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When the mask comes off

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Title: When the mask comes off: Mothers' experiences of parenting a daughter with autism spectrum condition

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Abstract

There is limited knowledge and research on the experiences of having a daughter with Autism Spectrum Condition (ASC) from a mothers' perspective. This study aims to explore the experiences of mothers' who care for a daughter with ASC, with a particular focus on female ASC presentation. Ten mothers of daughters with ASC took part in a semi-structured interview. Interpretative Phenomenological Analysis was used to analyse the data. Five superordinate themes emerged: 'Girls have autism too', 'She's a chameleon', 'The impact of the diagnosis', 'Impact on mum's, and 'Day to day life'. These findings add to our knowledge of how female ASC presents and of the experiences directly related to being the mother of a daughter with ASC. The findings have implications for clinicians that carry out ASC assessments and provide insights into areas where additional support can be provided to mothers and daughters.

Keywords

autism spectrum condition, mothers, girls, parenting, masking, daughters, interpretative phenomenological analysis

Introduction

Autism Spectrum Condition (ASC) is a neurodevelopmental condition which comprises of a range of core impairments in social interaction and communication, along with repetitive and restricted interests (American Psychiatric Association [APA], 2013; Scottish Intercollegiate Guidelines Network [SIGN], 2016). ASC is heterogeneous and impairments can occur along a continuum from mild to severe and be accompanied by intellectual disability or superior intelligence (Christensen, Braun, Baio, Bilder, Charles et al., 2016). The prevalence of ASC

in the UK is estimated to be between 1-1.7% (Baron-Cohen, Scott, Allison, Williams, Bolton et al., 2009; Russell, Rodgers, Ukoumunne, & Ford, 2014).

Autistic females are currently under identified and recognised in the general population and are often misdiagnosed (Gould & Ashton-Smith, 2011; Kirkovski et al., 2013). Current ASC assessment and diagnostic tools have been developed using predominantly male populations and may lack sensitivity with regards to female specific ASC symptoms. As such, females with ASC are often overlooked due to not meeting diagnostic criteria, thus creating the gender bias visible in epidemiological studies of ASC (Duvekot, van der Ende, Verhulst, Slappendel, van Daalen et al., 2017; Dworynski, Ronald, Bolton, & Happé, 2012; by Loomes, Hull and Mandy, 2017; Ratto, Kenworthy, Yerys, Bascom, Trubanova, et al., 2017). Arguably, theories of ASC, such as the ‘extreme male brain’ theory (Baron-Cohen, 2002), which implies that autism occurs at a lower level in females, further exacerbates the problem around female diagnosis. Despite limited empirical support for such theories that are based on an autistic male framework (Bejerot, Eriksson, Bonde, Carlstrom, Humble et al., 2012) these misconceptions of ‘typical’ autistic behaviours may contribute to the under-diagnosis of females that ultimately impacts health and wellbeing (Dworynski et al, 2012; Young, Oreve, & Speranza, 2018).

Indeed, research investigating gender differences report subtle variations in the presentation of ASC between males and females (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Autistic females are socially motivated to have friends, assimilate with a peer group and have interests more in line with their peers than males, have fewer behavioural issues and reduced ritualistic behaviour and have better coping skills than males (Kirkovski et al. 2013; Mussey, Ginn, & Kilinger, 2017). However, perceived strong social skills may be due to

camouflaging which may mask difficulties experienced in their social environment (Attwood 2006; Mandy, Chilvers, Chowdhury, Salter, Seigal, & Skuse. 2012) leading to later presentation to clinical services (Loomes, et al., (2017).

A major issue that accompanies the later diagnosis of ASC in females is documented experience of a range of mental health difficulties, with eating disorders being the most common (Bargiela et al., 2016). Increased disordered eating and internalising disorders are higher in females, which again may contribute to the difficulties in diagnosing ASC in women (Kirkoski et al., 2013; Solomon, Miller, Taylor, Hindsaw, & Carter, 2012). Often females with ASC describe that symptoms related to ASC are not being noticed, and that they instead received treatment for mental health conditions (Bargiela et al., 2016). This may continue as an issue since females with ASC often report that teachers and professionals lack knowledge of how ASC presents in females (Bargiela et al., 2016). The limited research on female ASC may also result in parents attributing their daughter's difficulties to their parenting skills rather than understanding the behaviour as being linked to ASC (Nevot et al., 2017).

A review of qualitative studies highlights that parents of children with ASC report additional challenges across a range of areas including family life, diagnosis, and support services (DePape & Lindsay, 2014; Ooi, Ong. Jacob, & Khan, 2016). Parents of children with ASC report increased stress, with the core features of ASC cited as being particularly problematic (Gray, 1993; Hayes, & Watson, 2013; Neely-Barnes, Hall, Roberts, & Graff, 2011).

Mothers have been found to have reduced health and wellbeing, experience high levels of stress associated with raising their child and report reduced quality of life compared to fathers, hence there may be differences in the personal experiences of parenting a daughter

with ASC (Koegel, Schreibman, Loos, Dirlich-Wilhelm, et al., 1992; Vasilopoulou, & Nisbet, 2016). Research exploring mothers' experiences of having a daughter with ASC report that mothers describe an increased involvement in their child's daily activities, and report disbelief from others regarding their child's diagnosis and the lack of information about girls with ASC (Cridland et al., 2014; Navot et al., 2017). It is important to find out more about how mothers of daughters with ASC make sense of their experiences from their perspective. This study aims to explore mothers' accounts of their experiences of parenting a daughter with ASC. Therefore, the main research question was, what are mothers' lived experiences of parenting a daughter with ASC, with a specific focus on female ASC presentation and the diagnostic process.

Methods

This study employed a qualitative research design utilising Interpretative Phenomenological Analysis (IPA). The study's main focus was on exploring the lived personal and social experiences of mothers parenting a daughter with ASC, with the aim of gaining meaningful insights and perspectives, making IPA an appropriate methodology (Smith, 1996; Smith & Osborn, 2007). The theoretical underpinnings central to IPA include phenomenology (examining lived experiences), hermeneutics (interpretation by the researcher) and idiography (examining participants experiences in detail). In IPA, the researcher is engaged in a double hermeneutic whereby they attempt to make sense of the participant making sense of their experience, with the aim of gaining meaningful insights and perspectives on the lived experience of the particular social group. IPA acknowledges the researcher's own perspective to contextualise participants' experiences in the context of theory and research in relation to the phenomenon under exploration. The researcher acknowledges his position and that certain prejudices or bias's as a man of a different age group and gender to participants,

may affect the dialogue between this researcher and the participants, and the interpretation of the results.

Participants

Ten mothers of autistic daughters were recruited. Participants ages ranged from 37 to 56 years old (M=45.5). The age range of daughters was between 12 to 18 years old (M=14.6). All daughters received a diagnosis of ASC or a variation (Autism, Asperger's Syndrome) through their local NHS board. Girls received their diagnosis between 4 and 18 years (M=9.6) (see Table 1 for participant demographics). The inclusion criteria were as follows: (1) Mothers' of daughters aged between 12-18 years old, (2) child has a formal diagnosis of ASC, (3) Mothers are the primary caregiver and (4) fluent English speaker. Exclusion criteria were, (1) if the child is currently undergoing an ASC assessment and (2) mothers who have significant mental health difficulties or physical/intellectual disabilities that would affect their recall and communication during interview.

Procedure

Following ethical approval by University of Edinburgh's Health in Social Sciences Research Ethics Committee, the researcher contacted ASC organisations to recruit participants. Organisations advertised the study via their mailing lists and social media accounts. Following participants contacting the researcher, a meeting was arranged to collect data by face-to-face or Skype interview.

[Insert Table 1 here]

Consent was obtained in written format via a consent form. Participants completed a short demographic form prior to the interview commencing and background information about their child was also collected. Information on socioeconomic status and educational level

was not collected. It is not known whether daughters were consulted by their mothers to take part in the study. However, the emphasis of the research focused on mothers' own experiences and not daughters' experiences or perspectives, and their respect for privacy was adhered to. It is hoped that mothers' voices and experiences will provide value to this area, and add to the literature around awareness of autism in girls and women. Data was collected through semi-structured interviews and the interview schedule consisted of seven questions (see Table 2). Interviews lasted between 32 and 64 minutes (M=46 minutes) and were recorded on an encrypted recorder. No differences were observed between face to face and Skype interviews regarding participant engagement and interaction during the interviews. Participants were verbally debriefed at the end of the interview and provided with a debrief form.

[Insert Table 2 here]

Analysis

The analysis was guided by Smith et al's., (2009) six stage IPA analysis process. Interviews were transcribed verbatim and read and re-read. Transcripts were analysed separately to maintain an idiographic focus (Smith et al., 2009). The analysis involved descriptive, linguistic and conceptual coding of the researcher's initial notes into emerging themes with the meaning held for participants. The themes were given succinct phrases which aimed to capture the quality of what was found in the text. This process enabled the development and clustering of emerging themes. The themes were then checked against transcripts to ensure fit with the source material. The researcher repeated this process with the remaining transcripts, considering similarities and differences between the experiences of cases. This process led to the development of the final superordinate and subthemes (Table 3). The

prevalence of themes across participants recorded. Yardley's (2000) framework (sensitivity and context, commitment and rigour, coherence and transparency and impact and importance) and Smith's (2011) guide for evaluation of IPA research was used to evaluate the quality of the current study. Several strategies were employed to strengthen the accuracy and credibility of the analysis, (1) the researcher kept a reflective diary and recorded personal reflections of the research process to monitor potential biases, (2) participants were contacted to check that the researcher's interpretation of their interview matched their experience, and (3) transcripts and themes checked by the second and third authors to ensure the analysis was conducted with multiple perspectives and experiences.

Results

Five superordinate themes, along with subthemes emerged from the analysis (Table 3). Excerpts and quotations were included to evidence themes and involve participants in the findings (Smith et al., 2009).

[Insert Table 3 here]

Superordinate Theme 1: Girls have Autism too

This superordinate theme considers participants' experiences of not thinking that their daughter's differences were due to ASC, scepticism that girls can have autism and a lack of information and knowledge of girls and ASC.

Subtheme 1: 'Girls don't have Autism'

Many participants described a prevailing sense of something being 'different' but most did not arrive at autism as the explanation for this difference. Some participants also described

that they were the only ones to witness the behaviour as behaviours only happened at home. Two participants described that it was a professional who suggested that their daughter may have autism rather than them identifying autism.

“I didn’t think girls could have autism I know it sounds a bit weird but I didn’t think it was a girl thing and I think it was about 2 weeks after she had been put forward to the assessment and me being completely like why are they doing this, this is ridiculous”
(P5)

“It was one of the teachers in primary that picked it up (...) she was kind of different from other children” (P9)

Several participants identified that it was mental health difficulties such as anxiety, self-harm, and grief that brought their daughters into contact with services. There was a strong sense from mothers that the core characteristics of ASC were secondary to mental health concerns at this point of entry into services.

“When she first got referred we didn’t feel like that (ASC) was the main issue the main issue was the self-harm” (P2)

One participant described that her daughter had been misdiagnosed before eventually being diagnosed with autism.

“At first she was diagnosed with ADHD and Oppositional Defiant Disorder none of which were actually right” (P7)

Participants' reported disbelief and scepticism from others that their daughter had ASC. Reasons for disbelief included a lack of understanding of how autism presents in girls, and that participants' daughters did not look like they had autism.

"People don't believe you exist in the first place, it's the usual 'you don't look autistic' (...) has she got autism, she doesn't look like she's got autism, girls don't have autism" (P7)

There was a sense of frustration from participants about the lack of awareness and recognition from others that girls do have autism and the biased perception that ASC only occurs in boys.

"I just wish there was more awareness out there that girls do have it (ASC) as well that you know get it out there that there is you it's not just boys because everybody thinks it's boys" (P5)

Subtheme 2: Lack of information on girls and ASC

The majority of participants described not being provided with a lot of information on female ASC from professionals after receiving the diagnosis. Participants were self-motivated to find information on girls and autism but shared that they found this difficult as most information and research is based on boys.

"No wasn't given any resources (on girls and ASC) at all. I literally had to just go online, try and find out about the stuff (...) but there's a lack of autism specific resources on girls" (P1)

Two participants described that joining online support groups on girls and ASC introduced them to information and strategies which was experienced as being more helpful than traditional sources.

“I’ll tell you the best thing I’ve done is join a Facebook group called colouring outside the lines. They honestly, I don’t know what I would have done without them”
(P5)

Superordinate Theme 2: She’s a ‘chameleon’

This superordinate theme reflects participants’ experiences of observing their daughter camouflaging with her surroundings, possessing increased social awareness, and the impact of social expectations on gender roles and ASC.

Subtheme 1: Masking

Participants have awareness that their daughters’ presentation of autism is subtle, with masking used as a way to cope, making it difficult to identify ASC in girls. They identified that their daughter was able to hold a conversation, make eye contact and blend in, ultimately making it difficult to tell that she may have autism.

“On Jane’s good days where you think she’s not autistic you know, on the good days Jane can have a chat with somebody she’ll do everything you ask her to do and she looks like she’s doing ok” (P4)

Participants identified that masking behaviours are used in school as a coping strategy. They explained that masking concealed anxiety, anger or gave the illusion that their daughters were functioning well.

“Girls much more internalise how they’re feeling and deal with it and it comes across as an anxiety (...) she looks like she’s functioning ok until you delve deeper (...) the minute she got in the [school] door I remember that Jane would immediately change you could see her physically change from being upset and angry to being almost like these mannequins” (P4)

Mothers’ identified the emotional consequences of masking when their daughter returned from school. Participants observed their daughters have a ‘meltdown’ at home which they attributed to her holding it together at school. They felt the action of ‘holding it together’ used up energy and resources. Several participants identified that their daughter needed time alone or to sleep when she got home from school.

“she was like Jekyll and Hyde because she would be lovely and excited and the minute we got home it was just awful and then she would scream and then she would sleep which I thought was great but now I realise how exhausted she must be” (P4)

Subtheme 2: Increased social awareness

Participants’ observed their daughters possess increased insight and social awareness of differences from peers. They described experiences where their daughters engaged in active strategies to develop social skills to enable them to fit in. Strategies included directly observing and analysing peers behaviours, reading books and watching online videos, which enabled them to mask their difficulties and look and sound like their peers.

“they [girls] really do they learn how to be a chameleon (...) if the kids were playing a game Victoria would stand on the edge watch, work out the rules like social rules as well as the physical rules and then go into the situation.” (P7)

Subtheme 3: Gendered social expectations

Participants described how their daughter and her ASC had been affected by gender expectations. Participants described the expectation that women should be more quiet and compliant and that bad or antisocial behaviour in girls is negatively evaluated.

“I think society expects men and women to act differently like girls are supposed to be a bit more compliant and not so loud and they learn that” (P7)

In contrast, participants identified that it is more acceptable for boys to be aggressive and display externalising behaviour compared to girls.

“I imagine if you have a boy with autism who’s more aggressive it’s almost more acceptable, you know because that sort of the aggressive angry is more typical of a male (...) it’s not what people expect to see I suppose” (P3)

Superordinate Theme 3: The impact of the diagnosis

This superordinate theme captures participants considering the diagnosis of ASC as helpful, but also having a strong emotional impact. For some participants, the diagnosis provided a sense of legitimacy to earlier concerns of feeling like a bad parent.

Subtheme 1: The diagnosis ‘it’s been a good thing’

Most participants described that the diagnosis as helpful as it enabled them to make sense of and understand their daughters’ behaviours. The diagnosis also increased some participants’

empathy for what their daughter had been experiencing as ‘tantrums’ and ‘meltdowns’ could now be understood in the context of ASC.

“A lot of things made sense. Things that I just thought were possibly tantrums were maybe more meltdowns (...) it helped me to ... be less angry with Louise because I think at that stage I was quite angry with her and really kind of allowed me to have more empathy” (P8)

The diagnosis was also experienced as a way to access support and financial assistance, indicating that this was important aspect of participants’ experiences.

“I think it’s been a good thing, helpful for us I think. Em well I wouldn’t have access to more support as we got the diagnosis” (P2)

Subtheme 2: Loss and empowerment

Participants emotionally processed their daughter’s diagnosis in different ways. Two participants described experiencing a strong emotional reaction to their daughters being diagnosed with ASC and likened this experience to ‘a grieving process’ for what could have been.

“I think you have a grieving process where you realise that you’re not going to have that girl that you thought you were going to have. I mean I think that was a bit of a kind of difficult thing to come to terms with” (P5)

This highlights that receiving the diagnosis of autism can be a profound experience. In contrast, many participants identified that the diagnosis provided them with a sense of

empowerment due to being aware of what they were dealing with. This enabled participants to make sense of things, research ASC and plan for the future.

“you just think right my attitude is right we know what we’re dealing with and my attitude is go research find out as much information and look up as much things that can help” (P4)

Subtheme 3: Sense of legitimacy

Participants described a sense of legitimacy when their daughter received the diagnosis. This enabled them to recognise that their own self-judgements and judgements from others were not because they were a bad parent, but because she has ASC.

“it obviously made me realise that all along it wasn’t just you you know. I had people saying maybe it’s just parenting or maybe you should try doing things a different way or maybe you should be more firm when she’s misbehaving (...) it let me know that actually you know there is a genuine reason, I wasn’t just a bad parent” (P10)

Participant 10 reflected that the diagnosis had increased her confidence and ability to parent.

“I think it’s made me a bit more confident (...) I think before it got to the stage where I was always second guessing if I was doing the right thing or if I should be more firm whereas now I feel more confident” (P10)

Superordinate Theme 4: Impact of ASC on mum’s

This superordinate theme highlights the effect that having a daughter with ASC had on participants. The impact was experienced as always being in ‘mum mode’, the importance of

having something of your own, negative health and wellbeing, but also finding positive aspects of having a daughter with ASC.

Subtheme 1: Always in 'mum mode'

All participants described being in a constant 'mum mode' and described that life had become about looking after their daughters' or thinking about their daughters' needs first whilst sacrificing their own needs.

"I'm always in mum mode. She's always first. I always put her first, her needs always come first" (P9)

In addition, participants identified the impact of the parental role stating that the responsibility was on them as the main caregiver because their daughter was more likely to want them when she is distressed.

"it's awful to say but you sometimes feel a little bit trapped (...) the onus is on me, because Jane will only text me all day if she's at school if she's unhappy she texts me so the onus is on me (P4)

One participant identified that she expected more independence given her daughter's stage of development and expressed that she would have liked to have been able to pursue her own interests.

"At this time of my life I would have expected to have a little bit more independence back in my life (...) I would be following more of my own interests and I can't actually go away or do things you would think with a 15-year-old daughter" (P2)

All participants described that caring for a daughter with ASC has had a negative impact on their health and wellbeing. They described increased stress, difficulty sleeping, struggling to maintain employment, and flare ups of medical conditions and coping with things through medication use and by 'just keeping going'.

"it had an effect on my health actually yeah (...) she's been very stressed and I've been very concerned about her (...) I've managed to keep my job just. I'm sure I've not always been functioning in work not sleeping all that sort of thing, it's just the stress too stressful an experience" (P2)

Subtheme 2: Positive impact of having a daughter with ASC

Participants recognised that their daughter's diagnosis has had a positive impact on them. Some participants identified that they view the world in a different way and have developed new ways of coping with difficulty.

"what I've realised is actually Kate having autism has made me a better person that might sound like a cliché but it has taught me how to fight it's made me realise you know not everyone is neurotypical and has a linear life" (P3)

Participant 9 described that her experience of being the mother of a daughter with autism had made her judge others less quickly and increased her empathy towards other mothers experiencing difficulties.

"I just kind of tend not to judge others quickly, I used to see kids in the supermarket kicking off (...) and just think it's badly behaved child but now I can see that maybe

that child has issues and can't deal with things (...) You kind realise now that it was having a bad day, you know what the mother is going through" (P9)

Superordinate Theme 5: Day to day life

This superordinate theme explores the practical impact of autism on family life, mothers increased involvement in their daughter's life, and access to support services and school experiences.

Subordinate theme 1: Family life

Participants' recognised that their daughters' diagnosis affects the entire family system and not just the individual with ASC.

"if more people recognised that autism doesn't just affect the individual who has autism, autism has a sort of effect on the family, brothers, sisters" (P3)

Several participants spoke of the impact that having a sister with autism has on their other children. Participant 6 described being less available to her other children and that her children were not able to do normal things or have a normal childhood due to having a sister with ASC as life tended to revolve her.

"you're trying to give another child a bit of time when you're one person trying to deal with four kids you find your other three are there but everything revolves around Kelly (...) they [Kelly's siblings] haven't been able to do normal things like have friends over sleepovers (...) just haven't had a normal life" (P6).

Subtheme 2: Increased involvement in daughter's life

Many participants described an increased involvement in their daughters' lives. Several participants articulated that they had become an expert on their daughter and needed to learn as much about autism to ensure their daughters' best interests were met.

“the buck stops with you and I need to learn as much as I could about autism that's girls, boys whatever cos ultimately it's me that's going to have to sort it and make sure they get the best” (P1)

One participant described feeling ‘a very great responsibility’ for being available for her daughter to help her navigate life and organise her social life. There was a sense that this mother has become her daughter's interpreter, which she reflected as being a different experience to parenting her other children.

“I've always felt responsible for arranging her social life. I've had to be in charge (...) I always feel that Claire is very reliant on me and I think it is to interpret the world, feedback what's going on and so you feel a very great responsibility to be there for them all the time” (P2)

Subtheme 3: Support

All participants described a sense of frustration when they tried to access support services. They strongly identified that there wasn't enough support from services and spoke of support coming from friends or other mothers of children with ASC.

“It just feels a bit em frustrated you feel frustrated because you’re stuck with no support other than other mums (...) I think we feel let down by our council and there is no support for us and for our children” (P4)

Many participants identified that it was those individuals who ‘shout the loudest’, or who were prepared to fight, that received support, with participants describing having to take on this approach.

“you have to fight tooth and nail all the time (to get support). It’s constantly micromanagement without controlling her world, it’s constant fighting” (P7)

Many participants identified that the internet and parent support groups provided useful support and advice in the absence of support from statutory services, and that other parents helped each other to navigate the system.

“I don’t know what I would have done a few years ago before Facebook and these groups existed I would have been so alone with it” (P5)

“there’s not support from statutory services at all so it’s about guiding each other through the non-statutory service the voluntary services that can help our kids (...) there’s a wealth of knowledge out there” (P7)

Discussion

ASC was not initially considered by mothers as an explanation of their daughter’s behaviours which may highlight a lack of recognition of the female presentation of autism. This finding adds to the growing evidence of an ASC gender bias which is fuelled by the view that Autism

is a male condition (Baron-Cohen, 2002), leading to failures in recognising the subtle ASC presentation associated with females. Scepticism and disbelief from others that girls have ASC based on an invisible presentation (e.g. not being able to tell that they are autistic) and autism being perceived as a male condition is consistent with previous qualitative studies (Bargiela et al., 2016; Nevot et al., 2017). Mothers also described a lack of information on females, with most available information based on boys and the typical symptoms that present in males. Online support groups appear to be an important and useful source of information than traditional resources which enabled mothers to connect with other parents and provide support whilst also increasing their understanding of female ASC. It is important to acknowledge that the sources of support and information discussed by mothers could be from autistic women themselves, given that many mothers have ASC.

Consistent with previous studies (Cridland et al., 2014; Hurley, 2014; Mandy et al., 2012) mothers' have awareness of their daughters camouflaging social difficulties and using masking behaviours. Negative consequences of masking when daughters returned from school are in line with previous research that reports female difficulties do not present consistently across contexts (Dworzynski et al., 2012; Hiller, Young, & Weber, 2014; Mandy et al., 2012). Observed increased social awareness from mothers of their daughters difficulties around peers and the development of compensatory strategies to overcome social difficulties, included observing and imitating peer behaviour, watching videos online, or reading books, which replicates research by Tierney, Burns, and Kilbey, (2016) who reported that girls with ASC are more socially driven and use coping strategies to fit in with peers.

Gendered social expectations and cultural norms that girls should be feminine, quiet and more passive than boys may cause girls with ASC to internalise their behaviours and develop

strategies to maintain typical social behaviours. This finding fits with previous research where the perception of gender roles influenced interactions with children, which may offer an explanation for some of the sex differences in ASC (Cheslack-Postava, & Jordan-Young, 2012; Young et al., 2018). It is possible that society's expectations and beliefs around females and femininity impacts our perception of how male and female autism presents (Kreiser & White, 2014).

Receiving an ASC diagnosis helped mothers' access additional support and financial assistance. Strong emotional reactions to the diagnosis including feeling a sense of loss and grief, but also feeling empowered were discussed. Mothers' mixed reactions to the diagnosis are consistent with previous research (DePape & Lindsay, 2015; Osborne & Reed, 2008; Ooi et al., 2016). Importantly, the diagnosis provided a sense of legitimacy since it absolved mothers of being bad parents. These experiences fit other parents' reports of feeling vindicated after their child received a diagnosis of ASC (Ooi, et al., 2016).

All mothers reported mental health difficulties, with some using maladaptive coping strategies, to manage the added difficulties of caring for a daughter with autism. This finding replicates previous qualitative research where mothers of children with ASC reported increased stress when personal and social resources are insufficient (Miranda, Mira, Berenguer, Rosello, & Baizauli, 2019). In addition, mothers of children with ASC report reduced wellbeing, quality of life, increased mental health difficulties, and increased stress and isolation (Barker et al., 2011; Desmarais, Barker, & Gouin, 2018; Vasilopoulou & Nisbet, 2016). Parenting a daughter with ASC appeared to have a profound effect on some mothers' sense of self. This finding supports a similar theme in McAuliffe, Tomomi, Thomas, Yvonne, Vaz, et al., (2019) where mothers of children with ASC report carrying

large responsibilities and managing multiple roles. When mothers were able to find time for themselves, either in work or socially, this was highlighted as an important means of coping, increasing wellbeing, and as providing a sense of identity and achievement. In addition, mothers identified positive aspects of having a daughter with autism, with mothers reporting to appreciate their daughters, more, which is again something reported in previous qualitative research involving mothers of children with ASC (Cridland et al., 201; Nicholas, Zwaigenbaum, Ing, MacCulloch, Roberts et al., 2016).

The wider family system was negatively impacted by having a child with ASC. Mothers also felt frustrated at the impact that their daughters' ASC had on typically developing siblings. This finding connects with previous research, which indicates that siblings' developmental experiences may be negatively affected by having a sibling with ASC (DePape & Lindsay, 2015). Future research should consider whether sibling's experiences differ depending on whether the child who is diagnosed with ASC is male or female.

Mothers described increased involvement in their daughters' lives. A finding that replicates a theme in previous research conducted by Cridland et al., (2014), with mothers reporting involvement in a variety of aspects of their autistic daughters' lives. This finding also fits with qualitative research of mothers' experiences of parenting children with ASC, where mothers report assuming the role of researcher, advocate and coordinator of services for their child (Nicholas et al., 2016). Access to formal support services was experienced as a constant fight. This finding is replicated in the wider literature where parents of children with ASC report difficulties accessing and knowing what support services were available (Desmarais et al., 2018; Gobrial, 2018; Keegan, 2016).

The current study highlights that increased awareness and dissemination regarding sex differences in autism presentation is needed. Clinicians also need to adapt the diagnostic process and be aware of gender bias when using standardised ASC measures as part of the diagnostic assessment (Mandy & Lai, 2017). This could be overcome by asking parents about camouflaging strategies described by mothers in this study, and how these present in different social settings. Importantly all mothers spoke of the negative impact on their health and wellbeing, highlighting a need for more support for parents (Desmarais et al., 2018).

The use of a small homogenous sample size in line with the principles of IPA, facilitated a diverse and in-depth exploration of mothers' experiences of parenting a daughter with ASC. This supported a detailed analysis of mothers' experiences across a range of key areas that revealed themes consistent with the wider literature on parenting a child with ASC. There was little diversity in the sample as all mothers lived in Scotland and identified as Caucasian, which makes it difficult to explore the representation of experiences outside of Scotland and how ethnicity might affect parenting a daughter with ASC. Several demographic variables (e.g. child's intellectual ability, wellbeing of family members, parental mental health, SES, and formal/informal support) known to impact family wellbeing were not collected in this study, which could have impacted how mothers make sense of their experiences. It would be valuable for future research to consider the role of these variables and how they impact mothers' experiences. In addition, the current study is only representative of mothers' perspectives only and not their daughter's experiences or perceptions. A related limitation is that it was not considered if mothers were themselves autistic. It is important to recognise and acknowledge that mothers' may be autistic or identify as autistic, and thus their experiences of parenting a daughter with ASC may be impacted by being autistic themselves. Future research should explore how being an autistic mother impacts experiences of being a

mother to a daughter or daughters with ASC. In addition, it would be valuable for future research to continue to explore daughters' own experiences of having autism similar to previous research (Stewart, 2012) as well as the experiences of other family members.

It is worth noting that some of the key issues highlighted in this study were being raised 10 years ago (Attwood, 2006), and it appears that not a lot has changed in this period. However, what appears to have changed is that there is more-awareness of autistic girls and women, yet more awareness is still clearly needed. It is important to acknowledge that much of the information available on autism and women discussed by mothers in this study is being produced by autistic women themselves as well as ASC organisations and co-productions between autistic women and researchers, many of whom are autistic themselves.

In conclusion, the findings of this study provide insight and understanding of the unique experiences and challenges of parenting a daughter with ASC. The challenges are somewhat related to the lack of understanding around how autism manifests in females, their use of masking and how male based theories and empirical studies convolute existing ASC literature. There is, indeed, a dearth of research surrounding female autism and how it manifests differently or similarly compared to males across a variety of contexts. The current study enriches our knowledge about girls on the autistic spectrum, however there are important implications for clinical practice and future research in order to provide increased understanding and support to this group and their parents.

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