-experiencing memories with a new understanding.

Initial reactions and search for understanding. The experience of the diagnostic process was described. The assessments were often intensely emotional, “*sad*” (Ruby) and even “*harrowing*” (Olivia). Many experienced anxieties about the unexpected and fear that they may receive no further answers. For others, it was painful to re-experience emotions associated with past experiences.

Some had spent a long time considering what the outcome may be and their initial reactions acted as confirmation about what they had been researching pre-diagnosis, providing a sense of relief, calm and validation. For some, this was coupled with a sense of “*vindication*” (Alice), that experiences they were ashamed of could be explained. The relief described across the data included a “*eureka*” (Lily) moment for some, a realisation that diagnosis allowed them to end the arduous search to understand how they experienced the world.

Some described conflicting feelings initially. One, of relief and at times, “*elation*” (Olivia). But also frustrations about what this might mean for their sense of identity and the potential for diagnosis to be limiting forced them to question themselves:

“....I thought ‘am I just anything other than these symptoms?’ Um, that really upset me....I sort of started doubting my ability to do my job.”(Celia)

For Elizabeth, one of the more difficult emotions was a feeling of shame:

“....kind of ashamed of myself because I was like ‘oh, this isn’t a nice thing, because it’s happened at a late age.’”

Her description suggests a fear about what being diagnosed at her age might mean. This may be exacerbated by the fact that, being autistic was never something she had considered and seeking a diagnosis was instigated by others. Thus, receiving a diagnosis required a significant shift to a new way of thinking about who she now was.

For many, the diagnosis created a springboard for learning and understanding with several participants describing an active process of researching what autism meant for them:

“....I got to work....learning everything I could....reading everything...I know everything there is now, ha, I read everything.”(Lily)

Lily’s description suggests a focused approach. For Olivia, the process of understanding the diagnosis provided her with a sense of purpose and possibly control over developing a new understanding of herself in the world:

“....it gave me a sense of purpose, it was.... ‘that’s why I don’t understand all of this, now I can go and research why I don’t understand that.’ And there was that sense of something new and something new to research.”

Alongside researching, some found connecting with others helped to develop their understanding. This included accessing groups with other autistic adults. For years, the understanding of the self had been limited and at times negatively prescribed by others. Research and connections provided concrete information participants could relate to and autonomy in this meaning making process.

Reliving life through a new lens. Several participants described a process of looking back, reliving their lives with a new perspective after diagnosis. For many, this happened almost instantly and for others, continued several years later. The metaphorical lens that participants had previously viewed their lives through had been coloured in part by the fact that they did not understand their experiences. Some participants described reliving past experiences as a process that was somewhat out of

the conscious awareness in a way that took them back to that time and magnified those memories:

“...your life flashes before your eyes....thousands of memories coming back, constantly of ‘oh, I remember when this happened....that’s why I had a meltdown and couldn’t understand why.’”(Alice)

In the moment, a different understanding of themselves had likely shaped participants’ reactions to those experiences and to how they thought of themselves in the social world. To experience this and to describe it during the interview was emotional for several participants:

“It’s good....at least now I understand why I’ve felt the way I have a lot of the time and why I’ve been the way I am a lot of the time as well. Sorry, it’s making me really emotional.”(Ruby)

Although these revelations in light of diagnosis felt positive, both quotes suggest a sadness and pain associated with not having these understandings earlier. With those, these life experiences may have been more manageable and provided answers to things that in the moment were confusing and at times devastating.

For some participants, reliving the past allowed them to shape interpretations and of others in the present:

“....taking my daughter to clinics...I’d say, ‘I think it’s because of this’ and I’d explain round it and they’d be like, ‘wow, oh, that’s really interesting and I think that you’re absolutely right’.”(Hannah)

For Hannah, reflecting on her childhood helped her to express to professionals what her daughter (also autistic) may be experiencing. Hannah was experiencing an ongoing battle for her needs to be recognised by certain services. Feeling powerless, increasing the knowledge of others allowed her to elicit some control over how her daughter was interpreted and supported.

Grief and reflections on the past. Although the expression of grief was unique to each participant, the experience included several common emotional elements.

Many participants explicitly referenced their experience post-diagnosis including a grieving process. Most portrayed a sense of sadness for their pre-diagnosis self and the significant struggles which may have been easier had their needs been understood:

“.... I felt really bad for myself as a child....blaming myself for things....not being good enough....or being slow and not like everybody else.”(Hannah)

“....to think that’s how that child was treated. It’s really sad.”(Ruby)

Some described current feelings of “*anger*” (Marie) that their difficulties were not understood earlier. For Elizabeth, learning that others had suspected she was autistic, exacerbated this anger about what might have been with an earlier understanding:

“[she said] ‘I always kind of thought you might have autism.’ And I didn’t say to her, but I thought, so why didn’t you do anything?”

Many participants felt that through learning and understanding what autism meant for them, and through new experiences, they had moved overall to a place of self-acceptance. However, grief was a fluid and ever changing process including many experiencing fluctuations in mood and periods of loss and fear about the lifelong nature of autism:

“.... you sort of realise that you’re stuck like this forever really, so that’s a bit....It’s a bit overwhelming....I’m going to struggle with things for the rest of my life, that’s hard.”(Celia)

Theme 3 - The impact of others post-diagnosis

This superordinate theme explores participants’ interpersonal experiences post-diagnosis and the impact on their lives in several settings.

Initial reactions of others. Some shared their diagnosis immediately, while others were more cautious about potential reactions. Some had positive experiences,

leading to a feeling of gratefulness about being finally accepted for who they are. This included continuing to be treated as individuals by the important people in their lives.

For others, this highlighted a contrast to their earlier experiences:

“....blessed to have such lovely people around....care enough about me not to be bothered by my weird quirks and funny ways....It makes a change after years of bullying and being penalised for being odd.”(Merrell)

For some, an openness of important others to understand what it meant for them to be autistic provided opportunities to develop communication. For Celia, this allowed for positive relationship changes as her husband became more attuned to her needs:

“....he got really into researching it....it's really improved our relationship because he's realised now that a lot of the arguments we had were me misunderstanding what he'd said and him misunderstanding how I'd reacted.”

In contrast, some participants found others being unsure what to do with the information or feeling let down by unhelpful and “patronising” reactions (Olivia, Marie). Mia's ex partner's approach had the potential to leave her feeling self-conscious or that her behaviour somehow needed modifying to meet the societal ideal:

“....if he considered I was talking too much if we were with other people he would like kick me to tell me to shut up....I just found it difficult.”

For Ruby, she felt most supported and validated by others online, or by her work colleagues. However, she experienced family members as dismissive with them not appearing to recognise the magnitude of what it meant to receive the diagnosis:

“....I just expected him [husband] to say something....or realise how massive this was for me and he didn't for ages, and about two weeks later I just said, 'look, this is huge for me....to you I'm no different, but to me I'm completely different'.”

Elizabeth received several helpful and positive reactions. However, she described an ongoing fear of disclosing. Some reactions highlighted the potential for invalidation, leading her to be selective when seeking support:

“....when I told my dad....he was.... ‘You don’t have autism, you’re perfect. There’s nothing wrong with you.’he thinks I’m his perfect little girl....who’s got nothing wrong with her, so I can’t talk to him about if I’ve had a bad day.”

The narrative, of being ‘perfect’ suggests a neurotypical ideal with the implied opposite being ‘imperfect’ and autistic. It is possible that this message contributed to the difficulty Elizabeth described with integrating autism as a part of her identity and fear of judgement.

Stereotyped assumptions. For many, the aforementioned need to ‘mask’ or develop a persona changed post-diagnosis. However, some participants experienced inner conflicts, wanting to show their true selves, but being fearful of reactions. For some, stereotyped assumptions about ASC, likely based on pre-existing schema led to frustrations about meeting the expectations of others:

“....it makes me a little bit cross, that they think I should fit into some sort of stereotype. Sometimes I feel that I’m letting them down because I don’t act how they think I should do!”(Celia)

Some transitioned from a psychological position of seeking to hide their true selves to feeling invisible and dismissed, fighting for their true needs to be recognised (for example, in the benefits system). Some postulated that the amount of effort placed on previously camouflaging their behaviours directly affected how they were viewed post-diagnosis:

“....anyone who’s got to middle age with undiagnosed autism has had to basically do Olympic level training in how to be a normal person....[when I]

appear sort of normal, that is because of the years of actual effort that I've put into it."(Alice)

Several participants experienced tailored and helpful support, with many describing supportive adaptations at work. However, some had continuing battles for these adaptations to be made. Others volunteered to offer training within their workplaces to add to knowledge.

Some experienced the diagnosis limiting the options for support that was individualised as people made assumptions about how they fit into a label based category. At times, this included a loss of mental health support. For Marie, this approach to supporting her in college felt oppressive and narrow in its view of who she is as an individual:

"Just stop looking at that damn word; that damn word doesn't make me, me."

Theme 4 - A new identity on the autism spectrum

This superordinate theme describes participants navigating relationships and changing relationships, alongside an ongoing process to understand how autism relates to who they are.

Negotiating relationships, connections and community. Many participants described ongoing changes in relationships post-diagnosis. Some included familial relationships and old friendships evolving supportively in light of new understandings:

"...he'll [husband] now take the lead in situations where he knows I'm not comfortable, whereas before he just thought I was being awkward."(Celia)

Others made life-changing relational decisions. Previously stuck in a passive position based on others' expectations of her as a woman, Lily took control and ended the relationship with her husband. Some had experiences where they recognised friendships that weren't supportive:

“...the implication....I was automatically wrong, because I had this Asperger’s thing....So that was unexpected, and I had to walk away.”(Alice)

“...one person that I talk in confidence to....and they treat me the same as everybody else. The people that have ignored me I don’t want to know.”(Kate)

The ability to make these changes signified a newfound confidence to live shaped by their values. It represented a parallel ‘letting go’ of an old life, pre-diagnosis, one where they no longer needed to assimilate to meet the social norm.

Descriptions suggest an intrinsic need for belonging, where participants found positives and validation in relating to others and recognising strengths, many of whom found friendships ‘offline’ difficult. For some, they found a shared value and identity, contrasting with past self-beliefs, and at times devaluation by others:

“I’ve never fitted in that jigsaw puzzle....[now]I fit somewhere, I belong somewhere with other people somewhere who are like me. Yes, it’s good.”(Ruby)

Conversely, Elizabeth, engaged in ongoing camouflaging behaviours:

“I won’t always tell him [husband] that I don’t understand, to make it less embarrassing, but then obviously that makes things ten times worse....”

The description suggests a belief that accepting support from others may mean accepting she is autistic, something she is not ready to do. In not doing so, she recognises this contributing to relational difficulties.

Changing wellbeing and views of the self. Diagnosis and new understandings provided many with the opportunity to let go of blame. Recognition that it was ok to be who they were rather than meet some idealised version of the self was freeing:

“I feel free, very much more free.”(Lily)

Many described ongoing anxiety and depression. However, others reported that adaptations they were able to make in their life meant that they experienced much less distress than previously:

“I don’t get as much anxiety as I used to.... because I’ve got better understanding of – and because I understand it better I’m actually able to deal with it better....So I build strategies around that really.”(Merrell)

Some, knowing mental health difficulties were still a fluctuating part of their lives, described finding ways to proactively develop “*coping mechanisms*” (Alice, Celia) to reduce the likelihood of becoming overwhelmed, experiencing elevated anxiety or “*going into crisis*” (Lily). This included managing social situations by doing the things that they could cope with and letting go of associated guilt. Descriptions suggest a newfound permission for participants to meet their own needs and a developing identity as someone who no longer needed to conform to be acceptable:

“I feel a lot better about myself....I can be happier being myself, rather than trying to fix myself and change myself and fit in.”(Ruby)

Many were kinder to themselves, signifying a progression from self-criticism to self-compassion:

“....to understand where those difficulties and stresses are coming from makes a difference in terms of how I think about myself.”(Mia)

This extended to engaging in soothing, often practical and enjoyable self-care activities, such as art, communicating online, spa days, learning and gardening.

The meaning of diagnosis. A minority of participants struggled to find overall value in the diagnosis whilst struggling with acceptance. However, others described it meaning “*everything*” (Lily, Ruby). Elaborations focused on newfound confidence to trust their own judgements, having a voice in society and recognising their contributions as valid and important:

“...other people have been telling you for years you’re wrong; now I trust that gut instinct because I know that I’m a grown woman and I know who I am now. So, it’s more powerful.”(Lily)

For some, the fact that their experiences could be explained was a novel thing, having lived for so many years searching for understanding:

“...it means there is a logical reason for my irrational behaviour and I like that, I like there to be a reason for everything....I can prepare myself better”(Celia)

The understanding was of profound importance, allowing several participants to make sense of a part of their “*identity*” (Hannah), one that identified part of who they were and provided a “*framework*” (Mia) for learning and improving their wellbeing. This extended to feeling there was power, strength and pride in diagnosis. Many experienced a changing view of themselves in society, one that was ‘different’ to some, but that difference was in fact neurodiversity and something to celebrate. Alongside pride participants felt in being individuals, some also recognised the resilience they had drawn from to overcome so much pre-diagnosis, a strength that they felt able to capitalise on with the support of diagnosis:

“...I’ve overcome so many things in my life, because of my inner strength....now I feel even more powerful now that I’ve got my diagnosis to back me up and to push me along to be even stronger still.”(Ruby)

Discussion

This study aimed to investigate the lived experiences of females being diagnosed autistic in middle to late adulthood using a qualitative interview methodology, Interpretative Phenomenological Analysis (IPA). The analysis revealed four superordinate themes: *A hidden condition; The process of acceptance; The impact of*

others post-diagnosis; A new identity on the autism spectrum. The themes are discussed below to consider how the current study relates to and extends existing knowledge.

Consistent with previous theorising, many participants referred to ‘camouflaging’ their characteristics (Bargiela et al., 2016; Hull et al., 2017). This was motivated by a desire to ‘fit in’, to navigate social relationships and to behave as they ‘should’ by societal standards. These attempts to cope often exacerbated difficulties with mental health, consistent with previous literature (Cage et al., 2017). In the current study, the need for acceptance into the social ‘in-group’ pre-diagnosis was evident. Awareness of remaining on the periphery despite significant effort was intensely distressing. Consequently, several women developed an internalised view that they were intrinsically flawed.

Mental health difficulties were present across the data, with many still specifically experiencing anxiety and low mood post-diagnosis. Some had been frequently mislabelled and misdiagnosed, consistent with previous findings (Bargiela et al., 2016; Eaton, 2018). For some, mental health struggles included past suicide attempts and self-harm. One influence on declining mental health pre-diagnosis was the lack of agency women had in understanding themselves, something these women had lived with for many years. This extends the current literature by highlighting that misdiagnosis and mislabelling was not only about a lack of understanding of autistic females across services, rather it also related to power issues where others made overarching statements about who participants were. Female struggles with empowerment are evident in many domains and societal dimensions (Ballon & Yalonetzky, 2018). In the current study, it was evident that participants experienced feelings of disempowerment whilst trying to understand themselves in a confusing world that exacerbated self-doubt, shame and negative self-image. The issue of power imbalance between healthcare professionals and patients and service users hinders

shared decision making in clinical settings (Joseph-Williams et al., 2014). It is also an issue that can emerge between participants and researchers (Kitchin, 2000). One way to reduce the effects is for individuals to be involved in the development of research and services via a participatory model (Fletcher-Watson et al., in press), thus the balance of power can be shifted more towards a needs based model of research and service provision.

Several participants expressed relief post-diagnosis. For some, this included a sense of “vindication” reducing long-standing shame associated with social misunderstandings. Others feared what diagnosis may mean for them, particularly at this stage of life. For many, diagnosis gave women the opportunity to commence a meaning making process, as seen in previous findings (Baldwin & Costley, 2016). The current study provides more insight into this process. For many, this was the initial step in regaining control of self-understanding.

Many participants reflected back on their life, both during assessment and post-diagnosis, as reported in previous literature (Hickey et al., 2018). It was painful to interpret life experiences in a new light, one where they were not to blame. For some, this included fear about the reality of ASC diagnosis. However, for many, expression of grief related to the intense pain for all they had previously endured, leading to ‘loss’ of a life where they were understood by themselves and others. Thus, increasing self-acceptance highlighted the sense of pain of what they had endured. Some found this grief complicated to process, leaving them ‘stuck’ in a place of despair about how things could have been different.

Many participants experienced supportive reactions and adaptations post-diagnosis. The study highlighted the importance of reactions that were validating and provided opportunities for relationship development. Post-diagnosis, some participants recognised that camouflaging had unintentional consequences, with females being able

to function ‘successfully’ in certain situations, leading to ongoing unrecognised needs, as seen in findings by Tint & Weiss (2017). Additionally, previously held schemas of others about ASC potentially contributed to difficulties, including lost benefits and battles for support. This appears to be specific to the experience of females, with their presentation not fitting previously male conceptualisations of ASC. Stereotyped understandings of ASC will likely increase the likelihood that females will not be referred for diagnoses in childhood (Dworzynski et al., 2012). A further problem caused by others’ misunderstandings and use of stereotypes, as highlighted by Treweek et al. (in press), is that this leads to negative consequences for autistic individuals, such as prejudiced behaviour and bullying. Given the amount of emotional distress experienced by women, this study emphasises the importance of developing an understanding of ASC in females across educational, governmental and employment settings to reduce the likelihood of women enduring the same.

Previous findings suggest those viewing ASC as a form of ‘neurodiversity’ positively relate it to the self (Kapp et al., 2013). Thus, unhelpful narratives experienced by two participants post-diagnosis may have partly influenced difficulties they experienced integrating diagnosis into their identity. Diagnosis in middle to late adulthood likely also shaped this experience. Participants had experienced many significant life-stages without a diagnosis. For several women, the prospect of a ‘new life’ at this age was psychologically daunting to contemplate.

Participants described changing relationships post-diagnosis. Some found comfort in identifying with others within the female autism community, suggesting, for some, a pull for relating and group membership. Previous findings indicate a sense of belonging to be of value to autistic women (Bargiela et al., 2016). Some still found social experiences difficult, but many found ways to navigate relationships, letting go of guilt associated with meeting their own needs. Several participants found power in

diagnosis, relinquishing the need to assimilate to the societal norm, allowing them more choice in the trajectory of relationships. For many, this process took time. However, for several women, the diagnosis provided a sense of permission to develop an identity where they were acceptable as they were. This study extends previous understandings about what diagnosis can mean to individuals. For many, this signified transitions to a place of self-compassion which was proactively nurtured by engaging in activities consistent with their needs. Some also experienced a sense of pride in being an autistic female, emphasised by newfound beliefs that being 'different' was acceptable.

The themes that emerged from this work dovetail with some themes that have emerged from other recent work aiming to better understand the experience of adulthood for autistic individuals. For example, the extent to which autism is a hidden condition clearly fits with discussion of intentional camouflaging of symptoms in females (Cage & Troxell-Whitman, in press; Tierney et al., 2016; Hull et al., 2017). The process of acceptance that the participants in the current study were going through echoed some experiences reported by autistic adult females by Milner et al. (in press). The themes of interpretation of self and self-identity were also described by a much broader group of autistic adults reported by Tan (2018). Further, participants in the Tan (2018) study also discussed the benefits of finding a new community which was along similar lines to the points made by participants in the current study on finding a new identity on the autism spectrum. Finally, discussions around the impact of others and struggling with the stereotyped assumptions that were often made, was aligned with the findings of Treweek et al. (in press) who observed that autistic adults felt that misunderstanding of autism by others had negative effects and consequences for them as individuals.

It is important to recognise that IPA studies have some inherent differences to other methodologies. IPA studies do not seek to be produce generalizable results, rather

findings from IPA studies are deemed to have potential relevance to other similar contexts as judged by the reader (Larkin & Thompson, 2012). Now that this study has produced detailed themes, further research would be required to examine the extent to which these might be generalizable. A survey-type study, potentially administered online, using a combination of quantitative and qualitative questioning could be one approach to do this.

An important issue to be considered in the transferability of the findings is consideration is that in the current sample, some individuals were recently diagnosed and others were diagnosed up to nine years previously, hence time since diagnosis could have had an impact on the nature of responses. Future research may wish to consider experiences at additional time points post-diagnosis in order to understand the progression of adjustment experiences. It was clear from the interviews that participants in the current study did not feel that their needs had been met by services and this had resulted in negative consequences. It is important that future research establishes how services should be improved and where the gaps in knowledge are of individuals who work in these services in order that the needs of autistic adults are met. We anticipate that a participatory approach (Fletcher-Watson et al., in press) would be optimal in order that services can be tested on, and improved in relation to, the factors that are most important to autistic individuals. Here we considered the experiences solely of women who received a diagnosis on the autism spectrum in middle to late adulthood who were able to engage in a spoken face-to-face semi-structured interview. This decision was to ensure a degree of homogeneity in our sample, as is required for IPA studies. However, it will also be important to consider the experiences of less cognitively able individuals, by using more flexible methodologies, and other genders in order that their experiences can also be understood. This is particularly important as being diagnosed in middle to late adulthood is becoming increasingly common but this

age group is currently very under-represented in terms of the published autism research literature.

Implications for clinical practice of the present study should be considered. While a minority of participants in the current study were struggling to find value in their diagnosis, others described it as meaning “everything” indicating the importance of receiving an autism diagnosis for many, even though they had already lived so many of their adult years without being diagnosed autistic. There were many participant reports on experiences of not being understood by professionals and the negative consequences of power imbalances, with the perception being that this was one factor that had contributed to declining mental health. It is therefore vital that clinicians possess a broad, comprehensive and up to date knowledge of autism in order to effectively and flexibly conduct diagnostic assessments and minimise the possibility of mislabelling, which can have severe and enduring consequences. It is important that clinicians do not over rely on the reports of others when considering whether a diagnosis is appropriate, as the participants here reported a high degree of camouflaging, even with very close family members. It will be important that clinicians engage individuals in discussion with regards to disclosure as it was clear from this study that there are a range of possible consequences to consider. Participants reported an ongoing battle for needs to be recognised by certain services indicating their experience was that understanding of autism in professional services is still relatively poor. The process of coming to terms with receiving an autism diagnosis happens over a long period of time. The participants here tended to report experiencing grief and a sense of sadness for their pre-diagnostic self, hence ongoing support will likely be needed as people go through the process of coming to terms with being given an autism diagnosis. Clinicians should consider ways to support autistic women to foster self-compassion due to its value within the sample.

Conclusions

Findings suggest widespread limited understandings of ASC in females, which influenced late diagnosis in the current sample. They also highlight issues of power and control, where autistic females reported times pre-diagnosis of feeling powerless or experiencing power imbalances. Post-diagnosis, participants overall had increased sense of agency, allowing them to take control of and make sense of their own experiences. Pre-diagnosis, participants reported misplaced labels and misdiagnoses being enforced upon them, contributing to ongoing battles with mental health, identity and a devalued sense of self. For many, diagnosis was an incredibly painful process as they re-experienced and grieved such a significant period of life. It is evident that diagnosis achieved in a timely manner would likely alleviate the distressing way life had been experienced by participants in the current study. It is paramount that training for professionals in mental health services, schools and wider agencies takes place to reduce the likelihood of unmet needs taking a significant toll on wellbeing in autistic women, and this should be delivered, at least in part, by those with lived experience. Results emphasise the value of understanding oneself within a diagnostic framework where needs and strengths can be assessed, nurtured and supported.

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Table 1.
Participant demographics

Participant	Age	Age at diagnosis	Diagnosis	Additional current diagnoses	Preferred terminology
1	50	45	AS ^a	ADHD ^d	Asperger's
2	43	40	ASD ^b	ADHD Dyslexia	Autistic
3	53	50	HFA ^c	Dyslexia	Not known
4	43	40	HFA	Epilepsy	Autistic
5	47	40	AS	None	Autistic
6	51	48	AS	PTSD ^e	Aspie ASC
7	64	62	HFA	Learning difficulties	Autistic/Asperger's OTS ^f
8	53	48	AS	Dyspraxia	OTS
9	60	51	AS	ADHD	OTS
10	44	44	ASD	None	Asperger's
11	51	49	ASD	Depression	Autism

Note. ^a = Asperger Syndrome, diagnostic description based on previous diagnostic criteria; ^b = Autism Spectrum Disorder (American Psychiatric Association, 2013); ^c = High Functioning Autism, a term used within the clinical service to describe level of cognitive ability; ^d = Attention Deficit Hyperactivity Disorder; ^e = Post Traumatic Stress Disorder; ^f = on the spectrum.

Table 2.
Interview schedule

Question number	Question wording
1.	What was the exact diagnosis you were given?
2.	What was your experience of receiving the diagnosis? Can you tell me about that day?
3.	How were you with the diagnosis of (insert name the participant uses) in the first 3 weeks after you had received it?
4.	Since that first few weeks, has anything changed?
5.	How has receiving the diagnosis affected your life in any other ways that we have not yet spoken about?
6.	What does the diagnosis mean to you now?
7.	Has receiving the diagnosis affected how you see yourself?
8.	Has receiving the diagnosis of (insert name the participant uses) affected your relationships with other people?
9.	Is there anything else that you feel would be important for me to know about your experience of receiving a diagnosis of (insert name the participant uses)
	The interview was recorded using an encrypted digital audio recorder.

Table 3.

Emergent themes and sub-themes, including the number of participants mentioning each

Theme	Subtheme	Frequency
A hidden condition	Pretending to be 'normal' and fitting in	9
	Mental health and mislabelling	9
The process of acceptance	Initial reactions and search for understanding	11
	Reliving life through a new lens	10
	Grief and reflections on the past	11
Post diagnostic impact of others	Initial reactions of others	11
	Stereotyped assumptions	8
A new identity on the autism spectrum	Negotiating relationships, connections and community	8
	Changing wellbeing and views of the self	10
	The meaning of diagnosis	10